Health Facts for You

Living well after kidney transplant surgery

UWHealth

Commitment to Follow-Up Care

Your care after a transplant is for your entire lifetime. The follow-up schedule is intense for the first few months.
This long-term care includes:

- Biopsies: A procedure where a small piece of tissue is taken from your kidney to look for damage.
- Labs (blood and urine tests)
- Medicines
- Transplant clinic visits
- Other tests and visits with providers

Keeping the Commitment

For a transplant to be a success, you need to commit to the following things:

- Follow the treatment plan.
- Daily blood pressure, heart rate, temperature and weight.
- Call the transplant office about any new problems or symptoms related to your transplant or about any new medicines or tests you have.
- If you have any non-transplant related questions or issues call your primary care provider.
- Take all prescription medicines as prescribed.
- Check with the transplant team when starting any new medicines to make sure there are no interactions.
- Follow the diet and exercise plan advised by your doctor.
- Go to your appointments, clinic visits, lab draws, and biopsies.
- Do not abuse your body by smoking, drinking alcohol, or using non-prescribed medicines and herbals.

Things to Remember After Your Transplant

Take medicines as directed.

- Your anti-rejection medicines and doses will be specific to you. The transplant doctors will order the medicines they feel will best fit your needs.
- It is important you do **NOT** miss doses of these medicines. Please let your coordinator know if you have missed a dose of these medication.
- Do not change your medicine doses or stopping taking any medicine without talking with the transplant team.
- Please call the transplant team before starting any new medicines including over -the-counter medicines or supplements.

Labs

- Take a copy of your lab order with you when you go to lab.
- Complete labs as instructed
- If you are scheduled to have labs completed on a holiday, it is OK to have them completed the next day instead.

Anti-rejection Medicine Levels

- Your anti-rejection medicine level is done with your lab draws. It may be done 1-2 times per week.
- This level should be drawn 12 hours after you last took a dose tacrolimus or cyclosporine. The level should be drawn 24 hours after your last dose of Envarsus® or sirolimus.
- After you have your labs drawn, you should take your anti-rejection medicines right away.

Home Care

Every day, check your weight, blood pressure, pulse, and temperature as instructed by the transplant team. Please call your coordinator if you have:

- Fever higher than 100.5°F.
- Systolic blood pressure (top number) above 180 or diastolic blood pressure (bottom number) above 90.
- Weight gain of 3 pounds in one day or 5 pounds in one week.

Going Back to Work

We encourage patients to return to work after having a transplant. You may not be able to do the same duties as before your transplant. It depends on the type of work you do, but that doesn't mean you can't work at any job. Your transplant team will talk about returning to work. They will help you with paperwork or questions you may have.

Always notify your transplant team of any current or future insurance changes or updates.

Vaccines

You must be screened for conditions or medicines that might make the vaccines unsafe for you because of your immune system. No one who has had a transplant should be given a live vaccine.

The list below includes general guidelines. Your situation may be different. **Always talk with your coordinator before getting any vaccines.**

Vaccines Recommended Before and After Transplant

- Inactivated influenza, injected
- Hepatitis B
- Hepatitis A
- Diphtheria/Tetanus/ Pertussis (Tdap, DTaP, Td or DT)
- Polio, Inactivated
- Pneumococcal polysaccharide or conjugate
- Human papillomavirus (HPV) (for ages 9-26)
- Varicella zoster (Shingrix®)

Vaccines NOT Recommended After Transplant

- Varicella (Varivax®)
- Influenza, intranasal live vaccine
- Measles, Mumps, Rubella
- Rotavirus

Other Vaccines to Discuss With Your Provider

- Quadrivalent meningococcal conjugate or polysaccharide
- Haemophilus influenzae type b

Blood (Lab) Tests

Why do I need to have labs test done?

It is very important that your health care team knows how well your new organ is working, and if there are problems with your medicines. To check these issues, you must have blood tests drawn on a regular basis after transplant. Blood tests are often the only way we are able to tell there is a problem with the new organ. Blood tests can often show us if there is a problem even before you have any symptoms.

Where can I have my lab tests done?

Blood tests are done daily in the hospital after transplant. When you go home, you can have blood tests done near home. Check your insurance plan to see if there is a certain lab you must use. Often, blood tests are drawn at any local clinic or hospital.

If your labs will be near home your transplant coordinator will give you a 'lab letter' (paper order) to give to your local lab. This letter tells your lab to fax the results to the UW Transplant Office at **(608) 262-5624**.

How often do I need to have my lab tests done?

Most often, in the first weeks after the transplant, you have blood tests drawn two times a week on Monday and Thursday. It is best to have your labs drawn early in the morning so you can get your results by mid-afternoon. The frequency of the blood tests decreases over time. The transplant team lets you know how often to do blood tests. **All** transplant patients have blood tests done at least once per month for the rest of their lives.

What should I do with my lab tests results?

Your local lab should also get the results to you as soon as they are ready. You should then record the lab values in the record book. If you have questions, or the values are outside of the expected ranges you have been taught, call the transplant coordinator or the transplant office. There will be times when you will know the results before your coordinator.

Anti-Rejection Drug Levels

We also draw blood to make sure you are getting the right amount of your anti-rejection drug. Right after transplant, these are often done once a week on Mondays. The blood test needs to be drawn about 12 or 24 hours from the time you took your last dose of the medicine depending on the instructions you have been given. You should **not** take your morning dose of this medicine until **after** the lab draw. Take your other medicines at the normal time.

Having your labs drawn the correct number of hours after you take your antirejection medicine is very important. The transplant team uses this number to make sure your antirejection medicines are at the correct dose.

