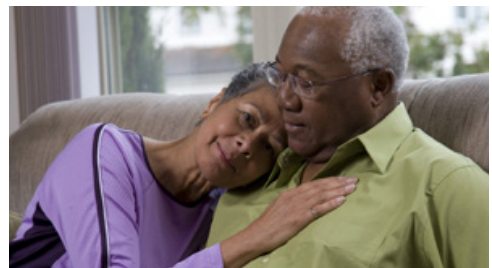
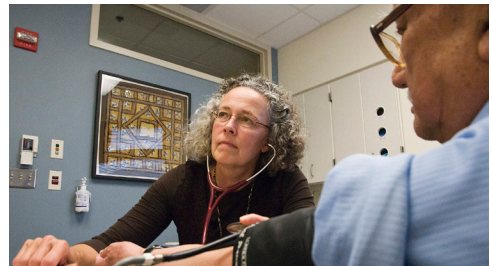


UW Medicine
UNIVERSITY OF WASHINGTON
MEDICAL CENTER

Your Kidney/Pancreas Transplant Guide

At University of Washington Medical Center



Third Edition, December 2016



Welcome

To “*Your Kidney/Pancreas Transplant Guide*”

Welcome to Transplant Services at University of Washington Medical Center (UWMC). Our medical center is one of the leading multi-organ transplant centers in the United States.

We are pleased you have chosen UWMC as your transplant center. Our transplant team is looking forward to working with you and your family.

You, the transplant recipient, are a vital member of the transplant team. We depend on you to be an active partner during the entire transplant journey. We want you to learn all you can about the evaluation process, the transplant surgery, and how to take care of your new organ after transplant.

This is why we created *Your Kidney/Pancreas Transplant Guide*. It is filled with useful information to guide you through every step of the transplant process, from getting referred for transplant to your long-term



University of Washington Medical Center is one of the leading multi-organ transplant centers in the United States.

care after a transplant. We hope this guide answers your questions about your treatment and your progress along the way. Keep your guide handy. Bring it with you to all clinic visits and when you are called in for your transplant.

UWMC believes in providing patient and family centered care. Please let us know how we can help you and your family.

About This Guide

Your Kidney/Pancreas Transplant Guide is a reference tool for you to use before, during, and after your transplant surgery. The chapters in this guide are:

- **Benefits and Risks**
- **Being Referred**
- **The Evaluation Process**
- **Tissue Matching**
- **Living Kidney Donors**
- **Deceased Donors**
- **Waiting for Transplant**
- **Coping**
- **Transplant Surgery**
- **Recovery in the Hospital**
- **Nutrition**
- **Medicines**
- **Discharge Checklist**
- **Care After Discharge**
- **Life After Transplant Surgery**
- **Transplant Renal Biopsy**
- **Resources**
- **Financial Planning**
- **Medical Terms**

Thank you again for choosing UW Medical Center. We look forward to working with you for a successful transplant.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Benefits and Risks

Of a kidney/pancreas transplant

A transplant can greatly improve your life, but it also involves serious risks. This chapter describes the benefits and risks of a transplant.

What are the benefits of having a transplant?

Transplant is a treatment for kidney disease, not a cure. A kidney or kidney/pancreas transplant is not the best choice for everyone. You and your doctors will decide together if the benefits of having a transplant outweigh the risks.

Benefits of a Kidney Transplant

Longer Life

Most people who receive a transplant live longer than those who stay on dialysis. Kidney patients who receive a transplant before starting dialysis have the best outcomes of all.

Better Quality of Life

Most people who receive a kidney transplant:

- Have a better overall quality of life as compared to those who stay on dialysis
- Are more satisfied with life and feel better emotionally and physically
- Are more likely to be able to return to work
- Are freer to travel since they are not tied down by their dialysis visits



Talk with your doctor if you have any questions about the benefits and risks of having a transplant.

Improved Health

Many problems that occur from long-term dialysis improve after getting a transplant. Some of these are:

- **Anemia (low red blood cell count) improves.** The bone marrow needs the hormone *erythropoietin* for creating red blood cells. This hormone is made in the kidneys. The healthy transplant kidney will be able to make this hormone that diseased kidneys no longer can. The result is an improved red blood cell count.
- **Thickening of the heart muscle (*left ventricular hypertrophy*) improves.** This thickening can lead to long-term damage and heart failure. Much of this problem is due to fluid overload that occurs when the kidneys fail. This overload eases after a transplant, and the risk of these heart problems lessens.
- **The risk of getting blockages in your blood vessels (*heart disease*) decreases.** Blocked blood vessels can lead to heart attack or stroke. The chance of this problem getting worse lessens after transplant.
- **Nerve damage (*neuropathy*) caused by kidney failure decreases.** Neuropathy can cause “restless legs,” pain, decreased sensation in the legs or arms, and sleeping and memory problems. These problems can become less severe after a kidney transplant.
- **Limiting fluids and certain foods is usually not needed after transplant.** For example, your intake of phosphorous or potassium may not need to be restricted any longer.

