



MedStar Health

MEDSTAR GEORGETOWN
UNIVERSITY HOSPITAL

MedStar Georgetown
Transplant Institute

Post-kidney- transplant **guide.**

**It's how we
treat people.**

Love for rescuing dogs leads to finding kidney donor.



Laurel W. received a kidney transplant from a friend she met through a German Shepherd rescue group.

It was a love of dogs that brought kidney donor Gary S., 64, of Pasadena and kidney recipient 49-year-old Laurel Weetall of Germantown together. They met through a German Shepherd rescue group a few years ago. When Laurel shared with her Facebook friends that she needed a kidney due to a painful condition called polycystic kidney disease (PKD), Gary came forward to help. He had donated platelets dozens of times and was listed as an organ donor on his Maryland driver's license but had not considered living organ donation.

"I had no idea you could donate a kidney," says Gary who rehabilitates cars at his collision repair center. "I saw what she was going through and wanted to help. I learned that the risks were minimal to me and the benefits to her were so huge. It was not a tough decision."

The end of more than a decade of pain

Laurel was diagnosed with PKD, a genetic disorder that causes cysts on the kidneys, in her mid-thirties. "I had been living with extreme pain for 13 years," she recalls. "I was always so sick."

When kidney failure became imminent, her nephrologist told her the best place to undergo her transplant was MedStar Georgetown Transplant Institute.

"Our kidney donors are amazing for giving of themselves in this way," adds Jennifer Verbese, MD, director of the Institute's Living Kidney Donor Transplant Program. "We encourage people who need an organ to discuss what they're going through with family members and friends who just might be willing to donate. Organ recipients can find their donors in so many different ways."

"Saying 'thank you' to Gary hardly seems like enough," says Laurel. "We both have a strong passion for saving animals and I think he just has rescue in his heart. He rescued me. He gave me the gift of life."

Contents.

Your clinical transplant team	2
What to expect during your hospital stay	4
Length of stay	4
A typical post-transplant hospital stay	4
Medications	5
Discharge and transition to outpatient care	6
Getting your medications	6
Physical therapy and regaining strength	6
Assistance at home	6
Outpatient follow-up	6
Outpatient post-transplant care	6
Follow-up schedule	6
Arriving for your clinic or lab visit	7
Post-transplant restrictions	10
Common post-transplant problems	12
When to call the transplant clinic	13
Transplant medications	14
Immunosuppression	14
Anti-infectious agents	15
Other medications	15
Other information	16
Insurance and finances	16
Important information about medicare	16
Obtaining secondary coverage	16
Minimizing drug costs	16
Coverage for being out of work	16
Letters to donor families	17
Philanthropy opportunities	17
Support groups	17

Your clinical transplant team.

Now that you have received your transplant, your hospital stay will be with our experienced transplant staff at MedStar Georgetown Transplant Institute. Your transplant team is made up of a variety of specialists who will help you through these first few days. They will see you at least once daily as a group, but all are available throughout the day if you or your family have questions or concerns about your transplant care. The members of your transplant clinical team include:



Members of the post-transplant team at MedStar Washington Hospital Center: Titi Orimogunje, NP; and Danica Rowe, NP

Surgeon

After your surgery has been completed, your surgeon will continue to follow you to ensure your recovery proceeds normally. You may have a number of intravenous (IV) lines, a urinary catheter, or other drains which will be monitored and removed as soon as it is safe. In addition, and most importantly, you will be on new medications to protect your kidney and your body from infection.

Nephrologist

You will see a nephrologist who will work with your surgeon in the adjustment and choice of your immune medications. In some cases you may need dialysis until the new kidney works, and your transplant nephrologist will manage the dialysis you need. After discharge from the hospital, your primary follow-up will be with one of our nephrologists along with a transplant advance practice provider (APP).

Pharmacist

The pharmacist is an essential member of the transplant team. Their role is to review the complete list of medications you were taking before transplant, anticipate any possible issues or interactions that may occur post transplant and minimize the potential for adverse effects that may occur. The pharmacist makes sure all your medications have an appropriate dose and indication. These include over the counter and prescription medications. There is always a pharmacist available to answer your medication questions. It is however very important that the patient know all the names of medications they are taking as well as the doses. We recommend keeping a list in your wallet or purse.

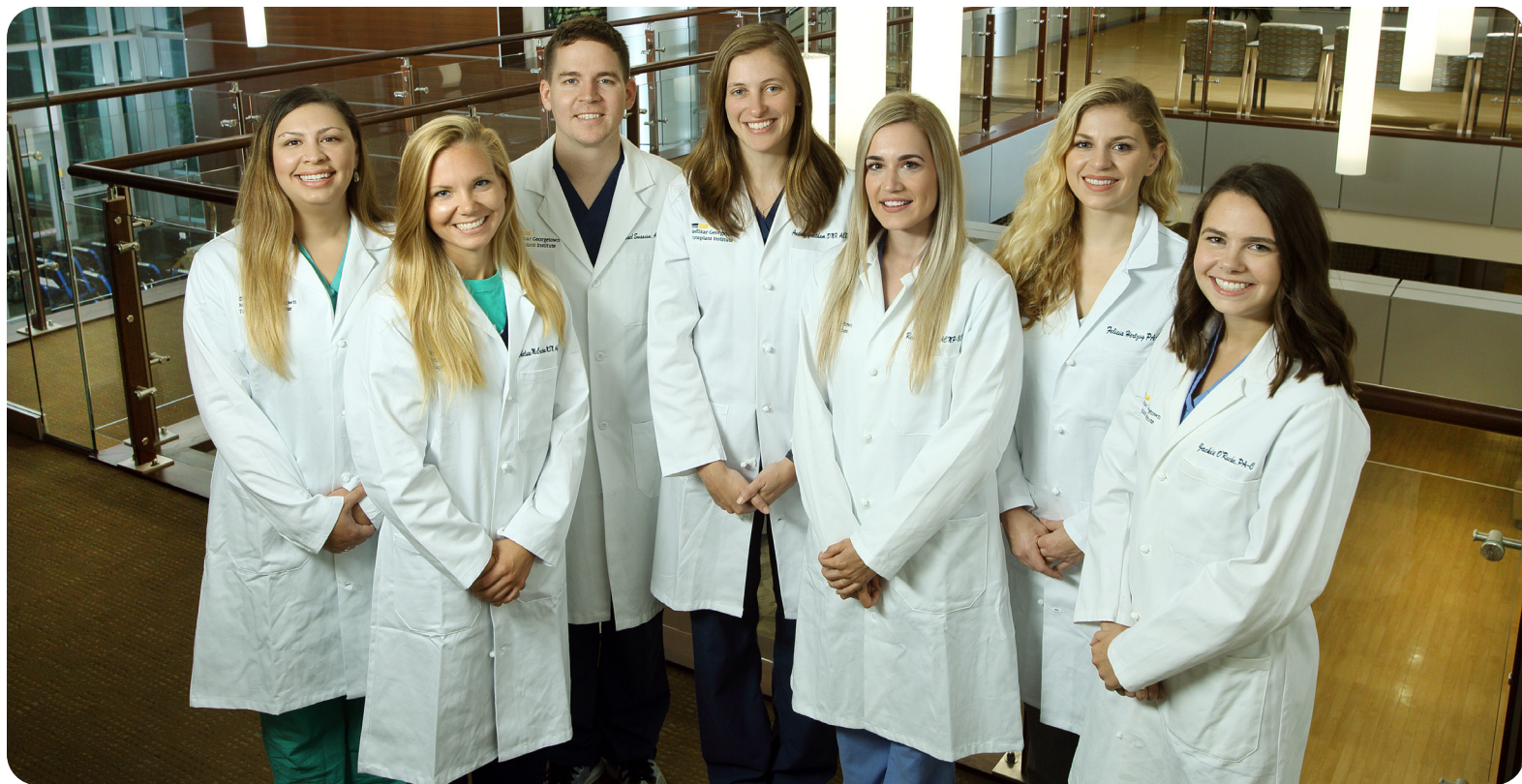
Not taking medication as prescribed is a major issue that can lead to failure of the new kidney. If you are having problems with taking your medications as instructed, the pharmacist and physician will work together to try and resolve this issue. Non-adherence is a significant issue and the transplant clinic should be contacted if you are having any issues with taking your immunosuppressive medications.

