

POST-OP KIDNEY TRANSPLANT PATIENT GUIDE



CONGRATULATIONS ON YOUR NEW KIDNEY!

This guide is for you and your caregiver. Please become familiar with this information. It will serve as a guide and resource to you in the coming months. Please understand that this is just a guide. Your surgeon and transplant nephrologist will decide your specific plan of care.

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TRANSPLANT CLINIC

Location

The Transplant Clinic is located on the third floor of the Kentucky Clinic, Wing D. (Park in the Kentucky Clinic parking garage; additional parking information is on Page 18 of this guide.)

Your schedule

You will have these clinic visits:

- For one to two weeks after you go home: Two visits a week.
- For the next two to four weeks: One visit a week.
- For the second and third month: One visit every other week.
- After three months: One visit a month.
- After nine months: One visit every six weeks.

Arrive at the clinic at your scheduled time. We will draw blood for tests. These measure kidney function, blood count, cyclosporine, and sirolimus (Rapamune), tacrolimus (Prograf) or everolimus (Zortress) levels.

Medicines

Always bring your medicines with you to the clinic.

On your appointment day, **do not take** the following medications until your labs are drawn: tacrolimus (Prograf or Envarsus), cyclosporine (Gengraf), everolimus (Zortress) or sirolimus (Rapamune).

What to expect

Once we draw blood for your labs, you can take your medicines and go eat in the cafeteria. It will take one to two hours to get your results. Please be prepared to spend all morning in the clinic. To pass the time, you may want to bring something to read or another quiet activity.

After your visit

We will call you on the day of or the day after your visit if your medicines need any changes. We must be able to contact you or leave a message. If you don't already know, please learn how to get messages on your cell phone or answering machine. Tell the transplant team if your phone numbers change.

After your transplant clinic visits

Your routine care

After three months, you will go back to seeing your family doctor or local nephrologist. The transplant team will still manage your care related to your transplant. You must have a primary care doctor. The transplant team must have correct and up-to-date contact information for your primary care doctor.

Your family doctor or local nephrologist will take care of your normal medical needs. These include stomach medicines, blood pressure checks, blood sugar medicine, chronic pain issues and thyroid issues.

Your lab tests

We will check your lab results on a regular basis. You can have your labs done close to home or at the transplant clinic. This is by appointment only. If you get your tests done close to home, we will give your physician lab orders.

You must make sure that the UK Transplant Center gets your lab results on a regular basis.

Please confirm that your provider faxes results to **859-257-8966**.

Your family doctor may contact the transplant center about your care. We will answer questions or give advice.

PROTECTING YOUR NEW KIDNEY

Wear your mask

It is important to wear a mask. This is especially critical right after your transplant.

- For three months after transplant, wear a mask everywhere outside your home.
- If you are treated for rejection, you may need to start wearing your mask again.
- Wear your mask to and from the transplant clinic. There is often construction in or near the hospital.

Incision care

When you are strong enough, you can take showers.

- Use soap and water. Wash right over the wound and staples.
- After you shower, replace the dressings that cover open wounds.
- The incision may itch, feel numb, be bruised and/or sore. This is normal.
- In most cases, we remove staples in the clinic two to three weeks after surgery.

Wash your hands often

This is the best way for you and your family to prevent infection. Use antibacterial soap or alcohol-based hand sanitizer.

Plants and soil

Avoid live plants. Do not touch soil for three months after transplant. You do not have to remove plants from your home, but do not have them indoors. After three months, you must wear gloves and a mask when you handle soil.

Yardwork

Do not mow grass until six months after transplant. This includes using a riding lawnmower or a weed eater. After the first six months, you must always wear a mask and gloves when doing yardwork.

Sexual activity

Once you feel strong enough, you may resume sexual activity.

- Take care not to become pregnant or cause someone else to become pregnant after transplant. The effects of most anti-rejection medicines on fetuses are still unknown. Cellcept and Myfortic are harmful and may cause birth defects.
- Always practice safe sex. Avoid the risk of sexually transmitted diseases.
- Contact your coordinator immediately if you become pregnant.