Benefits of a Pancreas Transplant

People with type 1 diabetes may qualify for both a pancreas transplant and a kidney transplant. With a successful pancreas transplant, blood sugar can be controlled without using insulin. You will no longer have problems with very low blood sugars (*hypoglycemia*), or *diabetic ketoacidosis* (DKA) or coma from very high sugars (*hyperglycemia*), both of which can be life-threatening. Normal blood sugars can also prevent long-term problems that often occur with diabetes.

If you have type 1 diabetes and your kidneys are working, getting only a pancreas transplant can prevent kidney disease from developing. If you have minor kidney disease, this can get better.

If you already have kidney failure due to type 1 diabetes, getting a pancreas transplant and a kidney transplant together can keep the new kidney from being damaged due to diabetes.

People with type 1 diabetes may have other problems such as:

- **Retinopathy** (damage to the retina of the eye). Retinopathy can cause bleeding in the eye, which can lead to blindness.

- *Neuropathy* (damage to the nerves that help with sensation or motor function). Neuropathy may cause severe pain, numbness, tingling in the hands and feet, or problems with motor strength. Lack of feeling, especially in the feet, can lead to injury, sores on the feet, and a greater risk of infection.

Retinopathy and neuropathy can get better after a pancreas transplant, but it may take 3 to 5 years after transplant to see improvement. The chance that problems related to retinopathy or neuropathy will get better after transplant depends on how much damage there was before transplant.

For example, if someone with diabetes has severe retinopathy and has had several laser surgeries to treat it, the scarring that is left from the laser surgeries cannot be reversed. This scarring decreases vision, and so the person's vision would not be expected to improve after transplant.

What are the success rates of transplants?

Success rates of transplants are usually given in 2 ways: *patient survival* and *graft survival*. The survival rates given below are from August 2016. To see the most recent numbers, visit the Scientific Registry of Transplant Recipients at srtr.org.

Patient Survival

Patient survival is the percentage of patients who are alive a certain number of years after transplant. It is usually measured at 1 and 3 years.

- **1-year patient survival rates:**

- In the U.S., the patient survival at 1 year after transplant is 97% (97 out of 100 patients are alive 1 year after transplant).
- As of June 2016, 1-year patient survival for UWMC's kidney transplant center is 99.54%. This means that more than 99 out of 100 patients are alive 1 year after transplant surgery.

- **3-year patient survival rates:**

- At 3 years, patient survival in the U.S. is 93% (93 out of 100 patients are alive).
- As of June 2016, the 3-year patient survival for UWMC's kidney transplant center is 96.73% (almost 97 out of 100 patients are alive 3 years after transplant).

Most people who receive a kidney transplant live longer than if they stay on dialysis. This is especially true for people who have both diabetes and kidney failure.

Kidney transplant lowers your risk for heart disease compared to staying on dialysis. But, in the first few months after a transplant, there is an

increased risk of having problems that could cause death. These may be problems from the surgery, infections, or heart attack or stroke. Over time, the risk of these life-threatening problems will decrease.

Graft Survival

Graft survival means that the transplanted organ is still working.

- **1-year graft survival rates:**
 - In the U.S., the graft survival at 1 year after kidney transplant is 95% (95 out of 100 kidney transplants are still working).
 - As of June 2016, the 1-year graft survival for UWMC's kidney transplant center is 98.68% (almost 99 out of 100 kidney transplants are still working).
- **3-year graft survival rates:**
 - At 3 years after kidney transplant, graft survival in the U.S. is 88% (88 out of 100 kidney transplants are still working).
 - As of June 2016, the 3-year graft survival for UWMC's kidney transplant center is 94.23% (94 out of 100 kidney transplants are still working).

What affects patient survival after transplantation?

Patients with kidney failure who receive a kidney transplant can live longer than if they stay on dialysis. But overall, transplant patients still have a higher risk of death than average.

The most common causes of death after transplant are:

- Heart (cardiovascular) disease
- Stroke
- Infections
- Cancers

We will work with you after your transplant to lower your risk of these types of problems.

Heart Disease and Stroke

Many patients have severe heart disease at the time of their transplant. This may affect the success of their transplant and may increase their chance of dying after transplant.

Kidney disease and high blood pressure increase the risk for heart disease. These problems are a major cause of patient death after a kidney transplant. If you smoke or have diabetes, the risk of having these problems can be higher.

We will talk with you about ways to lower your risk of having heart problems or stroke. These may include:

- Good blood pressure control
- Taking medicine to lower cholesterol
- Taking aspirin

Smoking

Smoking cigarettes can increase the risk of heart problems, stroke, and some types of cancer. We require that you **not** smoke if you want to be placed on the transplant list. We also require that you not smoke after receiving your transplant.

Infections

After transplant, you will take medicines called *immunosuppressants*. These drugs help prevent rejection of the new organ, but they also weaken the immune system. This can increase your risk of getting infections.

Most of these infections are minor and can be easily controlled, such as urinary tract infections. Rarely, infections can be much more severe, hard to control, or even life-threatening.

We closely monitor all patients for early signs of infection. We also do screening tests before and after transplant for certain infections. This helps us assess your possible infection risk or find early signs of infection.