Lab Test	Normal Values	What It Is	Reasons for High or Rising Values	Reasons for Low or Decreasing Values	When to Call Your Transplant Coordinator
Hematocrit (HCT)	**35 – 50**	The amount of red blood cells (RBCs) in the blood. RBCs carry oxygen in the body. When the hematocrit (HCT) is low you may feel tired or weak.	• Thicker blood • Smoking • Dehydration	• Anemia • Bleeding • Side effects of medicines • The kidneys not working well	• If the HCT drops by 5 or more points between readings, or slowly trends down. • If the HCT is less than 30. • If the HCT is more than 50.
White Blood Cell count (WBC)	**3,000 - 10,000 (3 – 10)**	The cells in the body that fight off infection.	• Infection • High doses of prednisone • If your spleen has been removed.	• Infection (CMV) • Side effects of medicines	• If your WBC is less than 3. • If your WBC is more than 10.
Creatinine	**0.5 – 1.5**	A protein waste product made by the muscles and removed from the body by the kidneys. Creatinine measures how well the kidney is working.	• Rejection • Infection • Dehydration • Side effects of medicines	• Improving kidney function	• An increase of 0.3 or more from your baseline value. • A slow increase over time.

Lab Test	**Normal Values**	**What It Is**	**Reasons for High or Rising Values**	**Reasons for Low or Decreasing Values**	**When to Call Your Transplant Coordinator**
Glucose (Blood Sugar)	**Fasting: 70 – 99**	The amount of sugar in the blood stream. Glucose is the main source of energy for the body. Insulin is a hormone that helps the body use glucose and keeps the glucose levels in the blood within normal ranges.	• Side effects of medicines • Diabetes • Infection • Not taking enough insulin	• Taking too much insulin • Not eating • Nausea, vomiting, diarrhea • Exercise	• If you do not have diabetes, call if the fasting glucose level is over 100. • If you have diabetes, call your diabetes team to adjust your medicines if blood sugars are higher or lower than goal range (about 70 to 150).
Potassium (K+)	**3.5 – 5.5**	An electrolyte the body uses that helps muscles function, especially the heart.	• The kidneys not working well • Eating foods that contain a lot of potassium • Dehydration • Side effects of medicines	• Nausea, vomiting, or diarrhea • Side effects of medicines • Not getting enough potassium in the diet	• If the potassium is less than 3.5. • If the potassium is 5.5 or higher.
Drug levels (tacrolimus, cyclosporine, or sirolimus)	**Your transplant team will tell you your target range.**	Measures the amount of medicine in your blood to know if you are getting enough medicine but not too much.	• Taking the medicine **before** your blood draw • Other medicines • Changes in diet • Diarrhea	• Missing doses of medicines • Other medicines • Changes in diet	• Your transplant coordinator will call you if you need any changes in your dose of medicines.

Organ Rejection

Rejection is when your body's immune system attacks your new organ. Your body is trying to destroy it. There are two kinds of rejection. Treatment varies for each. The signs and effects also vary for each type of organ.

All types of rejection are diagnosed by a biopsy. "Biopsy" means taking a small sample of tissue from an organ. It will be looked at under a microscope. A biopsy is often done when you have abnormal blood test results.

Acute Cellular Rejection

This type of rejection is a **direct** response to your new organ. The T cells (or "killer cells") of your immune system see your organ as foreign. A biopsy is done to diagnose this. The first treatment is high dose steroids. Starting treatment sooner improves the outcomes. If the steroids do not help, you may need to come to the hospital for IV medicine. Your doctor may also increase your anti-rejection medicines.

Acute Antibody-Mediated Rejection (AMR)

AMR is an **indirect** response to your new organ. The B cells (or "memory cells") of your immune system notice the cells from the new organ. An immune response begins. The body starts to make new antibodies to fight off the new organ. Treatment includes different medicines. If needed, antibodies can be removed from your blood. This process is called plasmapheresis. It is like dialysis. The goal is to remove harmful antibodies that are fighting your new organ.

Chronic Rejection

Chronic AMR may be diagnosed if the rejection has been ongoing or the biopsy shows tissue scarring. Your doctor will review the risks and benefits of ongoing treatment based on these results. You may need other medicines and treatments.

How do you test for rejection?

The sooner we find and treat rejection, the better the outcomes. Lab tests are often the fastest way to catch a problem. Make sure you have your labs done as scheduled by your transplant team. You will also need a biopsy. Other tests might include an ultrasound or scan.

What are the signs of rejection?

You may have signs of rejection. The first symptom you will often see is changes in your lab results. Other signs you might notice on your own. **Call your coordinator** for any of these signs.

Signs of Kidney Rejection

- Increased creatinine
- Increased temperature
- Increased weight
- Decreased urine output
- Ankle swelling
- Swelling or tenderness over kidney
- Body aches

Transplant Biopsy

"Biopsy" means taking a small sample of tissue from an organ. It will be looked at under a microscope. A biopsy is often done when you have abnormal blood test results or have been treated for rejection. You may also have biopsies at scheduled times after your transplant or as part of a research study you agreed to be in.

What will the biopsy tell us?

- The cause of your organ problem
- If there is rejection
- The best care plan for you and your new organ

How is a transplant biopsy done?

- An ultrasound machine locates the exact place to insert the needle.
- The area of skin will be numbed to reduce pain.
- A special needle is inserted through the skin and into the organ to obtain a small piece of tissue from the new organ. You may feel pressure when the needle is inserted.
- A small piece (or two) of tissue is taken and looked at under a microscope.

The procedure takes 15-60 minutes. But, you will spend most of the day in the Transplant Clinic. This is to prepare for and recover from the procedure.

How to Get Ready for the Biopsy

Medicines

- If you take blood pressure pills in the morning, take them as normal.
- Please bring all your medicines with you. You can take them after you have blood tests drawn.
- Stop aspirin 1 week before your biopsy.
- Do not take ibuprofen the day of the biopsy
- You may take Tylenol® if you need to.
- If you are on a blood thinner talk with your transplant coordinator before the biopsy. You may need to stop these medicines up to a week before the biopsy. You should never stop blood thinning pills without talking with your doctor first.
- If you are taking insulin, ask your the provider managing your diabetes and insulin about your insulin dose for the morning of the biopsy.