NUTRITION

Healthy eating

Eat a low-fat diet with lots of fruits and vegetables. You may eat fresh fruits and veggies, but wash them very well. Do not eat raw fish. Cook all meats to at least medium well. Avoid grapefruit, pomegranate, starfruit or any juices that may contain them as these fruits can interact with some transplant medications.

Weight gain

Cut out nearly all fat from your meals. Weight gain is a common problem after transplant. Often, this is because steroid medicines cause you to want to eat more.

Avoid fatty and fried foods. This will help control weight and cholesterol. You may need to see a dietary specialist if weight gain becomes a problem.

Weight loss

This is also common after transplant. Some people do not feel like eating much. The cause may be medicines or weakness. It may help to eat five to six small meals a day rather than three large ones. You may need to see a dietary specialist if you continue to lose weight.

CAREGIVER RESPONSIBILITIES

You must have at least one caregiver to help you after transplant. Here are some jobs the caregiver will do:

Patient care

- Come to the hospital before you go home so that the nurse coordinators can teach you both about your care.
- Call the transplant team in case of emergency.
- Make sure you take all medicines as ordered.
- Check and record your health information each day. This includes your blood pressure, blood sugar levels as needed, temperature and weight.
- Drive you to the clinic for each visit. Also, drive you to unscheduled clinic and emergency department visits.

Everyday tasks

- Run necessary errands. This includes grocery shopping, trips to the pharmacy and doing laundry.
- If needed, help with bathing and wound care.
- Help make meals.
- Encourage you to drink fluids and eat healthy.
- Encourage and help you to exercise daily.
- Make sure you wear your mask.

DOS AND DON'TS

THINGS YOU MUST DO

Protect your health.

- Wear your mask.
- Wash your hands often.
- Take your medicines as ordered.
- Walk at least every four hours when awake.
- Drink 68 ounces of fluid every day.
- Use an incentive spirometer (blow bottle) every four hours.

Know your numbers.

- Take and record your blood pressure several times a day.
- Take and record your temperature every morning and every night.
- Weigh yourself every morning and record the results.
- Check your blood sugar as ordered.

Be active in your care.

- Keep all of your doctor's appointments.
- Ask questions and keep notes.
- Always ask your transplant coordinator before you start taking a new medicine

THINGS TO AVOID

Avoid these activities.

- Do not drive until your doctor says it is OK. This is usually 30 days after transplant.
- Avoid swimming in pools, lakes, rivers or oceans for at least six months.
- Do not lift anything heavier than a gallon of milk until your doctor says it is OK.
- Do not use alcohol, cigarettes or other tobacco products, or illegal drugs.

Avoid these situations.

- Avoid direct sunlight. Wear long sleeves, a hat and sunblock with at least SPF 30.
- Avoid large crowds of people for three months.
- Avoid anyone with an illness you could catch. This includes colds, fevers and sore throats.
- Avoid anyone who has had a live vaccination for at least two weeks. Avoid changing diapers for children that receive live vaccines for two weeks if at all possible.

Avoid these medicine mistakes.

- Do not take any over-the-counter medicine without your doctor's approval.
- Do not adjust or change your medicines unless your doctor tells you to.



GUIDELINES FOR LIVING WITH YOUR NEW ORGAN

Physical activity

Be patient with yourself. Regain your strength through a gentle, gradual increase in the physical activity you do each day.

- Until your doctor says it's OK, do not lift anything heavier than a gallon of milk.
- Begin increasing your activity by walking.
- Over time, you may begin other exercise if your doctor says it is OK. Examples are jogging, playing golf or riding a bicycle.
- Avoid contact sports. These include boxing, martial arts, football, basketball and hockey.

Dental care

Good oral hygiene is a must.

- Visit your dentist once every six months.
- Have any infection treated right away. When you take immunosuppressive medicines, a minor dental infection can be very serious.
- Before you have any dental work done, you must have a short course of oral antibiotics.

Your dentist will arrange for antibiotic therapy before dental work and follow American Heart Association

guidelines. Please contact your coordinator for further guidance on antibiotic therapy recommendations in regard to your dental visit.