Advance practice provider (APP)

Along with the rest of the team are our advance practice providers who will be managing your care from day to day. Unlike the residents/surgeons/nephrologists, the APPs do not rotate from week to week. They are always available on the floor to manage your care from week to week. Aside from participating in daily rounds with the rest of the team, the APPs are responsible for arranging your discharge from the hospital.

Post-transplant coordinator

After discharge from the hospital, you will be assigned a post-transplant coordinator who is also an APP. They will be your primary resource for all things post-transplant. Your coordinator is there to manage all issues after your surgery. They are able to call upon any or all members of the transplant team as needed to solve whatever issues may develop. Their number is your most important contact with the transplant center. They should be your first call for any and all issues.



The advanced practice clinicians of the inpatient transplant service.

Floor nurses

While you are in the hospital, you will be under the care of one of our experienced transplant nurses. They are expert in the administration of transplant medications and the specific needs of our transplant patients. They can also provide any information you should need about hospital policy while you are an in-patient including rules about visitors, gifts, and outside food.

Dietitian

We have a full-time dietitian dedicated to the transplant service. They can provide information about food interactions with your medication as well as answer questions about foods to avoid given your other medical conditions. They typically see patients in the outpatient setting, but if you wish to speak with them during your inpatient stay, let your team know, and we can arrange a time for them to come speak to you.

Social worker

There are dedicated transplant social workers who are available to meet with you at any time during your hospital stay as well as your post-transplant visits. They can help you address the need for medical support or assistance with daily activities at home, or financial issues you may have with your care. Your social worker can assist you with transportation, caregiver support, and mental health concerns as well as help accessing affordable medications and managing co-payments.

Financial coordinator

Coverage of transplant medications is an ongoing concern. Our dedicated financial coordinators are available to speak with you at any time regarding questions of insurance coverage that you may have.

House staff

All MedStar institutions are teaching centers. This is a tremendous advantage because it allows us to have physicians in the hospital 24 hours a day. In addition to interns and residents, the transplant team includes both surgical transplant fellows and nephrology fellows who have already completed their training in internal medicine and general surgery but have chosen to do advanced training. While they work under the guidance of your attending nephrologists and surgeons, they are an important member of your healthcare team.

Research team

As an academic medical center, MedStar Georgetown Transplant Institute has at any one time a number of ongoing research studies. All research studies have been reviewed for their safety prior to recruiting patients. You are not required to participate and your care will not be affected should you decide to say no. If you choose to participate in these studies, however, you will help us learn and discover ways of doing transplants in a safer and more effective manner. You will meet members of the research team who help to explain and coordinate the study with your clinical care.

Your surgery.

Transplant surgery can take several hours, but each surgery is unique, which can affect how long it lasts. It is rare that following a kidney or pancreas transplant patients need to stay in the ICU. In most cases, you will be transferred to our dedicated transplant floor for your recovery. Your transplant team will let you know when you can expect to be discharged and return to normal daily activities.

What to expect during your hospital stay.

Your hospital stay will in large part depend on the type of organ transplanted (kidney, pancreas, or kidney/pancreas) and the type of donor (living or deceased donor).

Length of stay

For patients receiving a kidney transplant, your stay will generally be 3 days.

For patients receiving a pancreas or kidney/pancreas transplant, your stay will generally be 4 to 7 days.

During your stay, your team will be managing a number of issues. Initially after transplant, you will have an intravenous line which is used for your initial immunosuppressive medications as well as fluids to keep your newly transplanted organ well supplied with blood. You will also have a catheter in your bladder to collect and drain your urine so that we can closely monitor the amount. That catheter will remain in for at least 3 days. If you have been on dialysis for a long time, you may need to have this catheter remain for up to a week. For patients receiving a pancreas transplant, you will also start with a tube in your nose which is used to drain your stomach and the rest of your bowels to allow healing after your surgery. This will typically remain in place for 2 or 3 days.

A typical post-transplant hospital stay

Although every patient's hospital course can vary, here is a brief outline of what you can expect on the days following your transplant.



Alexander Gilbert, MD, Transplant Nephrologist, checks on a patient.

- **Day of surgery:** Immediately after surgery, you will be transported from the operating room (OR) to the Post Anesthesia Care Unit (PACU) until you fully wake up from the anesthesia. As soon as a bed becomes available on the transplant floor (6 Bles), you will be transferred to your room.
 - All transplant patients **MUST** be in a private room.
 - You will require closer nursing supervision given the frequency of lab draws, etc.
- **Post-Operative Day (POD) #1:** You will start on a clear liquid diet (jello, broth, juices) and will advance to a regular diet as we see you tolerate these. You will be given oral pain medications (narcotics) but will have IV pain medications available if needed. You will be getting intravenous (IV) fluids which we will gradually reduce during the day. We will closely monitor your urine output. You may require an ultrasound of the transplanted kidney if the urine output drops or if your kidney numbers (creatinine and BUN) start to rise.
- **Post-operative day #2:** Your remaining IV fluids are stopped. You should be out of bed most, if not all, of the day. You will begin walking with assistance and advance to a more regular diet. By this day, we want to see you begin to have bowel movements or at least pass gas.
- **Post-operative day #3:** Unless otherwise told by your surgeon, expect your bladder catheter to be removed. Since many patients have not used their bladder in quite some time, it can be difficult to know when you need to urinate. It is important to try and void every hour and drink at least 2-3 liters of fluid a day. If you are unable to void after 8 hours, there is a chance that the catheter may have to be re-inserted. For men who were previously taking medication for an enlarged prostate (BPH), please let the team know so that we can restart your existing medications.

Medications

Of highest importance will be your new immunosuppressive (IS) medications. Generally you will be on 2 to 3 IS medications. These will continue for the life of your transplant. It is important for you to start to become familiar with these medications. We will have you take an hour long class before discharge to better familiarize yourself with these medications.