Diet

- Do not eat solid foods after 4:30 a.m. the morning of the biopsy.
- You may have clear liquids until 6:30 a.m. the morning of the biopsy.

Recovery

- Wear loose, comfortable clothes.
- You may want to bring a book to read or some other quiet activity to do.
- If you want to receive medicine to help you relax, you must have a driver with you.

Biopsy Day

- **Please report to the lab no later than 7:30 am** (unless you have been told to arrive at a different time). You will have blood tests drawn. This will include a test to make sure that your is blood clotting like normal.
- After you have your blood tests, go to the Transplant Clinic.
- We will place an IV in your arm or hand.
- Transplant staff will meet with you, review your labs and decide if you can and should have the biopsy.
- We will tell you about the purpose and risks of the biopsy. We will ask you to sign a consent form.
- You may be able to receive medicine to help you relax. If you receive this medicine, you need someone to drive you home.
- The biopsy will be done in the Transplant Clinic or Radiology.
- Plan to be in clinic all day.

After the Biopsy

- Your recovery includes at **least 4 hours of bed rest**. Nurses will watch closely for any problems. Your family may join you in the room during this time.
- The site will be covered by an adhesive strip. A sandbag will cover the biopsy site for at least the first hour.
- You will have nothing to eat or drink for 1 hour. Then, you will be given a bag lunch. If you are on a special diet, please let the nursing staff know when you arrive in the clinic.
- We will check your blood pressure and pulse every 15 minutes the first hour, then every 30 minutes for the next 2 hours, followed by hourly until you go home.
- After three hours, we will take a blood sample to check for signs of bleeding.
- Early results may be ready before you leave. These will not be final results. We will discuss a plan for your care with you. This may involve staying in the hospital. You may be asked to stay in Madison overnight to wait for the biopsy results.
- Your transplant coordinator will call to discuss your final biopsy results and plan of care within 7-10 days.

After You Go Home

- For the rest of the day, plan quiet activities.
- If you receive any medicine to help you relax, you should not drive.
- Important decisions should wait until the next day.
- If you do not receive medicine to help you relax, you can drive yourself home.
- Do not drink alcohol.
- You may remove the bandage the next morning and take a shower.
    - You may notice a small amount of bruising or tenderness near the site for a few days.
    - You may have some local pain that you can treat with Tylenol®.
    - No vigorous exercise or lifting (greater than 10 lbs.) for 3 days.

Please go to your local emergency room if you are having any of these symptoms. The ER should contact the UW Transplant Program at **(608) 263-6400**.

- Sharp abdominal pain or worsening pain at the biopsy site
- Blood in the urine or stool
- Unable to urinate
- Dizziness
- Fever

Phone Numbers

Transplant Clinic, Monday through Friday, 8:00 a.m. – 5:00 p.m. **(608) 262-5420.**

Nights and weekends, the clinic number is answered by the paging operator. Ask for the Organ Allocation Specialist on call. Tell them you had a transplant biopsy and what problems you are having.

Kidney Obstruction

A kidney obstruction is when the tube that connects your kidney and your bladder (ureter) is narrowed. You will have a stent placed in the ureter during surgery to prevent blockage. A stent is a small, soft, hollow tube. This stent is usually removed in the clinic within 6 weeks after surgery. A urine sample is required before removal.

Signs of Obstruction

A blockage or obstruction that develops that prevents urine from draining out of the kidney into the bladder. This causes pressure in the kidney. Signs of this pressure include:

- Swelling of leg on same side as affected kidney
- Increased creatinine
- Increased blood pressure
- Increased weight
- Decreased urine output

If you have any of these signs, call your transplant coordinator.

Testing and Treatment for Obstruction

To check for an obstruction, an ultrasound of your new kidney will be done. You may need a percutaneous nephrostomy tube. This is a small, soft plastic tube. It enters the skin in your lower abdomen to drain urine from the kidney. The purpose of this tube is to relieve pressure in the kidney.

Infection Risk

Reasons for Infection Risk

When you have an organ transplant, a new organ is placed in your body to take over the function of your failed organ. As with anything foreign to your body, such as virus, your immune system will recognize the new organ as being foreign and try to get rid of it. This is called rejection.

After transplant you take medicines to prevent this rejection process. These medicines weaken your immune system to allow your transplant to be accepted by your body.

As a result of your weakened immune system, you are more at risk to get infections. This includes typical, everyday infections such as colds and flu, and also some unusual infections that are unique to transplant patients. When you get an infection, you will not be able to fight it as well because of your weakened immune system. Some symptoms of infection may be more severe, and they may not go away as quickly as before. Also, you may need medicine to help you get better. Sometimes you will need to be admitted to the hospital to give stronger medicines to treat the infections.

Your transplant team tries to adjust your medicines, so you get enough to prevent rejection, but not weaken the immune system too much.

How to Prevent Infections

It is important to protect yourself from infections. There are ways you can protect yourself.

- Frequent hand washing/hand sanitizer use
- Avoid direct contact with people known to be ill
- Avoid raw or undercooked meats
- Avoid changing cat litter boxes or cleaning birdcages
- Wear gloves when doing gardening, farm work, or outdoor work
- Practice good routine dental care
- Keep up to date on vaccinations
- Keep all pet immunizations up to date
- Avoid smoking and exposure to secondhand smoke

- Practice safe sex
- Wear protective clothing and insect repellent when outdoors
- If you have well water, contact the Department of Natural Resources or your county health department to have your well tested yearly.

Treatment

Many of these infections can be treated by your local doctor. However, you should tell the transplant team whenever you have any of the below symptoms of infection. You may need medicine to treat infections. Most of these medicines are safe to take. Some medicines used to treat infections can affect some transplant medicines. Be sure to contact the transplant team with any new medicine you are taking.

Types and Symptoms of Infections

Viral Infections

Many common upper respiratory and gastrointestinal infections are caused by viruses. There is no cure for these common viruses; they simply have to run their course. Try to get plenty of rest and drink plenty of fluids to help your body fight the virus. You should see your local doctor if your symptoms last longer than expected or if you seem to be getting worse instead of better as time goes on.