Cancer

Transplant patients can be at higher risk of some types of cancers, especially skin cancer. To lower your risk of skin cancer after transplant, protect your skin from the sun by using sunscreen and protective clothing.

Patients who have had skin cancer in the past have to be very careful. If you have had skin cancer, we advise seeing a *dermatologist* (skin doctor) for regular checkups.

Lymphoma is a type of cancer of the white blood cells. The risk of this cancer is higher in transplant patients, but it is still rare. The average rate of lymphoma in transplant patients is about 1% (1 out of 100 patients).

We advise all transplant patients to get regular health screening tests, such as a *colonoscopy* that checks for colon cancer. Women may have a higher risk of cancer of the cervix after transplant, so it is important to have yearly Pap smears. Women should also have routine mammograms.

Problems from Transplant Surgery

About 5% of kidney transplant patients (5 out of 100 patients) and about 10% of kidney/pancreas patients (10 out of 100 patients) have major problems from the transplant surgery. These problems can include:

- Blood clots
- Bleeding
- *Lymphocele* (buildup of lymph fluid)
- Urine leak
- *Renal artery stenosis* (narrowing of the renal artery)

Deep Vein Thrombosis or Pulmonary Embolism

There is a risk of blood clots in the legs after any type of surgery, including transplant surgery. Clots in the legs are called *deep vein thrombosis*. These clots are dangerous because they can travel to the lungs, form a *pulmonary embolism*, and cause breathing problems. To lessen the risk of blood clots, we may prescribe blood-thinning medicine (*anticoagulants*) and will also take other precautions.

Renal Artery or Renal Vein Blood Clot

After kidney transplant surgery, a blood clot could form in the *renal artery* or *renal vein* (blood vessels that move blood to and from the kidney). These clots are rare, but if one occurs, surgery may be needed. This type of blood clot could cause loss of the transplanted kidney.

Bleeding

There is an increased risk of bleeding from transplant surgery, from kidney failure, and from taking medicines such as warfarin.

- If bleeding occurs, you may need a blood transfusion.
- If the bleeding is severe, you may need another surgery to find the source of the bleeding and to stop it.
- Blood may also collect near the kidney transplant as a *hematoma*. This may go away on its own or it may require surgery.

Lymphocele

Lymph vessels are small tubes next to your arteries and veins. These vessels carry fluids from the tissues of the body back into the large veins and the heart.

Since they are very small, lymph vessels in the area of the transplant can be damaged during surgery. This can cause lymph fluid to collect in the area around the transplanted organ. This buildup of lymph fluid is called a *lymphocele*.

Most times, this is only a minor problem and it goes away without being treated. But if the fluid buildup causes symptoms such as pain over the transplanted organ, leg swelling, or compression of the transplanted organ, it may need to be drained. Usually it is drained through the skin using a small needle. Rarely, another surgery is needed to drain the fluid.

Urine Leak

Urine travels through a tube called the *ureter* as it goes from the kidney to the bladder. A urine leak can occur if there is a small opening where the ureter of the transplanted kidney connects to your bladder. Signs of a urine leak include:

- Unexpected pain in the area of the transplant
- Fluid draining from the incision
- Problems in how the transplanted kidney is working

To treat a urine leak, we place a *catheter* (tube) in the bladder to drain the urine and relieve the pressure. The catheter may stay in place while the area heals. We may also place a *nephrostomy* tube to divert the flow of urine. This allows the connection between the transplanted kidney and the bladder to heal.

Renal Artery Stenosis

Renal artery stenosis is a narrowing of the blood vessel that supplies blood to the kidney. It may be caused by the way healing has occurred between your blood vessels and the transplanted kidney.

This problem is rare. It can be seen 2 to 3 months or longer after the transplant. If it is severe, it may cause a large decrease in blood flow to the kidney. Signs of this problem include:

- Blood pressure is getting higher
- New leg swelling
- Kidney function is getting worse

An ultrasound exam of the kidney and artery may be done to check for this problem. Other tests such as an *angiogram* may also be needed. An angiogram is an imaging test that uses X-rays and contrast (X-ray dye) to study blood flow in arteries and veins.

Renal artery stenosis can often be treated by dilating the artery with a balloon at the time of an angiogram. Sometimes a stent is needed.

Ureteral Stenosis

Ureteral stenosis is a narrowing of the ureter. If this occurs, it may require a stent in the ureter or another surgery. We may also need to place a *nephrostomy* tube into the kidney. This tube diverts the flow of urine so that the ureter can heal after a stent or surgery.

Other Problems

Delayed Graft Function

Sometimes the kidney transplant does not work right away because of the shock from being removed from one body and placed in another. This happens in:

- Up to 30% of patients (up to 30 out of 100 of patients) who receive a kidney from a deceased donor
- Up to 2% of patients (2 out of 100 patients) who receive a kidney from a living donor

Most times, the kidney will start to work after a few days or even a few weeks. There is nothing we can do to speed up this process. You will need to continue dialysis until the kidney starts to work well on its own. Very rarely, the kidney does not start to work and must be removed.