Without taking these IS medications, it is impossible for the kidney to work. It is important to take them on time and to take every dose as prescribed. If you think you are having side effects, you must let your transplant team know. There are other options for medication, but simply stopping the medications on your own is dangerous both to the transplanted organ and to your own health.

In addition to the IS medications, you will also be on short-term medications to prevent infection.



Sisters Tina M. and Rolanda F.

Sister act

Few people get to see the words “Sissy’s Gone, 1/19/12” tattooed on Rolanda’s abdomen, but that’s fine by her. The Baltimore native knows why they are there.

“Sissy” is the name affectionately given to the kidney Rolanda donated to her older, half-sister Tina. Having already lost her hearing to Alport Syndrome, Tina had learned that her kidneys were on the verge of failure and that a transplant was the only alternative to dialysis.

Rolanda wanted to help Tina by donating one of her own kidneys but was unsure she would be a match because they had different fathers.

“After doing a lot of thinking and praying about it, I was determined to help my sister,” Rolanda says, “either by a direct donation or an exchange with other donors.”

Tina was thrilled and immediately called her specialists at MedStar Georgetown Transplant Institute. “I had an appointment the following week,” she says. “They told me, ‘bring Rolanda in with you to be tested!’”

Rolanda soon learned her kidney was indeed a match for Tina. As sisters prepared for the January 19, 2012, transplant surgery date, they decided this life-saving organ needed a name and decided on “Sissy” because, Rolanda says, “It just seemed right.”

Although Tina admits to being somewhat anxious about her sister’s generous act, Rolanda was ready to get the procedure done.

“The specialists had prepared me for everything,” she says. “I was totally at peace.”

Today, the sisters still reminisce about the surgery, along with other experiences they’ve shared, including the good-natured squabbles they got into as kids.

“We don’t do that anymore,” Tina says with a laugh. “I don’t want Rolanda to make me give Sissy back!”

Discharge and transition to outpatient care.

Our APPs are responsible for preparing and executing patient discharges. APPs will order your medications, arrange home health care and outpatient rehabilitation placement as needed, and set up your first outpatient follow-up. Our APPs help promote continuity of care by communicating frequently with the outpatient team.

Getting your medications

You will be discharged with a minimum of one month of medication, but cannot leave the hospital without medication and patient education.

Physical therapy and regaining strength

Patients, as deemed appropriate, are seen by physical therapy. Patients who need more intensive therapy may be discharged to a short-term rehab facility. Our case managers will work with you so that you are involved in the choice of rehab facility.

The case manager will work with you and your family to pick the most appropriate rehabilitation facility for you.

Assistance at home

Depending on each patient's individual needs, the inpatient APPs can arrange a variety of home health care support. Here are a few examples of common home health arrangements for patients:

- Home nursing to assist with transplant medication teaching, drain care, assistance with insulin and/or anticoagulation
- Physical therapy or occupational therapy for patients who require assistance but not a full rehab stay
- IV infusions for patients who need antibiotics at the time of discharge
- Home health aide to assist with activities of daily living (for example, bathing or dressing).

In addition, patients will be sent home with assistance devices (walker/wheelchair/cane) as necessary. It is important that patients participate in physical and occupational therapy while they are in the hospital so that these needs can be addressed.

Outpatient follow-up

MedStar Georgetown Transplant Institute has two locations where you can be seen for your post-transplant care, one is at MedStar Georgetown University Hospital where you had your surgery and the other is at MedStar Washington Hospital Center. The medications and follow-up schedule are the same regardless of the location you choose. You may choose whichever site is most convenient for you as the care provided is identical. It does not matter where you got your pre-transplant care.

Note: For patients with Kaiser Permanente insurance, your insurance company requires that you receive your post-transplant care at the MedStar Washington Hospital Center site.

Before you are discharged, your transplant team will ask you where you want your follow up care and will arrange your initial outpatient visits as well as informing your outpatient team of the specifics of your transplant and inpatient stay.

Outpatient post-transplant care.

Follow-up schedule

Completing your transplant surgery is only the beginning of your transplant journey. Over the first few months, there will be many issues to address including adjusting the levels of your medications, dealing with any side effects, monitoring your wound, controlling your blood pressure, and solving any other problems or concerns that you have. As you might expect this takes several visits with us at the transplant center with necessary lab tests. Fortunately, there is a fairly flexible schedule in the clinic which should allow you to schedule your visits on days that are convenient for you.

In general, we will be responsible for all your healthcare management for the first 3 months after your transplant. After 3 months, your primary nephrologist will begin to resume much of your day to day care, but you will still see us regularly for management of your immunosuppression. After the first year of transplant, patients are generally stable enough to see us only once per year, although we are always available in the case of any complications or severe illnesses.

A summary of your post-transplant schedule is:

Week 1

- 2 visits to see your surgeon/nephrologist/APP
- 2 sets of labs (done at your visits)

Week 2

- 2 visits to see your nephrologist/APP
- 2 sets of labs (done at your visits)

Week 3

- 1 visit to your nephrologist/APP
- Removal of your staples
- 1 set of labs (at your visit)

Week 4

- 1 visit to your nephrologist/APP
- 1 set of labs (at your visit)
- Removal of your ureteral stent (done in a clinic)
- Removal of your peritoneal dialysis catheter (if not already removed)

Weeks 5-8

- Weekly visits to your nephrologist/APP
- Weekly labs (at your visits)

Weeks 9-12

- Visits every 2 weeks with your nephrologist and APP
- Labs weekly

Months 4-6 (transition time)

- Visits every 2-4 weeks to your nephrologist/APP
- Labs every 2 weeks
- Assuming no significant complications, you will start seeing your original nephrologist at this time.

Months 7-12

- Visits every 1-3 months to your nephrologist/APP
- Labs every 2 weeks

After the first year, we recommend that you see a nephrologist every 3-4 months including seeing us in the transplant clinic at least once a year. Typically this means 2-3 visits to your general nephrologist and 1 visit to us each year. We also recommend that you continue to get lab tests every month for as long as you have the transplant. While this may seem like a lot, the most important thing in treating transplant problems is identifying them early.

Arriving for your clinic or lab visit

When coming to the transplant center please bring a form of ID, your insurance card, and your lab order forms (these will be provided for you at your first visit). After you have seen your transplant team you will be given a summary of your visit which will include instructions for your following visit. Bring this to the front desk to schedule your next appointment.