Respiratory infection symptoms:

- Fever (oral temperature over 100.5°F)
- Cough
- Yellow or green tinged phlegm
- Sore throat
- Fatigue

Gastrointestinal infection symptoms:

- Fever (oral temperature over 100.5°F)
- Chills
- Diarrhea
- Nausea
- Vomiting
- Fatigue

As well as common, general viruses, transplant patients need to be aware of other specific viruses that can cause problems following organ transplant

Cytomegalovirus (CMV)

Cytomegalovirus or CMV is a virus that most people have been exposed to. It lives in the body for years and often goes unnoticed until a person has a suppressed immune system. You will take valganciclovir (Valcyte®) or acyclovir (Zovirax®) for three to six months after transplant to help prevent CMV. These first three months are the time when you are most at risk for getting CMV, but you can develop CMV at any time.

Symptoms of CMV can include:

- Nausea
- Vomiting
- Diarrhea
- Feeling tired
- Decreased white blood cell count (often less than 2)
- Fever (oral temperature over 100.5°F)

There is a blood test for CMV. Your transplant doctor will decide if testing is needed. CMV can be a very serious infection, but there is medicine to treat it.

BK Virus

BK virus is a virus that may affect people who have had a kidney transplant. It usually stays hidden in the transplanted kidney but can become active and cause damage to the new kidney. Most people do not have any symptoms, so blood tests are done to check for it.

Herpes Infections

Herpes simplex is a virus most people have been exposed to sometime in their lives. It can remain hidden in our bodies for years and become active at any time. It most commonly causes **cold sores** on the lips and in the mouth. This can be treated with antiviral medicines. Another type of herpes simplex causes genital sores. You may have these viruses with no symptoms. After transplant when the immune system is weakened, symptoms may appear. These can be controlled with medicines.

Varicella zoster virus, also known as shingles, is another type of herpes virus. Shingles appear as a rash or series of small blisters. They may be painful and most often form on one side of the chest, back, hip or head. Shingles occur more often in older people. Transplant patients may get shingles because of the weakened immune system. Early treatment will help shorten the length of the illness and may ease symptoms.

There is a shingles vaccine that is safe for patients to get after transplant. This vaccine is called Shingrix. It is **not** a live vaccine. If your local medical team recommends this vaccine, please check with your transplant coordinator to see if the time is right for you. The other shingles vaccine (Zostavax) is a live vaccine and is **not safe** to get after transplant.

If you have never had **Varicella zoster** or the **chicken pox**, or received the vaccine with proven immunity, you will need to be very careful being around those who have chicken pox. The virus is highly contagious as early as 5 days before the person breaks out in the red, open sores, called vesicles. These fluid-filled sores are highly contagious; avoid contact with them even if you have had chicken pox in the past. You may be at-risk to develop the disease if your immunity is low. Contact your transplant coordinator if you have had close contact with someone who you think may be contagious.

Influenza (Flu)

Influenza is a viral infection of the nose and throat. It is more severe than the common cold and comes on suddenly. The flu is caused by germs found in the air and on surfaces.

Influenza can be mild to severe. You should get a flu shot (vaccination) every year to help prevent you from getting sick. There are many strains of influenza, so you may get influenza even if you got your flu shot. Symptoms include fever, head and muscle aches, extreme tiredness, and sometimes cold symptoms.

Epstein - Barr virus (EBV)

EBV can cause infectious mononucleosis (mono). It can also put you at risk for lymphoma, or a cancer of the lymphatic system. There is a blood test for EBV. Symptoms include enlarged lymph nodes, tiredness, sore throat, and fever.

Papillomaviruses
Papillomaviruses are a family of viruses that can cause warts on the hands, fingers, face, and genitals. Decrease your risk for these viruses by limiting close contacts and use safe sex practices.

Hepatitis B
Hepatitis B is a viral infection of the liver that is spread through blood and sexual contact. It can lead to liver failure. Patients should be vaccinated against Hepatitis B before transplant.

Hepatitis B can be treated with anti-viral medicines. After transplant, Hepatitis B can re-activate and cause liver damage, so patients with Hepatitis B need life-long anti-viral therapy after transplant.

Hepatitis C
Hepatitis C is another viral infection of the liver that can lead to liver damage. It is spread through blood or sexual contact. After transplant, Hepatitis C can re-activate and damage the liver. There are medicines to treat Hepatitis C and prevent liver damage after transplant.

If you have agreed, there is the possibility you may receive an organ with Hepatitis C or Hepatitis B, even if you do not have the virus before transplant. You have to sign a special consent form to receive these organs. After your transplant, the doctors will prescribe anti-viral therapy to treat these viruses. Hepatitis B anti-viral is taken life-long. Hepatitis C antiviral therapy is generally completed over the course of a few months. Your doctors will decide when you should start therapy for either virus.

West Nile Virus (WNV)
WNV is a virus that can affect the central nervous system. It is most often spread through the bite from an infected mosquito. In patients with weakened immune systems it can be very severe. It can cause encephalitis, meningitis, and even death. Transplant recipients should wear long-sleeved shirts and pants and use insect repellents to prevent mosquito bites. Symptoms can include fever, neck stiffness, tremors, muscle weakness, vision loss, confusion, or numbness.

Lyme Disease
Lyme disease is a tick-borne illness. It is spread through a tick bite and can start as a rash near the site of the bite. Symptoms of Lyme disease can include tiredness, loss of appetite, headache, neck stiffness, localized swelling and fever. If you had a recent tick bite along with these symptoms, notify your provider.

Toxoplasmosis
Toxoplasmosis is a parasite spread by consuming undercooked meat, contaminated water, or infected cat feces. Donors may not know they are infected, so all donors are screened for this infection. If your donor is positive for toxoplasmosis, you will need treatment to prevent active disease.

Bacterial Infections
Bacterial infections can and should be treated with antibiotics.