Rejection

Rejection is the body's natural response to the foreign kidney or pancreas. You need to take anti-rejection (immunosuppressant) medicines so that your body's immune system does not reject the transplanted organ. Rejection causes inflammation in the transplanted organ. If it is not treated, it will cause scarring and permanent damage.

The 6-month period just after transplant is when the risk of rejection is highest. Rejection occurs in about 15% to 20% of kidney transplant patients (15 to 20 out of 100 patients). The risk of rejection for pancreas transplants is a little higher.

Reversing rejection is most successful when it is caught and treated early. The only way to know for sure if there is rejection is to do a *needle biopsy* of the transplanted organ (see next page).

Acute Rejection

Acute rejection occurs within 6 months after transplant. Most times, acute rejection can be treated and reversed. Acute rejection can happen even when the patient is taking their anti-rejection drugs correctly.

Often, acute rejection does not cause any symptoms. Your doctor may suspect acute rejection based only on your blood test results.

Chronic Rejection

Rejection that occurs more than 6 months after transplant is called *chronic rejection*. This type of rejection can be harder to treat. It often occurs because the patient has not been taking their anti-rejection drugs correctly. There are also other reasons for chronic rejection.

Signs of chronic rejection of a kidney transplant include:

- A decrease in urine output
- Fluid retention
- Weight gain
- Pain or swelling in the area of the transplant
- Flu-like symptoms such as fatigue, aches, and fevers

Needle Biopsy

Your doctor may order a *needle biopsy* of your transplanted organ if there is concern about rejection. A biopsy may also be done to make sure rejection is **not** the source of problems with the transplanted organ.

In a needle biopsy, a thin needle is inserted into the transplanted organ. Small pieces of tissue are removed through the needle. The procedure is done very safely under local anesthesia. Ultrasound is used to guide the needle into the organ. There is a small risk of bleeding from a needle biopsy.

After the needle biopsy, a *pathologist* will look at the tissue samples under the microscope. A pathologist is a doctor who examines tissues and cells to diagnose health issues.

If you need a biopsy to check for rejection, we will monitor you afterward to make sure you do not have bleeding or other problems. Your doctor will talk with you about a biopsy and its risks in more detail, if needed.

See “Transplant Renal Biopsy” to learn more about having a biopsy.

Chronic Allograft Nephropathy

Chronic allograft nephropathy is when your transplanted kidney slowly starts not working. It is also called *chronic rejection*. This type of damage may be caused by your immune system. It is different from *acute rejection*, which usually happens more quickly.

Other issues such as high blood pressure, diabetes, high cholesterol, or high levels of immunosuppressants may also slowly damage your new kidney. The original cause of your kidney disease can also cause problems.

Your doctor will watch for any signs of these problems. A needle biopsy may be needed to find the reasons for ongoing problems with the kidney transplant. Whatever the cause, we know that controlling blood pressure can help slow the decline of kidney function.

Infection

Infection is a possible life-threatening problem after transplant. The anti-rejection medicines you need to take after transplant will lower your immune defense system. This will increase your risk of getting infections.

Your infection risk is highest in the first 6 months after transplant, when you are taking the highest doses of anti-rejection medicines. You are also at higher risk during treatment for rejection.

As your doses of anti-rejection medicines are lowered, your risk of infection will decrease. But, your infection risk is always higher than if you were not taking these medicines.

Infections may be caused by bacteria, viruses, or a fungus. For 6 months after transplant, you will be asked to take certain antibiotics to help prevent some of the more common types of infections.

You will need to watch for any signs of infection and report them to your doctor. These include:

- Fever
- Cough
- Night sweats
- Chills
- Sore throat
- Abdominal pain
- Diarrhea
- New headache
- Pain when you urinate

Cancer

Cancer is another possible life-threatening problem after organ transplant. Taking immunosuppressants increases your risk of these cancers:

- **Skin cancer:** The risk of skin cancer for transplant patients is much higher than average. The cancer can also be more severe and aggressive. *Squamous cell* and *basal cell carcinoma* are the types of skin cancer that occur most often. If you had skin cancer before receiving a transplant, your risk is even higher.

We recommend that you:

- See a dermatologist for close monitoring after your transplant
 - Avoid long, unprotected sun exposure
 - Use sunscreen every time you go outside
- **Lymphomas:** Most lymphomas that occur after transplant are *non-Hodgkin's* lymphomas. They are also called *post-transplant lymphoproliferative disease*, or PTLN. PTLN is a very rare problem. It occurs in less than 1% of kidney transplant patients (less than 1 out of 100 patients).

Early signs of lymphoma include unexplained weight loss, fevers, or enlarged lymph nodes. If you have lymphoma, you will need to see an *oncologist* for treatment. An oncologist is a doctor who specializes in cancer treatment.

Joint and Bone Disease

Kidney disease can cause bone problems. Anti-rejection drugs called *corticosteroids* (steroids) are also linked to bone loss. Because of this, we use the smallest doses of steroids possible for anti-rejection.