Immunizations

You may only get killed-virus immunizations (shots). You may not get any live or weakened virus vaccine. These include mumps, measles, rubella, chicken pox, shingles and oral polio.

- You may get a flu shot three months after transplant.
- Family members should get a flu shot right away.
- You and your family must avoid the nasal vaccine for the flu.

Smoking

Stop smoking and tobacco use.

- The blood vessels in transplanted organs harden faster. Smoking and using other types of tobacco makes this problem even worse.
- All tobacco products have nicotine. It causes arteries to spasm, even the ones in your new kidney.
- Chewing tobacco is also a known cause of oral cancer.

CONTACTING THE TRANSPLANT TEAM

The team's office hours are Monday – Friday, 8 a.m. – 4 p.m. If you call with a non-emergency after 3 p.m., we might not call you back until the next business day.

For emergencies

Call the 24-hour UK answering service at 859-323-6667. Follow these steps:

- You or your family will call 859-323-6667. You do not need to dial the area code if you are calling from Lexington.
- A UK operator will answer. Tell the operator that you need to speak with the on-call kidney transplant nurse coordinator. Do not use the emergency contact for non-emergency questions.

Call the emergency contact right away if you have any of the following:

- Temperature greater than 100.5° F.
- Systolic (top number) blood pressure greater than 180 or less than 100
- Diastolic (bottom number) blood pressure greater than 100.
- Much more drainage from your wound.
- Vomiting, diarrhea or constipation lasting more than two days.
- Vomiting that is so bad you cannot keep your immunosuppressive medicines in your stomach.
- Pain that is not helped by your pain medicine.
- Bright red blood in your urine or stool.
- Sudden weakness.
- Less urine or dark urine.
- Major change in your weight – a gain or loss of more than three pounds in 24 hours.
- Major change in blood pressure.
- New pain at the site of your transplant after the wound has healed.

For non-emergencies

- Call your nurse coordinator.
- Please note that nurse coordinators see patients in the clinic so your coordinator may not be in the office.
- If your coordinator does not answer, you can leave a voicemail and your nurse will call back as soon as possible. This is usually within 24 hours or the next business day.

For prescriptions

- You must tell the transplant team seven to 10 days before you run out of medicines.
- Many insurance companies need to have preauthorization.
- You must make requests to your coordinator during regular business hours.



POSSIBLE COMPLICATIONS

Most patients do well after transplant, but some experience complications. These can lead to long hospital stays and even death. Here are some possible complications:

Primary nonfunction

This is when the kidney does not start working right after transplant. This complication is serious but rare. There are many things that can cause it.

Bleeding

In any surgery, there is a risk of bleeding. If there is bleeding after surgery, you may have to return to the operating room.

Rejection

This is how your body responds to anything it thinks is foreign. Your body will not think the new organ is a part of you. Anti-rejection medicines will help your body accept the new organ. Rejection can happen anytime after your transplant. We can usually treat it successfully.

Rejection has no symptoms. Some signs you may have rejection include:

- Discomfort at the site of the transplant.
- Fever greater than 100.5°F.
- Less urine output.
- Weight gain.
- Changes in blood pressure.
- Abnormal lab test results. If this happens, you may need a biopsy.

You may be admitted to the hospital for treatment. When you go home, you may have medicine changes. You may also need to have lab tests and clinic visits more often.

Infections

Anti-rejection medicine makes it harder for your body to fight infections. So you must avoid people with an illness you could catch. This includes colds and flu. Here are some common infections:

- **Viral:** Common types are cytomegalovirus, BK virus, Epstein-Barr virus and the herpes virus. Most people have been exposed to these during daily life. Anti-rejection medicines may activate them. This can be a serious problem that needs treatment. There is medicine to treat these infections. If the infection is severe, you may need to go to the hospital for IV medicines.
- **Bacterial:** These may be infections in the wound. Most are treated with antibiotics. Sometimes surgery is needed.
- **Fungal:** Fungal and yeast infections may occur. Medicine and good hygiene will help prevent them. They can be very serious in the lungs. This may happen if you breathe in dust or mold.