Pneumonia
Pneumonia is a lung infection. There are different types of pneumonia caused by bacteria, viruses, or fungus. Symptoms include cough with green, yellow, or brown mucous, fever, chills, shortness of breath, chest pain, and weakness.

One type of bacterial pneumonia is **Pneumocystis carinii** or **PCP**. You are at higher risk for this type after transplant This is an infection in your lungs. After your transplant, you will take TMP/Sulfa (Bactrim), atovaquone or an inhaled medicine called pentamidine to help protect you from this infection. Symptoms include cough, fever and problems breathing.

Urinary Tract Infections

Urinary tract infections (UTI) occur when germs get into the urinary tract. Symptoms include burning or pain with urination, increased pressure, or feeling the need to urinate right away, urinating small amounts more often, bloody urine and fever or chills.

Clostridium difficile

Clostridium difficile (C. diff) is a germ that lives in the digestive tract (stomach and intestines or bowel). C. diff can make toxins that cause watery diarrhea, belly pain/tenderness, fever, loss of appetite, and nausea. People who are taking antibiotics can get sick with C. diff. There are medicines that can be used to treat C. diff.

Wound Infections

If you develop an infection in your **incision, drain, or catheter site**, contact your transplant coordinator right away. You may need antibiotics to treat the infection. Symptoms of wound infections include:

- Increased redness or warm to the touch.
- Pus-like or green drainage.
- Temperature by mouth is greater than 100.5°F or 38.3°C.
- Excessive swelling or bleeding or bruising.
- Increased pain you cannot control with your pain medicine.

Fungal Infections

There are different types of fungal infections. They can be difficult to treat in transplant patients and most often will require the use of anti-fungal medicines.

- **Thrush:** The most common fungal infection after transplant is a yeast infection in your mouth called thrush. Right after transplant, you may be on a medicine called Nystatin or another antifungal medicine to help prevent thrush. Symptoms include small, white bumps or patches in your mouth or throat. They may be painful or cause problems swallowing.
- **Athlete's foot** is another common fungal infection. You may use over-the-counter remedies to relieve the symptoms of athlete's foot. Contact your transplant coordinator or local doctor if symptoms persist.
- **Aspergillus:** Aspergillus is a common fungus found indoors and outdoors. Most people breathe in aspergillus spores without being affected. When your immune system is weakened, exposure to this fungus can cause illness. The most common place for this infection is the lung but can be found in other parts of your body. In addition to lifestyle changes to lower your risk of exposure, you may need antifungal medicines to prevent this infection. Type and length of treatment are based on your risk.
- **Other common fungal infections:** Other common sites for fungal infections after transplant are fingernails or toenails. Avoid sharing manicure and pedicure tools with others. It is very hard to get rid of a fungal infection in the nail beds.

You may develop symptoms of a yeast infection in your surgical incision, in skin folds, in the vagina, urinary tract, lungs, or eyes. Symptoms of a fungal infection may include white or yellow discharge or film, itching and pain. If you develop any of these symptoms, contact your transplant coordinator or local doctor.

Nutrition

Nutrition plays a key role in the transplant process. Eating well and being at a healthy weight may help you recover faster after surgery. Good nutrition plays a key role in transplant success and your overall health.

After transplant, you will need to maintain a healthy lifestyle. This helps to prevent problems like diabetes, osteoporosis, and heart disease. Making healthy food choices can help prevent these problems too.

Keeping a Healthy Weight

People tend to gain weight after transplant. Causes include a bigger appetite when taking steroids, unhealthy eating habits, lack of exercise, or a family history of obesity. Here are some ways to maintain a healthy weight.

- Eat regular meals: 3 meals per day or small, frequent meals.
- Control portion sizes at meals.
- When dining out, split a meal with someone or order the kids portion size.
- Choose healthy snacks.
- Limit intake of high calorie, high fat sweets (cakes, cookies, ice cream, and candy).
- Make physical activity part of your daily routine. Be active at least 4-5 days a week.

Heart Healthy Choices

Eat a heart healthy diet by:

- Choosing lean meats. Choose fish and skinless poultry more often than red meat. Eat 6-8 ounces per day. Trim the fat off the meat. Remove the skin from poultry before cooking.
- Avoid high fat, processed meats such as brats and sausage.
- Lower your use of butter and lard. Choose trans-fat free margarine.
- Use olive oil, canola oil, or other vegetable oil with cooking.
- Choose low fat dairy products (skim or 1% milk, low fat yogurt, and low-fat cottage cheese). Limit intake of high fat dairy products (whole milk, ice cream, and custards).
- Choose low fat salad dressings, mayo, sour cream, and cream cheese.
- Choose baked or low-fat crackers and chips.
- Eat more fiber foods. Examples include whole grain breads and cereals, whole grain pastas, brown rice, dry beans and peas, fruits and vegetables.

Low Sodium Foods

A diet low in sodium (salt) helps control blood pressure and prevent fluid retention. To lower your sodium intake:

- Avoid adding salt to your foods. Use herbs, spices, or blends such as Mrs. Dash® instead of salt. Avoid salt substitutes with potassium.
- Avoid foods with large amounts of sodium. Examples include ham, bacon, sausage, cheese, canned vegetables and soups, and boxed meals.
- Read food labels to find out if foods are high in salt.

Carbohydrates

If you have diabetes or high blood sugars, you may need to limit carbohydrates. Eating consistent amounts of carbohydrate at each meal may help. Foods with carbohydrate include breads, cereals, pasta, rice, starchy vegetables such as potatoes, corn, and peas, fruits, milk and yogurt, and sweets. Suggestions include:

- Choose a variety of foods like fruits, vegetables, proteins, and carbohydrates.
- Do not skip meals. Eat about the same amount of carbohydrate at each meal.
- Limit your intake of concentrated sweets such as regular soda, candy, or jams.

Dietary Supplements

Avoid herbal or dietary supplements unless approved by the transplant team. Avoid potassium supplements or salt substitutes that contain potassium.