Bone loss occurs mostly in the spine and hip bones. It can lead to *osteoporosis* (thin, weak bones) and increase your risk of fractures. Your doctor will talk with you about whether you may be at higher risk for this problem, and what treatment you may need to help your bone density. One way to prevent osteoporosis is to exercise with weights.

People with diabetes may have low bone density if they also have *peripheral neuropathy* (nerve damage in the outer limbs). Nerve damage in the feet and ankles means a higher risk for fractures in these areas. We do not know if steroids add more risk for people with diabetes, since bone loss from steroids usually does not affect feet and ankles as much as other areas.

Steroids can also cause a bone problem called *avascular necrosis* (AVN). AVN can lead to arthritis, mostly in the hip joint. But, it may also affect other bones such as the kneecap and some bones in the wrist.

Gout

Gout is a painful, red swelling of a joint, usually the big toe. It can occur as a side effect of some of your transplant medicines. People who have had gout before transplant are at highest risk for it after transplant.

Diabetes

Some people who do not have a history of diabetes may have diabetes after their transplant. This is because the anti-rejection drugs affect how the body makes and uses insulin.

You may need to start taking medicine, either pills or insulin shots, to control your blood sugar. If your blood sugar is not controlled, it can cause a higher risk of infections. Over time, high blood sugar can damage your kidneys, cause eye problems, and raise your risk of heart disease.

You may have a higher risk of developing diabetes after transplant if you:

- Are overweight
- Have a family history of diabetes
- Have type 2 diabetes, pre-diabetes, or borderline diabetes, even if you did not need diabetes treatment while on dialysis before transplant

For overweight people, even a small weight loss and regular exercise can improve blood sugar control. This can eliminate their need for insulin or pills, or at least lower the amount of medicine needed.

Side Effects of Anti-Rejection Medicines

(See chapter on “Medicines” for more complete information.)

- **Tacrolimus** is the most commonly used *calcineurin inhibitor* drug. Its side effects include:
 - Shakiness or tremor
 - Headaches
 - Heartburn
 - Diarrhea
 - High potassium levels (*hyperkalemia*)
 - Mild hair loss (usually lessens over time)
 - Diabetes
 - Gout
- Side effects of **mycophenolate** include:
 - Heartburn
 - Diarrhea
 - Hyperkalemia
 - Low white blood cell count
 - Low red blood cell count (*anemia*)
- Side effects of **prednisone** include:
 - Thinning of the skin
 - Bruising
 - Joint and bone disease

Weight Gain

Many people gain weight after transplant, and prednisone is usually blamed for this. But, many patients who are not on prednisone also gain weight. This may be because their appetite is better and they feel better overall after transplant. We ask patients to be aware of this. Monitor your diet and exercise regularly to keep from gaining too much weight.

What can I do to avoid problems?

Many patients ask this question after transplant. Some things, such as the risk of early rejection and infection, are not within your control. But, there are things you can control. This includes understanding all your medicines and taking them correctly, especially your anti-rejection drugs, to help things go as smoothly as possible.

We know that we ask a lot of you, especially right after your transplant. We ask you to have many clinic visits and blood tests, but this is so that we can find any problems early.

We want you to tell us about any problems or concerns that you may have. We would rather have you call about something that turns out to be minor than not to hear about an issue that turns out to be important. Even after you return to your referring doctor for long-term follow-up care, you can always call us about problems related to your transplant. Please feel comfortable asking us for help.

Costs

There are many costs involved with transplant surgery. The surgery, your hospital stay, clinic visits, and medicines are all major expenses.

Depending on your insurance, you may need to pay some of these costs out of pocket. You will need to have good health insurance for the rest of your life to help cover your medicines and follow-up visits.

Being Referred

For a kidney/pancreas transplant

Your doctor has referred you to University of Washington Medical Center (UWMC) for a kidney/pancreas transplant. This chapter reviews the steps you will take as you start your journey.

Your First Step

After being referred for a kidney/pancreas transplant at UWMC, your first step is to meet with the *transplant nephrologist* (a doctor who specializes in kidney transplant).

Our scheduling coordinator will call you to set up this visit. If you need to talk with the scheduling coordinator, please call 206.598.3882.

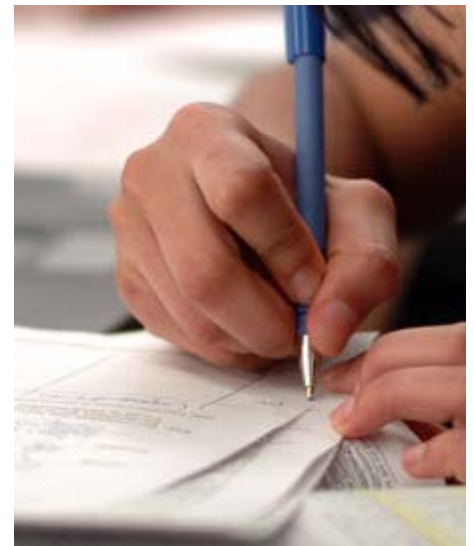
<p>My first visit is on _____ DAY _____ DATE at _____ TIME.</p>
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After you set up your visit, we will mail you a packet of information. The packet will contain:

- A cover letter, this guide, a video of our transplant class, and information about UWMC
- Forms and 2 pre-addressed, stamped envelopes
- Directions, maps, and parking information

Before Your Visit

- Review everything in the packet you received.
- Fill out and return the forms in the pre-addressed, stamped envelopes that were in the packet.
- Write down your questions to ask the transplant nephrologist.