Urinary tract infections (UTIs)

Call your coordinator if you experience any of these symptoms when you urinate: fever, pain, having to go quickly, going often, burning or foul smell.

Dependence on ventilator

Dependence on a ventilator, or breathing machine, may be caused by a lung problem or pneumonia.

Poor nutrition

This may happen if you experience a loss of appetite after your transplant.

Delayed graft function

Sometimes a transplanted kidney is slow to start to functioning. In most cases, the kidney will start working on its own after a few days. However, in some cases, dialysis may be required for a short time until your kidney is functioning well.

Neurological side effects

These can range from mild confusion to seizures and stroke.

Blood supply

Blood supply to your new organ may become compromised after surgery, requiring an additional operation.

Development of tumors

Medicines that lower your immune system increase the risk of cancer. Skin cancer and lymphoma are the most common. You need to follow up with your doctor to get tests. These include mammograms,

Pap smears, prostate exams, skin exams and colonoscopies.

Call your family doctor if you develop any new skin lesions. Tell your transplant coordinator if your doctor finds any cancer.

Mood changes

Examples are depression, crying spells, irritability, difficulty sleeping, night sweats or memory loss. Your caregiver and transplant team will help you get through this. Let us know if you have any of these issues for more than a week.

MEDICATION REMINDERS

You must take your medicines as ordered. This is the most important thing you can do to protect your new kidney. Never skip a dose or change your dose unless your doctor orders it. Here are some general rules for taking transplant medicines:

- Always call the transplant team before you start taking a new medicine. This includes over-the-counter or prescription medicines your other doctors have prescribed.
- Store all medicines at room temperature unless the instructions on the medicine container say otherwise.
- Do not store medicines in the bathroom cabinet. Keep them in their prescription bottles or your pill box.
- Please make sure children cannot get to your medicine.
- When flying, keep your medicines in your carry-on bag. Legally, when you fly, you must keep all medicine in the original pill bottles. If not, they will be thrown away.
- Make taking your medicines part of your daily routine, just like eating and sleeping.
- While you are in the hospital, the transplant pharmacist will teach you about your medicines.
- Always bring your pill bottles to every clinic visit.

Medication resources

- Abbott, the maker of Gengraf®
www.abbott.com
- Astellas, the maker of Prograf®
www.us.astellas.com
www.prograf.com
- Novartis, the maker of Neoral® and Myfortic®
www.novartis.com
www.myfortic.com
- Genentech, the maker of Cellcept® and Valcyte®
www.cellcept.com
www.valcyte.com
- RxAssist, patient assistance program
www.rxassist.org
- Rx Outreach, patient assistance program
www.rxoutreach.org
- Pfizer, the maker of Rapamune®
www.rapamune.com
- Partnership for Prescription Assistance
www.pparx.org
- Transplant Experience
ukhealthcare.uky.edu/transplant-center
- MyMedSchedule
medactionplan.com/mymedschedule

TRANSPLANT MEDICINES

Tacrolimus (Prograf® or Envarsus-XR®)

Type of drug: Anti-rejection

How often to take: Every 12 hours for Prograf® or 24 hours for Envarsus®

Possible side effects:

- Decreased kidney function: We will closely check your kidney function with lab tests. Keep to the correct dose to minimize the risk.
- Tremor of hands: This usually stops as the dosage is reduced. If tremors come back, it may indicate the level is too high.
- Increased blood pressure: We will use medications to keep your blood pressure under control.
- Headache.
- High blood sugar: We will closely check your blood sugar with lab tests.
- Flushing of the skin.

What to do if you miss a dose: If you remember it within six hours, go ahead and take it. If you remember after six hours, **do not** make up for the missed dose. Take your next dose at the regular time and get back on schedule. Never take a double dose. If you miss two or more doses, call your transplant nurse coordinator.

If your body cannot handle tacrolimus, we may replace it with cyclosporine (Neoral® or Gengraf®).

Do not eat grapefruit, pomegranate or starfruit or anything that includes their juices while taking this medicine.