Food Safety

Transplant patients are at higher risk of foodborne illnesses. To prevent these illnesses, practice food safety. The booklet "Food Safety for Transplant Recipients" provides ways you can lower your risk of foodborne illness. You can find it online at: https://www.fsis.usda.gov/shared/PDF/Food_Safety_for_Transplant_Recipients.pdf. You can also find it by searching the booklet title.

Food Safety When Dining Out

- Avoid entrée items that have uncooked or undercooked ingredients like eggs, poultry, meat, or fish. Don't hesitate to ask your server about the menu items.
- Avoid buffets. It is hard to control portion sizes at buffets. Foods may also be undercooked or have been at an unsafe temperature for too long.
- It is safe to dine at the hospital cafeteria. The food is prepared fresh and does not sit out for long periods of time.

Specific Foods to Avoid

- Hotdogs, deli meat, luncheon meat, smoked fish or meats, and precooked seafood should be reheated to steaming hot or ≥165°F
- Unpasteurized pates or meat spreads
- Unpasteurized/raw milk
- Cheeses made from unpasteurized milk. (Check the food label to be sure.) Common cheeses made with raw milk: feta, brie, camembert, blue, and queso-fresco.
- Unwashed fruits and vegetables
- Raw sprouts (alfalfa, bean, or other sprouts)
- Unpasteurized juices, ciders, or kombucha
- Raw or undercooked meat, poultry, seafood, or fish (raw sushi)

Internal Cooking Temperatures

It is important to heat up some foods to certain temperatures. The list below gives recommended internal cooking temperatures.

- Beef, pork, veal, and lamb (≥145°F); ground meat (≥160°F)
- Poultry (ground, parts, whole and stuffing; ≥165°F)
- Eggs (cook until yolk and white are firm); egg dishes (≥160°F)
- Fin fish (≥145°F or flesh is opaque)
- Shrimp, lobster, and crabs (flesh is pearly and opaque)
- Clams, oysters, and mussels (shells open)
- Scallops (flesh is milky white, opaque, and firm)

- Leftovers (cook or reheat to ≥165°F)

Other Food Safety Tips

Clean: Wash hands and surfaces often.
- Wash your hands with warm water and soap before eating, handling food, after using the bathroom, changing diapers, and handling pets.
- Wash cutting boards and dishes, used to prepare raw meats, in hot soapy water.
- Rinse and scrub fresh fruits and vegetables under running tap water. Do this even for foods with skins and rinds that are not eaten.

Separate: Separate raw meats from other foods.
- Use one cutting board for fresh produce. Use a separate board for raw meats.
- Never place cooked food on a plate that had raw meats on it unless the plate has been washed with hot, soapy water.
- Separate raw meats from other foods in your grocery bags.
- Store raw meats separately in fridge (for example, on a bottom shelf).

Cook: Cook to the right temperature.
- Cooking to recommended internal temperatures kills harmful bacteria.
- Use a food thermometer to ensure proper cooking temperature.
- Bring sauces, soups, marinades, and gravy to a boil when reheating.

Chill: Refrigerate foods promptly.
- Use an appliance thermometer to be sure the temperature stays below 40ºF for refrigerator and below 0ºF for freezer.
- Divide large amounts of leftovers into shallow containers for quicker cooling. Refrigerate within 2 hours (1 hour if air temperature is > 90°F).
- Never thaw food at room temperature. Defrost in the fridge, in cold water, or in the microwave.
- Check the dates on foods and throw away if expired.
- Discard or freeze leftovers after 3 days.

Fluids

It is important to know how much fluids you should drink at home. You may need to drink more fluids or restrict your fluids depending on your health.

Dehydration (Dry)

Dehydration is when your body loses fluid. This happens when you don’t drink enough fluids. It can happen if you lose fluid through diarrhea or vomiting. High blood sugars or fevers can also cause dehydration.

Signs of dehydration:
- Decrease in weight
- Decrease in blood pressure when standing
- Increase in pulse when standing
- Lightheaded or dizzy when standing
- Thirst
- Decrease in urine output
- Muscle cramps

What to Do If You Are Dehydrated

Drink plenty of fluids. Avoid caffeine and alcohol. If you exercise, increase your fluids so you do not get dehydrated. If you have a lot of vomiting or diarrhea, you may need IV fluids. Your blood pressure and pulse should be close to the same when you are lying down and when you are standing.

Overhydration (Wet)
Overhydration is when your body has too much fluid. This may be because of side effects of medicines or something could be wrong with your kidney.

Signs of overhydration:

- Increase in weight
- Swelling

What to Do If You Are Overhydrated
Limit your fluid intake. Call your transplant coordinator.

Cancer Risks After Transplant

Reasons for Higher Risk After Transplant

Transplant patients take medicines life-long to prevent rejection of their new organ. These medicines suppress the body's normal immune system response of attacking foreign objects and abnormal cells, like cancer. Being immune-suppressed can also make your body vulnerable to viruses. Some viruses are known to stimulate certain types of cancer. Also, many patients have a family history of cancer, a history of cancer before transplant, or ongoing disease that may put them at a higher risk for certain cancers.

Most Common Types of Cancer After Transplant

Transplant patients have 5 times the risk or greater for these types of cancer:

- skin cancer,
- lymphoma,
- Kaposi Sarcoma,
- liver cancer, and
- cancer of the anus, vulva and lip.

Other common cancers that are more common after transplant include:

- lung,
- kidney,
- colon,
- pancreas,
- Hodgkin lymphoma, and
- melanoma.

Skin cancer is the most common type of cancer after transplant. Skin cancer is the uncontrolled growth of abnormal skin cells. Transplant patients have a 20-60 times higher risk of skin cancer than the general population. Risk factors include life-long sun exposure, fair skin, history of burns, and family history. The level of anti-rejection medicines and amount of time taking them also increase risk.