Please review everything in the packet we send you, and fill out and return the forms.

- If you have any recent changes in your address, phone numbers, or insurance, please call us with your new information. To do this, call 206.598.4388 and press 1.

On the Day of Your Visit

- Bring your medicine list, a valid photo ID, and your insurance card(s).
- We advise you to bring a support person with you. This person can be a family member or a friend.
- **Arrive at the hospital 15 minutes before your appointment time.**

What to Expect

Your first visit with the transplant nephrologist may take up to 2 hours. Afterward, you will find out if you are a potential candidate for kidney transplant.

If you are a potential candidate, you will:

- Have some tests done (see the chapter on “The Evaluation Process”)
- Then meet with the transplant team

Your First Visit with the Transplant Team

Bring your support person with you to your first visit with the transplant team. This visit may take 4 to 6 hours. At this visit, you will:

- Meet your team members: a social worker, a surgeon, your transplant nurse coordinator, and a dietitian. You may also meet a nurse practitioner or psychiatrist.
- Learn more about transplants, what needs to happen before you can be placed on the transplant list, and what else to expect on the transplant journey.
- Review factors that will increase the success of your transplant.
- Have blood and urine tests.
- Give us a detailed medical and social history.
- Receive immunizations, if needed.

Parking in the Triangle Parking Garage

The Triangle Garage is on N.E. Pacific Place, across the street from the hospital. The garage has 500 parking stalls with 67 disability-parking stalls and 9 wheelchair-accessible parking stalls (see “Parking for Oversized Vehicles” on page 3). After you park, you will go through an underground tunnel that leads to the main entrance of the hospital.

The Evaluation Process

For a kidney/pancreas transplant

The evaluation process is complex, and differs for each patient. It begins with a referral your doctor makes to UWMC.

Who is eligible for a transplant?

To be eligible for transplant surgery, you must either:

- Have a GFR (*glomerular filtration rate*) below 20 mL/minute, or
- Be on dialysis

We can assess you for transplant if your GFR is below 30 mL/minute, but your wait time for transplant will not start until your GFR is below 20 mL/minute. Your *nephrologist* (kidney doctor) will help you decide when to start the transplant evaluation.

To be considered for kidney transplant, these statements must be true:

- Your doctors have told you that you can expect to live at least 5 years.
- Your body is healthy enough for surgery. This means that your heart is strong, you do not have any blockages in the blood vessels in your legs, and you do not have active cancer.
- You do not smoke.
- You are not too overweight.
- Your financial resources and caregivers will support you throughout the transplant journey.

You may be eligible for kidney/pancreas transplant if you have type 1 (*juvenile*) diabetes. Most people with type 2 diabetes still have a working pancreas.

If you live outside the U.S., you are still eligible to receive a transplant at UWMC, if you meet all the criteria.



Be sure that you and your caregiver ask your doctors your questions about the transplant process.

What happens during evaluation?

Before you are accepted for transplant, your evaluation team will:

- Review your medical records.
- Ask for your medical history and do a physical exam.
- Talk with you and your support person about:
 - The transplant process
 - Risks related to transplant
 - What is involved in the surgery
 - The use of *immunosuppressant* drugs (drugs you will take that keep your body from rejecting the new organ)
 - Your eating habits, dietary needs, and food and drug interactions
- Briefly review:
 - What to expect during your hospital stay
 - The routine for clinic visits and follow-up after a transplant
 - Your financial plans
- Assess your support system after surgery. You will need:
 - Caregiver(s) to help you 24 hours a day for at least a few weeks. You may stay with them, or they may stay with you.
 - Help with rides to the clinic at 7:30 a.m. several days a week.
 - Help with learning your new medicines.
 - Help with lifting anything more than 10 pounds (a gallon of water weighs almost 9 pounds).

Our social worker can help your caregiver(s) with their *Family Medical Leave Act* (FMLA) forms if they need to take time off work.

You can help move your evaluation along by seeing your own doctor for your tests and visits. If you want to have your workup and testing done at UWMC, our Transplant Services will set up your appointments.

We understand that being evaluated can be overwhelming, tiring, and stressful, for both you and your loved ones. One of the hard parts about this process is knowing that you may not be a candidate for transplant. It may help you to share your thoughts and feelings with someone you trust.

Please know that we carefully review all of the information we gather during your evaluation to try to achieve the best outcome for you. Feel free to ask the transplant team staff any questions you have as you go through this process.

Labs, Tests, and Procedures

During your evaluation, you will have many tests to look at your lungs, heart, circulation, stomach, and intestines. A check mark (✓) in the table below means that these tests are required before transplant.

There may be other tests you will need to take, depending on your medical history. You may be also referred to other specialists, such as Infectious Disease or Cardiology, to be cleared for surgery.