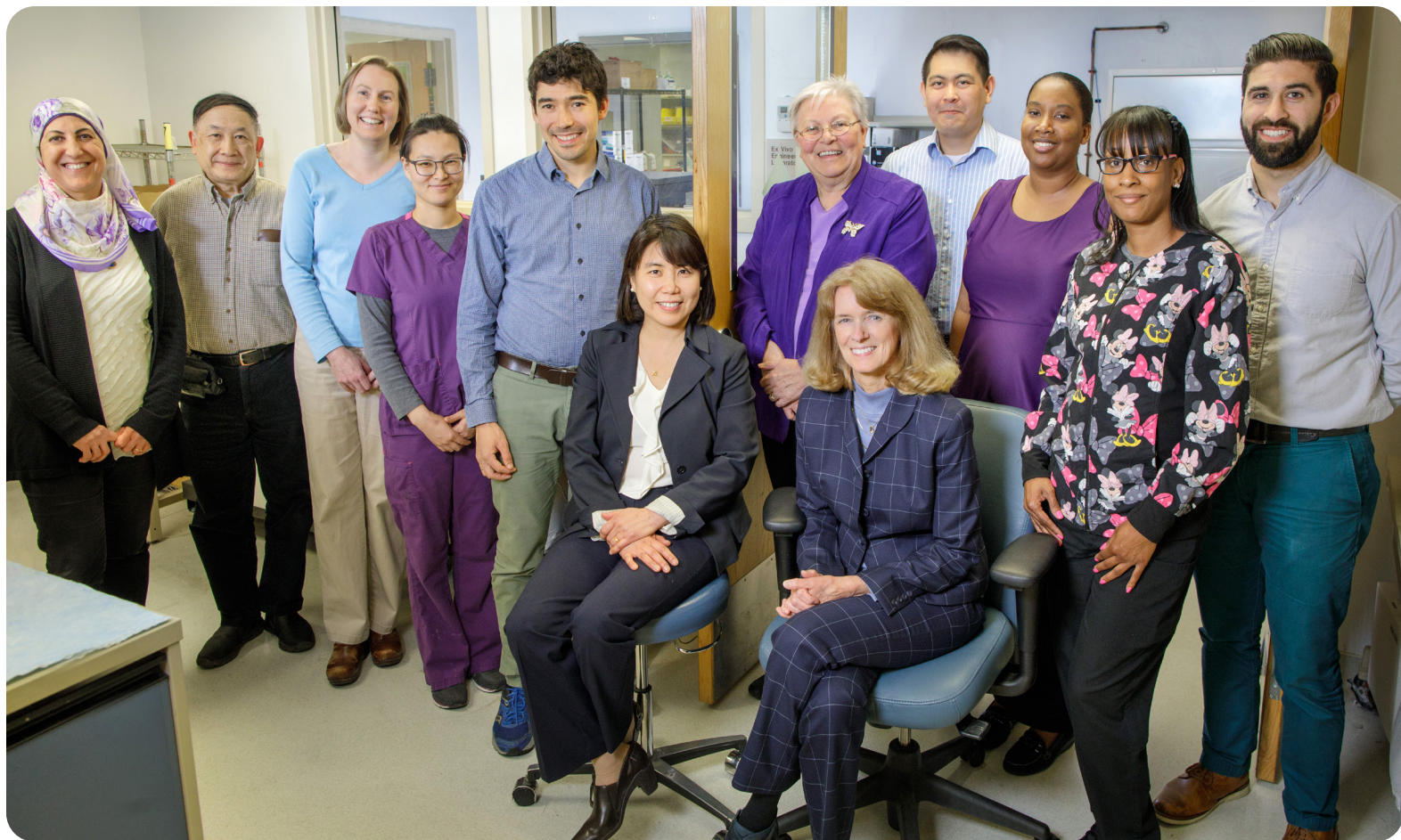
Lorna Wellington, Phlebotomy Team Coordinator

For patients seeing us at MedStar Georgetown University Hospital:

- When scheduling a clinic appointment and a lab appointment on the same day, make the lab appointment for 60 minutes before your clinic visit to minimize delays. **If you need to schedule or change an appointment from home, you should call 202-444-3700** and speak with the administrative assistant for the kidney/pancreas program.
- If you need a medication refill, you do not need an appointment. Instead, call either your post-transplant coordinator, or **the prescription refill line: 202-444-3700.**

For patients seeing us at MedStar Washington Hospital Center:

- Your first appointment will be scheduled by your in-patient APP. Your labs will be drawn at the start of your appointment. **To schedule or change an appointment, or to fill prescriptions at this site, you should call 202-877-6389.**



The Histocompatibility Lab team led by Sandra Rosen-Bronson, PhD

The importance of routine labs.

S.S. was a young 32-year-old man who was thrilled to get a kidney transplant after being on dialysis for 8 years. His kidney worked beautifully and he always took his medications on time.

For 3 years, he had a smooth transplant course. He knew he had to take his medications and took them all perfectly. For 3 years, he did everything his transplant team could ask, but he always hated the needles involved in getting his blood tested.

After 3 years, he figured that everything was going so well, that he stopped getting his routine labs. He continued to be very careful with his medications, he knew that they were critical to his kidney working.

After 4 months of no labs, he came back, feeling fine, and got his blood checked. Much to his shock, his kidney function was much worse. A kidney biopsy showed advanced rejection. The damage to the kidney was permanent, and a year later, he went back on dialysis.

S.S. took his transplant seriously. He took his medication religiously, and in many ways he was an ideal patient, but he made the mistake of assuming that because he felt good that he did not need to continue with his labs. While understandable, he was unlucky and so his transplant team did not find out until too late that he was having a rejection. This is why we ask for patients to continue to get labs regularly.

Catching rejection early is the most important factor in being able to treat it successfully and save a kidney.

Clinic visits

Your clinic visits will be with your post-transplant APP as well as a nephrologist. Your APP is your primary source of contact and they will be making your day to day management decisions in discussion with your nephrologist. Although other members of your transplant team will not routinely see you, everyone, from financial coordinators to social workers to dietitians are available if you need their assistance and we encourage you to let us know ahead of time if you need to speak to them so we can make sure they are available.

Post-transplant clinic is typically a morning visit so that we can measure your immunosuppressive medications but if afternoon visits are needed, please let us know and we will try to accommodate you.

If possible, we would like those people who will be your primary support after transplant to come with you to your clinic visits. As they will be helping you, they may have questions for your team as well.

Lab testing

Standard post-transplant testing includes labs for kidney function, electrolytes and blood count, as well as tests for common viruses (BK virus and CMV), drug levels (for tacrolimus, sirolimus, and everolimus) and a urinalysis and urine culture to look for urinary tract infections.

For patients taking tacrolimus, cyclosporine, sirolimus, or everolimus, you should not take these medications until you have had your labs drawn the morning of your test. You should take all other medications.

In the first 2 weeks after your transplant, we may ask you to stay in the hospital area until your results come back so that we can address any problems immediately and save you a return trip back to Washington, D.C.

Staple removal

This is a simple procedure done in the office, typically 3 weeks after transplant. No local or general anesthesia is needed. Most people have no or minimal discomfort.

Ureteral stent removal

Most patients at the time of transplant have a plastic tube (stent) placed in the bladder to assist in healing. This needs to be taken out to prevent future infections. This is typically done 4-5 weeks after your transplant. It is done by a surgeon and takes about 15 minutes. An anesthesiologist will monitor your pain and provide anesthesia should you need it. This is done in a clinic, but no incisions are necessary.