Lymphoma or Post Transplant Lymphoproliferative Disease (PTLD) has the highest incidence within the first year of transplant. This is when anti-rejection medicines are at their highest, although it can occur any time after transplant. PTLD is often related to Epstein Barr Virus.

Signs and symptoms of lymphoma can include:

- unexplained fevers,
- night sweats,
- unintended weight loss, and
- enlarged lymph nodes (in the absence of other infection).

Treatment varies based on extent of disease, time frame after transplant, age of recipient, and amount of current anti-rejection medicine. The transplant team works closely with the cancer and infectious disease teams if lymphoma occurs.

How to Prevent Skin Cancer

There are many things you can do to prevent skin cancer.

- Reduce your exposure to sun as much as you can.
- Use sunscreen daily. Apply sunscreen with SPF 30 or higher. Apply a thick coat of sunscreen to all exposed skin 30 minutes before going out in the sun. Reapply every 2 hours that you remain in the sun. Re-apply after swimming or sweating. Even if the sunscreen is water-resistant, some will wash off.
- Wear clothing that covers the skin. Wear wide brim hats and UV (ultraviolet) blocking sunglasses.
- Avoid mid-day sun (10:00 AM-4:00 PM). This is when the sun's rays are most intense
- Remember that sunburns can occur on cloudy days or from water or snow glare.
- Find shade under a tree, umbrella or other ways when you can.
- Use lip balm or cream that has SPF to protect your lips.
- Never go to UV tanning booths.
- Know which medicines can make your skin more likely to sunburn.
- Check your skin head-to-toe every month. Skin cancer usually appears as a growth that changes in color, shape or size.
- See your skin doctor (dermatologist) yearly for a full skin exam.

How to Prevent Other Cancers

- If you smoke, quit now.
- Avoid second-hand smoke.
- Eat a diet rich in fruits and vegetables and low in saturated fats.
- Exercise regularly.
- Attend yearly physical exams with your local health care team.
- Let your doctors know of any new symptoms or complaints. See your doctor if you notice a suspicious lesion. This includes a non-healing sore, red scaly patch, shiny bump, wart-like growth or irregular shaped mole.

Early detection and treatment save lives. Cancer screenings (pap tests, mammograms, colonoscopies, prostate tests) should be guided by your primary care provider.

For More Information

www.transplantliving.org
www.cancer.org
www.skincancer.org
www.lymphoma.org
www.healthytransplant.com

How to Lower Your Risk of Heart Disease

Things You Can Do on Your Own

Smoking and Tobacco Use

Smoking causes damage to the blood vessels and makes your blood more likely to clot.

- Avoid secondhand smoke.
- Quit now! You will see benefits right away. Here are resources:
  - **1-800-QUIT-NOW** (1-800-784-8669)
  - **Text READY to 200-400** for free resources
  - **WI Tobacco Quit Line** (1-879-270- 7867)

Eating Habits

A healthy diet can reduce the risk of stroke and improve your health. Eating healthy doesn't have to be hard.

- Start with fresh fruits and vegetables.
- Add sources of lean protein, such as chicken and fish.
- Build in enough carbs to make the meal tasty.
- Avoid processed and fried foods.

Stress

Stress negatively affects other risk factors such as high blood pressure, smoking and weight gain.

- Managing stress is different for everyone.
- Ideas to lower stress: meditate, take a walk outside, read a book, watch TV or talk with a friend.

Physical Activity

Being active every day helps to lower your risk of heart disease and stroke. It improves blood pressure, weight loss, and even improves mood and energy levels.

- Start by walking more. Use the stairs or park in the farthest space from the store.
- Aim for 150 minutes of walking a week or 75 minutes of jogging per week.

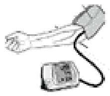
Healthy Weight

Extra weight makes your heart work harder and can lead to high blood pressure, diabetes, and stroke.

- Losing only 5-10 pounds. can make a big difference.
- Use a food diary to keep track of what, how much, and when you eat.
- Manage portion sizes of foods you eat.
- Read nutrition labels. Lower the number of calories, sugar, saturated and trans-fat that you eat.
- Increase your daily activity.
- Ask your doctor about meeting with a dietitian.

Things to Talk About With Your Doctor

High Blood Pressure



High blood pressure is the number one cause of stroke and heart disease.

- Monitor your blood pressure at home and share readings with your doctor.
- Your top number (systolic) should be less than 120 mmHg. The bottom number (diastolic) should be less than 80 mmHg.

High Blood Sugar (Diabetes)

Too much glucose (sugar) in your blood can lead to fatty deposits or clots inside blood vessels. Clots can narrow or block blood vessels in the brain or neck.

- Hemoglobin A1C of 6.5% or higher means you have diabetes.
- Your A1C result______ %
- Talk with your team about how to manage diabetes such as diet changes, activity, and/or medicines.

Sleep Apnea

If you snore and have trouble with sleep, you may be at a higher risk of stroke and high blood pressure. Talk with your doctor about the need for a sleep study and ways to treat sleep apnea.

Atrial Fibrillation ("A-Fib")

A-fib is a type of irregular heartbeat that can cause blood to pool in the heart. It can then form a clot which can travel to the brain and cause an ischemic stroke.

- Decide on the best choice of blood thinner with your doctor and take as prescribed.
- Do not stop taking your blood thinner without talking to your doctor.

High Cholesterol (Atherosclerosis)

Cholesterol is a fatty substance in blood. It is made by the body and is also found in food. If there is too much cholesterol in your blood, it can clog arteries.

- Medicine may be used to lower your cholesterol.
- Eat a diet high in fruits, vegetables, nuts and whole grains such as the DASH diet.

Women's Health

Women have unique risk factors for stroke:

- Migraine with aura.
- High blood pressure during pregnancy.
- Use of hormone replacement or birth control medicines (especially if smoking).
- Women have higher rates of aneurysms than men.