Health Area	Lab Test	Kidney Transplant	Pancreas Transplant
Bladder	Voiding cystourethrogram (if history of bladder problems)	some	some
Blood cell counts	WBC, RBC, platelets	✓	✓
Blood chemistry	Electrolytes/minerals	✓	✓
Blood fats	Cholesterol, HDL, LDL, triglycerides	✓	✓
Bones	DEXA scan	some	some
Cancer screening	Men: PSA (depends on age)	✓	✓
	Women: Pap smear	✓	✓
	Women: Mammogram (if over 40 years old)	✓	✓
Clotting	PT/PTT	✓	✓
	Coagulation labs (if history of blood clots)	some	some
Eyes	Fundus exam, refractory index, slit-lamp	some	✓
Gastro-intestinal	EGD (if history of stomach problems)	some	some
	Colonoscopy (if family history of colon cancer or over age 50)	✓	✓
Heart	EKG	✓	✓
	Cardiac stress test	some	✓
	Coronary angiogram	some	some
	Echocardiogram	some	✓
Histo-compatibility	ABO, Rh, HLA, PRA	✓	✓

Health Area	Lab Test	Kidney Transplant	Pancreas Transplant
Kidney	BUN, creatinine	✓	✓
Liver	Albumin, bilirubin, alkaline phosphate, GGT, SGOT, SGPT	✓	✓
Liver/ gallbladder	Abdominal ultrasound	✓	✓
	CT abdomen/pelvis	some	some
Lungs	Chest X-ray	✓	✓
	Pulmonary function test (if history of breathing issues)	some	some
	Low-dose chest CT (if over age 55 and history of smoking 30 <i>pack years</i> *)	some	some
Pancreas	Amylase, Hgb A1c, insulin antibodies, C-peptide	some	✓
Parathyroid	PTH	✓	✓
Teeth	Dental exam	✓	✓
Thyroid	TSH	✓	✓
Tuberculosis exposure	Quantiferon blood test	✓	✓
Vaccinations	Hepatitis A	✓	✓
	Hepatitis B	✓	✓
	Pneumonia (2 vaccines)	✓	✓
	Influenza	✓	✓
	Tetanus/diphtheria/pertussis	✓	✓
	Shingles (if over age 50)	✓	✓
Vascular	Carotid arterial duplex	some	some
	Iliac and LE arterial duplex	some	some
Viral exposure	CMV, VZV, EBV, HSV, HIV, RPR, HAV, HBV, HCV	✓	✓
Other	Biopsy, if needed	✓	✓

* *Pack years* are calculated by multiplying the number of cigarette packs smoked each day by the number of years. A person can reach 30 pack years by smoking 2 packs a day for 15 years, or half a pack a day for 60 years.

Evaluation Outcome

Your evaluation team can advise either going forward with a transplant or stopping the process. This decision can come at any time during your evaluation. We cannot tell at the start of your evaluation how it will go or what the final outcome will be.

Members of your evaluation team will meet to talk about the results of your tests and to decide next steps. It is possible that:

- Your tests may show health concerns that need to be treated before transplant.
- The team may decide that transplant is not a safe treatment for you.
- You may need to see a specialist to give another opinion about an abnormal test or exam. This provider might be a cardiologist, infectious disease specialist, pulmonologist, or psychiatrist. These providers will then offer their opinions about your having a kidney/pancreas transplant.

After your full medical workup is done, we will send you a letter. This letter will tell you if you are approved for the national organ transplant waiting list.

If You Are Denied for Transplant at UWMC

- If you are denied as a candidate at UWMC's transplant center, you can ask your nephrologist for a referral to another transplant center.

If You Are Accepted for Transplant at UWMC

Once you are accepted for transplant at UWMC:

- **If you smoke, you must stop smoking before you can go further in the process.** This is because smoking:
 - Lowers your ability to survive transplant surgery
 - Increases your risk for infection, heart disease, and cancer

Ask the transplant social worker if you need a referral to a stop-smoking program.

- **You will need to make your final decision about transplant.**
 - The final decision about transplant is yours. A transplant is only a treatment for kidney disease or diabetes. It is not a cure.
 - If you do not think you can do what is needed before and after the transplant to get the best results possible, please think carefully about whether a transplant is the right choice for you. The transplant team will respect whatever decision you make.

Listing at More than One Center

The United Network for Organ Sharing (UNOS) policy says that it is OK for you to be listed at more than one transplant center. Being listed at more than one center might shorten your wait time. But, there is no advantage to being listed at more than one transplant center in the same Organ Procurement Organization (OPO) area.

You can also transfer wait time from one transplant center to another, if you wish.

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Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Tissue Matching

For a kidney/pancreas transplant

You will have 4 tests that will show how compatible you are with a potential donor. This chapter describes those tests and explains how the results are used.

What is tissue matching?

Tissue matching is a way of finding out if 2 people are *compatible*, or alike. The results of tissue matching help us know if it is safe for us to place a donor's organ into your body.

What is donor compatibility?

Donor compatibility is when your tissues and the donor's tissues are enough alike that your body is more likely to accept the transplanted organ.