Mycophenolate Mofetil (Cellcept®)/Mycophenolic Acid (Myfortic)

Type of drug: Anti-rejection

How often to take: Every 12 hours

Possible side effects:

- Decreased blood counts: We will follow your labs closely and adjust this medicine as needed.
- Dizziness or drowsiness.
- Nausea, vomiting or diarrhea.
- Insomnia.
- Mood changes.

What to do if you miss a dose: If you remember it within six hours, go ahead and take it. If you remember after six hours, do not make up for the missed dose. Take your next dose at the regular time and get back on schedule. Never take a double dose.

Prednisone

Type of drug: Anti-rejection, steroid

How often to take: Once a day, in the morning

Possible side effects:

- Salt and water retention: This may make your ankles puffy.
- Stomach ulcers: Always take this medicine with food. You will take medicine to prevent ulcers until we reduce your dose.
- Weight gain: This may be from storing extra fluid or extra fat. A common problem is “moon face.” Weight gain in the face is a common with steroids. It becomes less of a problem as your steroid dose is lowered.
- Increased appetite: You may have to limit portions or make changes to your diet to avoid weight gain.
- Muscle weakness: Be careful when you get out of chairs or climb stairs until you get your strength back. Continue to walk and exercise to keep your strength.
- Blurred vision: This problem gets better as your steroid dose is lowered. Do not get new glasses right after your transplant. Your vision will change

over the next six months. You may also develop cataracts. Have an ophthalmologist check your eyes regularly.

- Sleep problems.
- Slow wound healing.
- Mood swings: You may feel happy one minute and depressed the next. You should feel like your normal self again when your steroid dose is lower.
- Increased risk for infection.
- High blood sugar: Tell your doctor if you have any sign of high blood sugar, such as increased thirst or tiredness. You may need to start on insulin if your blood sugar stays high.
- Osteoporosis or low bone density: This medicine can make your bones brittle. You should have your family doctor check this every year. You may need to take a medicine to treat osteoporosis.

What to do if you miss a dose: If you remember it within 12 hours, take it right away.

If you remember after 12 hours, do not make up for the missed dose. Take your next dose at the regular time and get back on schedule. Never take a double dose. Do not stop this medicine unless the transplant team says it is OK.



Sulfamethoxazole/Trimethoprim (Bactrim, Septra, Cotrim)

Type of drug: Antibiotic (to prevent infection)

How often to take: Once a day, in the morning

Possible side effects:

- Nausea, vomiting, cramps or diarrhea: If you have these, take the medicine with food.
- Skin rash or itching: If you have these, call your doctor right away.
- Sensitivity to sunlight: Always wear sunscreen when outdoors.

What to do you if you miss a dose: If you remember it within 12 hours, take it right away.

If you remember after 12 hours, do not make up for the missed dose. Take your next dose at the regular time and get back on schedule. Never take a double dose.

If you are allergic to sulfa drugs, we will use dapsone instead.

Valganciclovir (Valcyte®)

Type of drug: Anti-viral drug (to prevent viral infections)

How often to take: Once or twice a day

Possible side effects:

- Lower blood counts: We will follow your labs closely and adjust this medicine as needed.
- Nausea: If you feel nauseated, take your dose with a meal or snack.
- Tremors and neurological side effects: Let us know if you have tremors or confusion. You may need to reduce the dose or stop taking it.

What to do you if you miss a dose: Wait for your next scheduled dose and keep taking it as ordered. Do not take a double dose.

Some patients may take another drug called acyclovir. It has similar side effects. You will take it once or twice a day.

Fluconazole (Diflucan)

Type of drug: Anti-fungal (to prevent fungal infection)

How often to take: Once a day in the morning

Possible side effects:

- Upset stomach.
- Change in sense of taste.
- Headache.
- Dizziness.

What to do if you miss a dose: If you remember it within 12 hours, take it right away.

If you remember after 12 hours, do not make up for the missed dose. Take your next dose at the regular time and get back on schedule. Never take a double dose.

Docusate (DOSS)

Type of drug: Stool softener

How to take: Twice a day as needed

Possible side effects:

- Upset stomach.
- Cramping.
- Diarrhea: If you have diarrhea, do not take this medicine.