Alcohol Use

- If you drink alcohol, limit yourself to no more than 1 drink (women) or 2 drinks (men) per day. Less may be safer based on your personal risks.
- Talk to your doctor about your drinking. Your medicines can be affected by alcohol.
- Seek help. There are free self-help programs, such as Alcohol Anonymous (http://www.aa.org/). There is also Al-Anon (https://al-anon.org) for family members.

Drug Use

Drugs such as cocaine, amphetamines, and heroin can cause the blood pressure to be higher.

- It can be a hard decision to quit. You don't have to do it alone. Counseling helps people quit.
- Counseling services in your area: https://www.samhsa.gov/find-treatment or call the Substance Abuse and Mental Health Services Administration (SAMHSA) National Helpline: 1-800-662-HELP (4357)
- If you need more info, please talk with your social worker or call UW Health Patient Resources at 608-821-4819 or 1-800-552-4255.

Clinic Visits and Follow-up Care

We will see you at UW Health for follow-up care. Your transplant team at UW Health will include a:

- Surgeon
- Nephrologist (kidney doctor)
- Transplant coordinator
- Social worker
- Dietitian
- Clinic staff

Primary Care Provider Visits

The transplant team will be a part of your life with your transplant. We do require you to have a primary care provider at home. You need a primary care provider before and after your kidney transplant. The transplant team will care for your transplant and transplant medicines. The transplant team will address any issues about your new organ. Your primary care provider will care for all your other health needs. We rely on this primary care provider to address routine health issues such as diabetes and minor infections.

Having a local (home) provider may make it possible for you to get some transplant care closer to home. This may include IV treatments and radiology studies. To get care close to home, a local doctor may need to cosign the orders from the UW transplant team.

You will need to follow the advice of your local doctor and the transplant team about diet, exercise, and other health needs. We want you to live a normal, healthy life after transplant. We will work closely with your doctor to give you the best care.

Ask these 3 questions of your home provider:

1. Are you comfortable taking care of me after my kidney transplant?
2. Will you cosign orders from my transplant team if needed?
3. Do I need to continue to see the person who managed my kidney disease before the transplant in addition to the transplant team at UW?"

Transplant Clinic Visits

Your follow up appointments may be in person, telephone, or video, depending on your health. Your in-person follow-up visits will be at the Transplant Clinic. Your first clinic visit is about 2-3 weeks after you leave the hospital. This will be scheduled before you go home. Future appointments will be made by the clinic. Plan on spending 3-4 hours at UW Health for your clinic visits if they are in person.

What to Bring to Clinic Visits

- Your medicines
- A list of your current medicines
- Your patient education materials
- Records of your weight, blood pressure, heart rate, and temperature at home
- Records of your local blood test (lab) results
- Records of your blood sugar readings if you have diabetes
- A snack
- A list of questions

Labs Before Clinic Visits

You will have your blood drawn about 90 minutes before your clinic visit. This allows the team to have test results when they see you in clinic. Go to the outpatient lab on the 2nd floor. The orders for your tests will be ready for you when you arrive at the lab. Your coordinator will let you know if you need to stop eating or drinking before these labs. **If you have a clinic visit in the morning**, do not take your tacrolimus or cyclosporine until after the lab draw. It is okay to take your other medicines. **If you have a clinic visit in the afternoon**, talk with your coordinator.

If your insurance company does not allow you to have lab tests drawn at UW Health, make a plan with your coordinator to have the lab tests done before your clinic visit. If you are being seen by phone, video or at an outreach clinic, a lab order will be faxed to your local lab to have your labs drawn at your there before the visit.

Arrive Early for Clinic Visits

Plan to arrive at the Transplant Clinic at least 15 minutes before your scheduled appointment time. You need to register and check in. Staff will weigh you, take your blood pressure, and review your medicines. If you need any supplies or prescriptions, please tell the staff at this time.

What to Expect During Clinic Visits

You will see the provider for your clinic appointment. If you would like to meet with a pharmacist, dietitian or social worker please let your coordinator know before your appointment.

Before Leaving the Transplant Clinic

- Obtain an After-Visit Summary. This will have an updated medicine list, your lab results, and any follow up instructions.
- Obtain an updated standing lab order if needed.
- Schedule your next visit.

Outreach Clinics

We have transplant outreach clinics throughout Wisconsin and Illinois. UW Transplant providers see patients at these clinics. These clinics are for stable patients only. If you need further care, like a biopsy, you will need to come to UW Health Transplant Clinic in Madison. Talk with your coordinator if you would like to move your visit to an outreach clinic.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 1/2021 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8182.

Who and When to Call

Who	Why	When/ Phone Number
Transplant Coordinator/ Transplant Office **Your Coordinator:** ____________________	• Medicine refills • Lab results • Questions about transplant medicines, symptoms or other transplant-related questions	Monday-Friday 8:30a.m.-4:30p.m. **608-263-1384**
Transplant Clinic	To schedule, change or cancel a transplant clinic appointment	Monday-Friday 8:30a.m.-4:30p.m. **608-262-5420**
Social Worker	• Worries about your emotional health • Problems paying for your medicines • Questions about your insurance or Social Security Disability	Monday-Friday 8:30a.m.-4:30p.m. **608-262-5420** **608-263-1384**
Financial Counselor	• Questions about new Medicare applications	Monday-Friday 8:30a.m.-4:30p.m. **608-263-8770**
Organ Allocation Specialist (On-Call)	• Fever over 100.5°F or chills • Nausea, vomiting or diarrhea for more than 24 hours • Blood in urine or problems urinating • Problems with drains • Other urgent symptoms	Monday-Friday 8:30a.m.-4:30p.m. **608-263-6400**
Local doctor/ health care provider	• Problems not related to your transplant • Refills of non-transplant medicines	
Call 911 or go to the nearest emergency room	• Trouble breathing • Heavy bleeding or bleeding you can't stop • Chest pain • Fainting or passing out • High blood pressure with headache or vomiting • Unable to take medicines for 24 hours • Seizure or stroke • Severe pain • Anything else you think might be an emergency	If you are in a local emergency room or hospital, call your Coordinator.