If you need a kidney biopsy

This usually occurs if your transplant function declines without an obvious reason or there is a concern about rejection. If it is an urgent biopsy, you might be admitted to the hospital for the procedure. Otherwise it will be scheduled as an outpatient same-day procedure.

Dialysis catheter removal

For patients on peritoneal dialysis, the catheter typically is not taken out at your initial hospitalization. If you go home with the catheter in place, we will plan to take out your catheter when we remove your stent. In these cases, you will need general anesthesia for the removal rather than a local anesthetic. If you have a tunneled catheter for dialysis, once your kidney function is adequate we will schedule removal.



For patients with acute rejection of their transplant, we have available treatments including plasma exchange and maintenance dialysis provided by the inpatient plasmapheresis/dialysis team.

Post-transplant restrictions.

After your transplant, you will have questions about restrictions in your daily life. You should not hesitate to call your APP with any questions. Below are some general guidelines for transplant patients but your specific case may require some different restrictions, which your post-transplant team will let you know.

General activity

Following your surgery, you can engage in light activity including walking, climbing stairs, and exercise other than weightlifting. You should not lift items more than 15-20 lbs. (a medium bag of groceries) until 3 months after your transplant. You will not have your full energy or strength immediately after your transplant, but this will steadily improve over the first 2 months after surgery. Patients often complain of difficulty sleeping. You should let your transplant team know if you are having sleeping problems. If needed, they can prescribe medication to help you sleep. You can take a shower when you go home. Once your staples are removed you can also take baths and swim. While on immunosuppression, you should only swim in salt water or chlorinated (pool) water. You should avoid freshwater such as ponds and lakes.

You should not drive immediately after your transplant. Once you are off narcotic pain-killers and have your staples removed (typically week 3) you can begin driving again, but you must ask a provider first.

Return to work

Following transplant, we expect you to be out of work for 2-4 weeks. Patients typically feel they lack the energy to return to work during this time. In addition, the number of follow-up appointments during this time typically makes a return to full time work difficult.

For those with jobs involving heavy lifting or extreme physical activity, it may be 2-3 months before you are able to return to full time work. The transplant team can provide any needed letters for your employers regarding these restrictions.

Diet and fluids

Because you are more sensitive to infections, we recommend you do not eat raw meat or fish for the first 6 months after your transplant. For patients with high blood pressure you should still watch your sodium (salt) intake. Many patients have no potassium restriction, but occasionally the post-transplant medications can cause some elevations in potassium. Check with your transplant team before eating high potassium foods. You should have no restriction on your phosphate intake nor will you need your phosphate binder after transplant.



Matthew Cooper, MD, Director, Kidney and Pancreas Transplantation

The one food that you should never have after transplant is grapefruit. There is an enzyme in grapefruits which interferes with the medications protecting your kidney. Remember not just to avoid the juice, but be careful of things like prepared fruit salad which might contain grapefruit as well. This is the one case where moderation is not enough- you must avoid it entirely. Oranges, lemons and other citrus fruits do not contain the enzyme and are perfectly safe to eat after transplant.

You will not be on a fluid restriction. In fact, it is better for you to drink more. **Typically transplant patients should drink 2 liters of fluid per day (minimum).** The best measure of how you are doing with your fluid is the color of your urine. If it is a light yellow (almost water colored) you are doing a good job. If it is a darker yellow, drink! How much you need to drink will depend on your activity level, the temperature, and what medications you are taking.

It is not uncommon for patients to have a decreased appetite in the weeks after their surgery. This is normal and generally improves by week 3-4.

Your medications do not have significant interactions with alcohol. While drinking to excess is always to be avoided, it is acceptable to drink in moderation after a transplant.

Medications

We ask that you check with us before starting any new medications. Even common medications may interact with your transplant medications in unpredictable or dangerous ways. This includes both prescription medications given by other doctors, and over-the-counter medications such as ibuprofen, aspirin and naproxen. Before starting ANY new medication or supplement, you should check with the transplant team to avoid interactions.

Some of the common medications that cause problems with the immunosuppressive medications are as follows:

Blood Pressure Medications

Diltiazem
Verapamil

Medications for Infections

Flagyl (metronidazole)
Erythromycin
Fluconazole
Rifampin

Pets and animals

Caring for pets needs to be limited after a transplant. While you can keep pets we ask you to find someone else to clean up after the animal or care for the litter box. You can feed and pet animals although cats should be de-clawed. This restriction typically lasts for 6 months after the transplant.

In the case of birds the risk of infection is high enough that we do not recommend keeping and caring for any type of bird following transplant.

Travelling and going outdoors

You can go out in public without a mask or gloves. (This does not include guidance about masks from the CDC to prevent the spread of COVID-19.) You should avoid constricted areas (a concert, a subway, etc.) for the first 3-6 months post-transplant. Otherwise, common sense is the rule. You should stay away from close contact with people who are visibly ill (coughing, feverish) and young children. You can be in the room with your grandchildren, but do not hug them closely. This restriction ends 6 months after transplant.

Your risk of getting skin cancer is higher after transplantation. You can go out in the sun, but should always use sunscreen (SPF 25 or higher), wear a hat and a shirt. The general rule is if you are tanning, you are getting too much sun exposure. This is true whether you go out in the sun, or use a tanning salon.

We ask that you not travel for extended time or outside the country for the first 6 months post-transplant. This is partly due to the infectious risk on airplanes. The other reason is that your clinic follow-up is important and is generally frequent enough in the first 6 months that it makes such travel difficult.

Sexual activity and pregnancy

We recommend avoiding sexual activity for the first month following transplantation. Women are able to become pregnant and have children with a transplant, but we recommend waiting at least one full year after your transplant before having children. In addition, not all immunosuppressive medications are safe for the fetus, so any pregnancies need to be planned so that your medication can be adjusted before conception and so that we can have you evaluated by an obstetrician with expertise in managing transplant recipients. It is NOT safe to change medications only after you become pregnant. If you are a woman of childbearing age who has received a transplant and are sexually active, you should always use at least one form of birth control.

Common post-transplant problems.

Urinary tract infections

Urinary tract infections (UTIs) are common especially in women after kidney transplant. Patients with a history of UTI prior to transplant are more likely to have UTI complications after transplant. UTI can cause significant temporary injury to the kidney if not treated in a timely fashion; therefore, prompt diagnosis is crucial to minimizing any negative impact on the transplant.

The typical signs and symptoms of UTI include pain with urination, darkening of the urine, as well as fevers and chills. Advanced stages of UTI will cause tenderness over the location of the kidney transplant in addition to the other changes. Treatment of UTI after transplant usually involves oral antibiotics but can require intravenous antibiotics if the infection spreads into the bloodstream. To prevent this, it is important to catch these infections early. The first step in evaluating any of these abnormalities is contacting your transplant coordinator or the coordinator on-call at night. Do not wait to call the transplant center until after you are seen by your PCP. Please involve the transplant program in helping to address these medical concerns.

Viral infections

Viral infections are much more likely to occur in patients after transplant due to the IS medications. There is a wide spectrum of viral infections, including viruses that have little to no impact on the transplant organ as well as other viruses that have a significant negative impact on the long term health of the kidney.