Pain medications

Pain medications will be prescribed for a short while after transplant. If you were taking pain medications for chronic pain before transplant, contact your local physician for new prescriptions to continue these medications. The transplant team will prescribe pain medications related to the transplant surgery only.

Other medicines

Other medications may be prescribed for you after your transplant. Common drugs include antibiotics, blood pressure medication, supplements and insulin. However, not all patients will need these medications.

Disclaimer: This list does not include all medicines and side effects. Only use this information as a guide. It is not a formal drug reference. Please call the transplant center for more information.



SERVICES AT UK CHANDLER HOSPITAL

ATM

There is an ATM on the first floor of Pavilion H, near the registration desk. There is another ATM near the elevators on the ground floor of Pavilion A.

Buses and cabs

Lextran bus schedules are available at the information desks. Our desk staff can also assist you if you need to call a cab.

Dining options

(Hours may vary.)

- The hospital cafeteria is on the first floor of Pavilion A.
- Courtyard Café is on the ground floor of Pavilion A, near the auditorium.
- A vending area is on the first floor in Pavilion H, near the cafeteria. It is open all the time.

Don and Cathy Jacobs Health Education Center

This resource center is open to patients and visitors. The staff can help you find health information you can trust. There is also internet access, a printer and

a fax machine. It is on the first floor of Pavilion A, near the bridge to the garage. For information, call 859-323-7808.

Gift shops

Our gift shops sell various personal care items, reading materials, candy and gifts. One gift shop is in the Pavilion H lobby, across from the information desk. A second gift shop is on the first floor of Pavilion A. The phone for the Pavilion H shop is 859-257-1559; for Pavilion A, it is 859-323-4127.

Mail

A post office is on the ground floor of Pavilion H in Room M63. It is open Monday – Friday, 8 a.m. – 4:30 p.m. Mail slots are located at the main elevator on each floor.

Parking

Garages:

- The Kentucky Clinic Parking Garage is located at 140 Huguelet Ave.
- The UK HealthCare Parking Garage is located at 110 Transcript Ave.

Parking fee: There is a fee for parking. Please note the rates posted as you enter the garage. Parking is free on weekends and at certain hours of the day. You may buy extended-stay parking passes in the parking office on Level A of the UK HealthCare garage. After you buy seven-day passes two weeks in a row, parking in the garage is free for the rest of your visit. You may call the parking office at 859-257-5757 or 800-333-8874.

Shuttle from garage to hospital: Free shuttle service provides door-to-door service from the UK HealthCare Parking Garage to the hospital. Shuttles leave from Level A of the main parking garage every three to five minutes.

There is an ambassador in the parking garage from 6 a.m. – 11 p.m. daily to answer questions and help patients and visitors onto the shuttles, which are wheelchair accessible. Passengers who have a hard time walking may be dropped off in the passenger drop-off and pickup areas. These are on each floor

of the garage near the elevators. The UK Transplant Clinic is located on the third floor of the Kentucky Clinic, Wing D.

Concourse bridge to the hospital: Instead of taking the shuttle, you may walk across the bridge from Level C of the main garage. Golf cart service is available.

Pastoral services

A chaplain is at the hospital 24 hours a day, seven days a week. You can call the chaplain at 859-323-5301. There is a sanctuary on the first floor of Pavilion H in Room H-122. In Pavilion A, the non-denominational Myra Leigh Tobin Chapel is located on the ground floor.

Tobacco-free campus

The UK HealthCare campus is tobacco free. You may buy nicotine replacement products in the gift shops.





An Equal Opportunity University

Section 1557 of the Affordable Care Act
STATEMENT OF NONDISCRIMINATION
For UK Health Programs and Activities

The University of Kentucky complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. The University of Kentucky does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

Language assistance services, free of charge, are available to our patients in more than 200 languages. Please let us know if you need an interpreter.

Si usted habla español, tiene a su disposición servicios de asistencia con el idioma sin costo alguno.

如果您使用繁體中文，您可以免費獲得語言援助服務

UK HEALTHCARE TRANSPLANT CENTER
859-323-1691