Typical signs and symptoms of a viral infection include fever, malaise, muscle pain, sore throat, and occasionally diarrhea and/or nausea as well as vomiting. Most viral infections do not require treatment other than maintaining adequate fluid hydration while the virus infection is occurring. The first step in evaluating any of these abnormalities is contacting your transplant coordinator or the coordinator on-call at night. Do not wait to call the transplant center until after you are seen by your primary care doctor. Please involve the transplant program in helping to address these medical concerns.

Vaccines

You are taking prophylaxis against cytomegalovirus (CMV) to minimize the risk of CMV infection or reactivation. You are encouraged to get yearly "flu shots". Please contact your transplant coordinator if you have questions about which vaccines are acceptable. Please avoid all live virus vaccines. Acceptable vaccines include pneumovax, hepatitis A and B, influenza and tetanus-diphtheria.



Members of the MedStar Washington Hospital Center Patient Services Team: Lori Robinson, Patient Registration Associate; Roland Walker, Patient Services Manager; Rachel Cross, Patient Registration Associate

Dehydration

Although dehydration sounds like a simple problem, it can lead to very serious consequences in kidney transplant recipients. A healthy transplant recipient must drink 2-3 liters of water per day in order to optimize kidney transplant function. When a recipient gets sick with issues like diarrhea or vomiting, it is not unusual for the fluid requirement to double or triple in order to maintain the health of the kidney. For this reason, dehydration is taken very seriously in kidney transplantation and is a very common reason for temporary hospitalization.

There are many causes of dehydration which will not be included here. The typical signs and symptoms of dehydration include decreased urine output, darkened urine and sometimes changes in alertness. The first step in evaluating any of these abnormalities is contacting your transplant coordinator or the coordinator on-call at night. Do not wait to call the transplant center until after you are seen by your PCP. Please involve the transplant program in helping to address these medical concerns.

Post-transplant kidney injury

There are many reasons kidneys can be injured after transplant, from dehydration to rejection. Rejection occurs in about 5% of transplant patients in the first year post transplant with rates declining as time goes on. The major risks for rejection include missing medications, lab appointments, and routine follow-up. Signs of kidney injury, regardless of the cause, include pain at the transplant site, blood in the urine, low urine output, and swelling. However, there are times when there are no symptoms, so keeping up with labs and visits is important.

Delayed graft function

The diagnosis of delayed graft function (DGF) occurs when your new kidney does not function well enough to avoid dialysis after transplant. Approximately 20-40 percent of kidney transplants will demonstrate DGF. The vast majority will begin to function well enough to avoid dialysis for years afterwards. If your kidney demonstrated DGF, you are in a higher risk category for rejection (your transplant team knows this, and will adjust your lab schedule and medications accordingly).

When to call the transplant clinic

You should always feel free to call the transplant clinic for any questions or concerns. Routine questions should be saved for normal business hours (9 a.m. to 5 p.m.), but for emergencies, there is a transplant coordinator, surgeon, and nephrologist on call 24 hours a day. The afterhours number is **202-444-3700**. There are some problems where we ask you to always give us a call:

Fever

Your temperature will normally change by up to 2 degrees over the course of a day. However, for temperatures greater than 100.6° F (38.0° C) you should always call. Even if you are otherwise feeling well, the medications we give you make you less aware of an infection, so call us for all fevers.

Decreased urine output

If you have any difficulty or pain while urinating, change in the color of the urine, or notice a significant decrease in the amount of urine that you make, you should call the transplant center.

Lost/missing medications

Your immunosuppressive medications are critical to the success of your transplant. Even missing a single dose can cause a problem. If you should lose or forget your medication, you should call the transplant center immediately (even if after hours) and we will do our best to find you another supply. We do not keep extra medication at the transplant center, so you will either need to pick up (and possibly pay for) a new supply, or come to the emergency room to receive medication.

Refills of medications typically take 5 to 7 days for your pharmacy to process and deliver, so please be aware when you are running low on medication. It is also important to realize that pharmacies may not be open or fully staffed on weekends. **Always keep track of your medication supply and plan ahead.**

Readmission to the hospital

It is not uncommon that at some point in your post-transplant course you will need to be admitted to the hospital. Most commonly this is because your kidney function is abnormal, and we need to find the cause. When possible, we will try to admit you directly to the hospital and skip the emergency room. After normal business hours, or when the hospital is full, this may not be possible. Make sure that you notify the Emergency Department team that you are a transplant recipient when you arrive there.

When you are an inpatient, you will again be under the care of our inpatient team. Your usual post-transplant nurse coordinator will resume your care after you leave the hospital. During your hospital stay, all questions should be directed to your inpatient team instead.

If you are admitted to an outside hospital, please contact the transplant center, or have your local doctor contact the transplant center so that we can help your team manage your health. In many cases, we will arrange transfer to the Transplant Institute to better manage your care.

Transplantation is always changing.

Transplantation is an area of ongoing research. New drugs are always being studied to improve patient and kidney survival.

You may find you are on drugs not included in this section. That is OK—we are always looking for newer and better drugs. If you are curious about the medications we are using, please ask your team and they will explain both the reason for the medication and also the risks of the medication.

It is always better to talk with your team in person than to do research on your own—online research can often be confusing and may even be misleading.

If you do decide to gather your own information about the medications you are on, please discuss your findings with the team and allow them to review what you have found. They will be able to put your information in the context of your medical condition and help you come to a decision on what medications are best in partnership with your doctors.

Transplant medications.

Following are common medications used post-transplant. We have provided basic information about them, and where possible, pictures. Please be aware that as new producers make the medications, you may find that your pills look somewhat different than what is pictured here. If you have any questions about your medications, please call the transplant center immediately.

Immunosuppressants

Tacrolimus (Prograf, Envarsus, Astagraf)



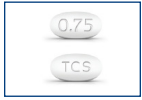
Tacrolimus 0.5 mg



Tacrolimus 1 mg



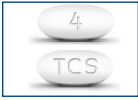
Tacrolimus 5 mg



Envarsus 0.75 mg



Envarsus 1 mg



Envarsus 4 mg



Astagraf 0.5 mg



Astagraf 1 mg



Astagraf 5 mg

Indications: Most important medication to prevent rejection

Possible side effects:

High blood pressure
Diabetes
Increased creatinine
Tremors
Headaches
Confusion
Nausea/vomiting/diarrhea
Low magnesium
High potassium
Hair loss

Patient information:

- Take medication 12 hours apart.
- Envarsus and Astagraf are long acting (once a day) forms of Tacrolimus. They are not interchangeable with Tacrolimus. **You should be careful and clear about what specific tacrolimus brand you are taking.**
- Tacrolimus is best absorbed on an empty stomach; however, it is okay to take it with food. **It is most important to be consistent.**
- Tacrolimus should be taken separately from any magnesium pills you are taking.
- No grapefruit juice because this can increase the Tacrolimus level.
- Doses may change frequently after transplant. Make sure you know the correct dose you should be taking
- Make sure you are able to identify your medication as different generics are available.
- Do not skip doses unless instructed by physician.
- On clinic days, do not take the morning Tacrolimus dose until after your labs are drawn.
- There is minimal data on the use of this drug in pregnancy. Women should not become pregnant while taking this drug.

Cyclosporine, modified (Neoral)



Cyclosporine 25 mg



Cyclosporine 100 mg

Indications: Important medication to prevent rejection when one can not tolerate Tacrolimus

Possible Side Effects:

High blood pressure
Diabetes
Increased creatinine
Tremors
Headaches
Confusion
Nausea/vomiting/diarrhea
Low magnesium
High potassium
Hair growth (facial)
Joint pain
Increased gum growth

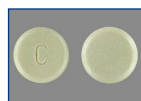
Patient information:

- Take medication 12 hours apart.
- Cyclosporine is best absorbed on an empty stomach; however, it is okay to take with food. Be consistent.
- Cyclosporine should be taken separately from any magnesium pills you are taking.
- No grapefruit juice because this can increase the drug level.
- Doses may change frequently after transplant. Make sure you are aware of the correct dose you should be taking.
- Do not skip doses unless instructed by physician.
- On clinic days, do not take the morning dose until after your labs are drawn
- Can be used in pregnancy and when breast feeding.

Mycophenolate mofetil (Cellcept) or Mycophenolate Sodium (Myfortic)



Cellcept 250 mg



Myfortic 180 mg



Myfortic 360 mg

Indications: Very important medication that works together with Tacrolimus or Cyclosporine to decrease the chance of rejection

Possible side effects:

Diarrhea
Nausea/vomiting
Low white blood cell count
Swelling in arms/legs
Low red cell count
Shortness of breath

Patient information:

- Take medication twice a day (morning and night)
- Doses may be decreased by your doctor if you have an active infection
- If severe nausea or cramping occur, the dose may be split up to 4 times a day
- Do not crush tablets or capsules. Avoid direct contact with active ingredient.
- Causes severe birth defects. Women should not become pregnant while on these drugs.

Sirolimus (Rapamune) Everolimus (Zortress)



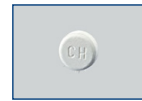
Sirolimus 1 mg



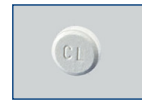
Sirolimus 2 mg



Everolimus 0.25 mg



Everolimus 0.5 mg



Everolimus 0.75 mg

Indications: May be used in combination with, or as a replacement for, Tacrolimus and Cyclosporine

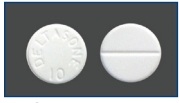
Possible side effects:

Poor wound healing
Diarrhea
Rash
Low red blood cell count
Protein in urine
Low platelet count
High cholesterol
Mouth ulcers
Low potassium

Patient information:

- Sirolimus is taken daily.
- Everolimus is taken twice a day (12 hours apart).
- May take with or without food but must be consistent
- Do not take morning dose before lab draws when you have a clinic appointment.
- Do not crush or chew tablets.
- If you need major surgery, you should be switched to a different medication before the procedure.
- These medications should not be taken in pregnancy.

Prednisone (Deltasone)



Prednisone 5 mg

Indication: Works with other immune suppressive agents to prevent rejection in organ transplants

Possible side effects:

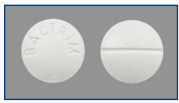
Hair growth
Diabetes
Osteoporosis
High cholesterol
High blood pressure
Swelling in arms/legs
Increased appetite
Glaucoma
Mood changes
Bruising

Patient information:

- Normally used immediately after transplant with other agents and then discontinued
- Can be used to treat rejection (higher doses)
- If diabetic and on steroids, check blood sugars regularly and inform your physician if it is not controlled
- Do not skip doses. Take as directed by physician for best results.

Anti-infectious agents

Sulfamethoxazole/trimethoprim (Bactrim)



Bactrim SS (single strength)

Indication: Prevents infection, specifically for prophylaxis for pneumocystis pneumonia (PCP)

Possible side effects:

Headache
Nausea/vomiting
Diarrhea
Appetite loss
Sensitivity to light
Rash

Patient information:

- Given daily, or if there is active infection, twice daily
- Dose needs to be adjusted if your kidney is not fully working
- You will take this medication for up to 3 months after transplant.
- Do not use if you have a sulfa allergy.
- Do not skip doses.

Pentamidine Isethionate (Nebupent)



Indication: Protects the body from pneumonia

Possible side effects:

Fatigue
Lightheadedness
Cough
Decreased appetite

Patient information:

- An inhaled monthly treatment, not a pill
- Monthly nebulizer treatment to protect the body from pneumonia for those allergic to Bactrim
- Patient will be on this for up to 3 months or as specified by physician.
- Appointments will need to be scheduled at the infusion center to receive these treatments.
- Do not miss doses

Nystatin suspension



Indication: Prevents fungal infections in the mouth and throat due to immune suppression

Possible side effects:

Poor sense of taste in mouth

Patient information:

- Liquid should be kept in contact with the tongue for 30-60 seconds before swallowing.
- Time after meals and before bed
- Do not eat or drink for 10-15 minutes after taking.
- Brush your teeth before bed.
- You will be on this medication for 1 month or as specified by physician.

Valganciclovir (Valcyte)



Valganciclovir 450 mg

Indications: Antiviral activity and protection against cytomegalovirus (CMV) in low, moderate or high risk patients

Possible side effects:

Fever
Headache
Diarrhea
Nausea
Confusion
Anemia
Low white count

Patient information:

- Dose needs to be adjusted if your kidney is not functioning perfectly
- Do not break or crush
- Available as 450 mg tablets and 50 mg/ml solution
- You will be on this between 6 weeks and 6 months.
- Do not miss doses.

Other medication

Pain medication

Narcotics (Percocet, Dilaudid, Oxycodone)



Percocet



Dilaudid



Oxycodone

Indications: Assists in returning to normal activity while controlling the pain post transplant

Possible side effects:

Drowsiness
Nausea
Constipation

Patient information:

- Take with food so as to prevent an upset stomach.
- Do not drink alcoholic beverages or drive when taking this medication.
- Always take a stool softener if actively taking pain medication.
- Percocet is a combination pill—it has Tylenol in it. Do not take extra Tylenol with Percocet.

Other Information.

Insurance and finances

There are many costs related to transplant. The most common is the cost of medication. Our financial team has made every effort to have a coverage plan to minimize your medication costs. There are other costs that are less obvious, including the cost of transportation, the cost of your insurance premium, and the cost of lost wages due to being out of work. You may also have co-pays for testing or office visits. Your post-transplant team, including your social worker and financial coordinator, will work with you to minimize these costs.

Important information about Medicare post-transplant

- Medicare alone is **not** sufficient coverage for post transplant expenses. You will need a secondary plan to cover those expenses not covered by Medicare.
 - Medicare covers only 80% of drug costs, doctor costs, or lab costs. The government does not allow us to assist you with the remaining 20% of costs.
- If you received a transplant from a living donor, you must keep your Medicare plan for at least 3 years after the transplant in order to keep your donor's expenses covered.
- Medicare part A is automatic, but Medicare part B, which covers your transplant medications requires you to continue to pay monthly premiums. If you forget to pay these, even if you are 'eligible' for Medicare, you will lose your coverage.
- Most drugs are covered by Medicare part D, but **immunosuppressive drugs are covered by Medicare part B and do not require pre-certification or pre-approval.** Your outpatient pharmacist may not know this. If you are told to get pre-certification for these medications, tell your pharmacist to bill under part B, or have them contact the transplant center and we will explain it.
- If you are younger than 65, and not on disability, but covered by Medicare, **you will only be eligible for Medicare for 3 years (36 months) post-transplant.** At that time, you will need to find other coverage until you turn 65, become disabled, or return to dialysis (when you will again qualify for Medicare).

Obtaining secondary coverage

If you have Medicare and have lost your secondary coverage you will need to seek alternative coverage. Your options for this include:

- If you are not working you may be able to apply for a State Medicaid plan.
 - **medicaid.gov**
- Enroll in a Medicare Advantage plan
 - **medicare.gov**
 - o Go to: Sign up/change plans
 - o Go to: About Medicare health plans
 - o Go to: find and compare Medicare health plans in your area
 - o Enter your Zip Code (this will navigate you to plans that are specifically in your area). Important to pick a plan that has maximum overall coverage.
- If you are married and your spouse has insurance you may want to have them enroll you in their plan.
- If you are a military veteran you may access the VA for prescription medications
- All patients are encouraged, if able, to return to or seek new employment following transplantation.

Minimizing drug costs

A variety of medication assistance programs are available to help. These can often change so please ask your social worker for a complete and up-to-date list, and to help determine if you qualify for the programs. You can also look on-line at: **needymeds.org** which is a search engine for medication assistance programs. Some of the current programs providing assistance include:

- Health Well Foundation
healthwellfoundation.org
 - Helps pay medication co-payments
 - Helps pay insurance premiums
- Patient Access Network
panfoundation.org
 - Helps pay medication co-payments
- Genentech
genentech-access.com
 - Assists with both Valcyte and CellCept medications
- Novartis
us.novartis.com/index.jsp
 - Assists with both Hecoria and Myfortic medications
- Astellas
astellas.us/index.aspx
 - Assists with Astagraf medication

You should be aware that eligibility requirements of these programs change frequently and assistance is not guaranteed. Further, the programs are funded by annual grants which often are depleted by end of the calendar year. You are more likely to find assistance and receive your medications in a timely manner if you notify your social worker as soon as you possibly can.

Coverage for being out of work

If you choose to use the Family Medical Leave Act (FMLA) which provides you with 12 weeks of legal leave time, please provide your physician with the appropriate documents in a timely manner.

If you are receiving social security disability insurance (also known as SSDI or “disability benefits”), you may need to re-submit proof of disability after receiving a transplant. If you are able to return to work, you will no longer be eligible for disability. While we anticipate that you will return to work, if you have a complicated recovery and remain disabled, having a transplant does not prevent you from receiving disability.

Letters to donor families

Recipients who wish to write letters to the families of deceased donors are welcome to do so. Many times, it provides comfort to families who are still grieving over the loss of a loved one. The MedStar Georgetown Transplant Institute will work as an intermediary to deliver all such letters. We can not share personal information about donors or their families, but if you choose to provide your contact information and the donor families are willing, they can contact you directly.

Philanthropy opportunities

For those patients who wish to help future transplant recipients, the MedStar Georgetown Transplant Institute has several opportunities for giving, including a medication assistance fund to help with post-transplant costs, as well as several projects to improve transplant services for patients. Please let any member of your team know of your interest and we can put you in touch with a philanthropy officer.

Support groups

The Transplant Institute offers monthly support groups for both pre- and post-transplant patients and family members. If you are interested in attending, please let us know and our social workers will provide the information. We also have a number of patients who ask to speak with people who have already gone through the transplant process to find out what it is like. If you would be willing to talk about your experience with others, please let us know and we will add your name to our list.

The screenshot shows the myMedStar patient portal homepage. At the top, there is a navigation bar with the MedStar Health logo, a 'Login to myMedStar' button, and an 'Enroll in myMedStar' button. Below the navigation bar, there is a 'Welcome to myMedStar.' section with a sub-header 'myMedStar is a free, secure online patient portal where you can keep track of your health information 24/7.' and a list of services available through the portal: Prescriptions, Medical records, Appointments, Communications with your provider, Test results, and Enroll now. There are also sections for 'Access a Loved One's Health Information', 'Quick Links' (Find a Doctor, Find Urgent Care, Video Visit, Pay Your Bill), and 'Read Our Frequently Asked Questions'. A yellow 'Alert' box contains information about COVID-19 monitoring. At the bottom, there is a footer with copyright information, a disclaimer, privacy policy, feedback, and social media icons.

myMedStar patient portal

myMedStar is a free, secure patient portal where you can keep track of your health information 24/7.

With myMedStar, you can:

- View and manage appointments
- See test results
- Communicate with your provider
- Renew prescriptions
- Access your health records
- And much more

It's easy to enroll:

1. Visit myMedStar.org/Enroll
2. Click “Enroll Now”
3. You will need:

- First and last name
- Date of birth
- MedStar Health Patient ID—Your unique Patient ID can be found on the first page of your visit or discharge summary. If you don't have your Patient ID, complete the secure request form at myMedStar.org/Enroll.

Visit **myMedStar.org** or call **877-745-5656** for more information.

You're never far from the MedStar Georgetown Transplant Institute.

The MedStar Georgetown Transplant Institute is making it more convenient for you to be evaluated for transplantation. We're everywhere you are. Our convenient locations throughout the Washington, D.C., region make it easy to access our experienced multidisciplinary team. We are now evaluating kidney and pancreas transplant candidates at eight convenient locations. To make an appointment, please call **202-444-3700**.

- A. MedStar Georgetown University Hospital**
3800 Reservoir Rd., NW
Washington, DC 20007
- B. MedStar Washington Hospital Center**
110 Irving St., NW
Washington, DC 20010
- C. MedStar Georgetown Transplant Institute in Fairfax**
3020 Hamaker Ct., Ste. 501
Fairfax, VA 22031
- D. MedStar Southern Maryland Hospital Center**
7503 Surratts Rd.
Clinton, MD 20735
- E. MedStar Georgetown Transplant Institute in Frederick**
163 Thomas Johnson Dr.
Ste. E
Frederick, MD 21702
- F. MedStar Georgetown Transplant Institute in Annapolis**
Annapolis Tech Park
2629 Riva Rd., Ste. 110
Annapolis, MD 21401
- G. MedStar Franklin Square Medical Center**
9000 Franklin Square Dr.
Baltimore, MD 21237
- H. MedStar Georgetown Transplant Institute in Ellicott City**
9501 Old Annapolis Rd.
Ste. 220
Ellicott City, MD 21042



[MedStarGeorgetown.org/Transplant](https://www.MedStarGeorgetown.org/Transplant)