Why is donor compatibility important?

Your body has a built-in *immune system* that recognizes substances that could harm it. This system protects your body against anything that is different from your body. Its main job is to react to bacteria and viruses that could cause infections or disease.

Since a transplanted organ comes from another person's body, your immune system naturally sees it as a threat and tries to reject it. If you and a potential donor are compatible, there is a lower chance that your body will reject an organ from that donor.

How is tissue matching done?

As part of your evaluation, blood tests will tell us about your immune system. The results of these tests will show:



You will have blood tests during your evaluation that tell us about your immune system.

- Your blood type (O, A, B, or AB)
- Antibodies in your blood that may react against the donor organ
- Your tissue type (*human leukocyte antigens* or *HLA analysis*)

We will use the results of these tests to find out if a certain donor is compatible with you.

To improve the chances that your body will accept a compatible organ, you will also receive *immunosuppressant* drugs after transplant. These drugs suppress your immune system to keep it from rejecting your new organ.

Compatibility Tests

You will have 4 tests that will show if you are compatible with your potential donor. They are:

Blood Type (ABO) Compatibility

There are 4 main blood types O, A, B, and AB. We will test blood samples from both you and the potential donor to see if your blood types are compatible.

This chart shows which blood types are usually compatible:

Blood Type	Can Receive from	Can Donate to
O	O, A2	O, A, B, AB
A	A, O	A, AB
B	B, O, A2	B, AB
AB	O, A, B, AB	AB

- People with blood type O can donate to all other blood types. It is called the “universal donor.”
- People with blood type AB can receive from all other blood types. It is called the “universal recipient.”
- Some people with blood type A have unique proteins on their red blood cells. This “subtype” of type A blood is called A2. This type of blood looks like blood type O to the immune system. People with subtype A2 blood may be able to donate to people with blood types O and B. More tests are needed to see if this is possible for a donor-recipient pair.

Antibody Testing

Antibodies are proteins in your blood that identify and react against a “foreign object” in your body, such as a virus, bacteria, or a transplanted organ. Your antibodies usually react to proteins called *antigens* that are on the foreign object.

Antibodies that react against a transplanted organ are often reacting to *human leukocyte antigens* (HLAs). Your body usually does not make HLA antibodies unless you have been exposed to them before. Events that can cause your body to produce HLA antibodies include pregnancies, blood transfusions, infections, or a previous organ transplant.

There are 2 types of tests to find out if you make HLA antibodies:

Panel Reactive Antibody Test

A *panel reactive antibody* (PRA) test compares your blood to the white blood cells of people who have donated blood. This shows how *reactive* (sensitive) your immune system is against their HLAs.

Your PRA is calculated as a percent. For example, if your PRA is calculated as 50%, this means that your immune system will react against organs from 50% of donors. The more HLAs you react against, the higher your PRA percent.

A high PRA means:

- There is a higher risk of rejection when you get a transplant.
- You may need more immunosuppressant medicines.
- It may be harder to match you with a donor. This may make your wait for a transplant longer.

Pregnancy, blood transfusions, and infections can make your immune system create new HLA antibodies, which increases your PRA. If you become pregnant or have a blood transfusion after you have had your PRA test, contact your transplant nurse coordinator. You will need to have another PRA test done.

Cross Matching

Cross matching also checks for HLA antibodies. It compares your blood to a certain donor's blood. This can be a living donor or a deceased donor.

- With a living donor, cross matching is done early in your evaluation to see if that donor is compatible with you.
- With a deceased donor, your blood is tested against the donor's blood when the organ becomes available.

If antibodies in your blood react against the donor's blood, it is called a *positive cross match*. This usually means the antibodies in your blood would cause rejection of the donor organ right away. Most times, you would not be able to receive an organ from that donor.

There is a treatment that removes HLA antibodies and keeps more of them from forming. This treatment is called *desensitization*. This may allow more donors to be a match for you.

We will talk with you about desensitization, if it might work for you. But even with this treatment, the HLA antibodies may return, making the risk of organ rejection higher than if you never had the antibodies at all.

Tissue Typing

HLAs are *antigens* (proteins) found on human tissue or cells. Your antigens are decided by your genes.

The more closely related you are to someone, the fewer genetic differences you have. This means your antigens are more alike. Your immune system is more likely to accept an organ from a donor who is closely related to you.

People inherit 2 copies of DNA called *haplotypes* from their parents, 1 set from each parent. This means you are a tissue “half match” with each of your parents. These haplotypes define whether or not a donor is a match for you.

Transplant recipients can develop antibodies against the donor HLAs, called *donor-specific antibodies* (DSAs). This can happen both before and after transplant.

We will check your blood for DSAs after your transplant. If you have DSAs, it may be an early sign of rejection. If other tests show that you might be rejecting the transplanted organ, we can start treatment to keep this from happening.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Living Kidney Donors

Benefits, risks, and what to expect

Donated kidneys may come from either deceased or living donors. This chapter explains living donation.

Who can be a living kidney donor?

There are 2 types of living kidney donors:

- A **living related donor** (LRD) is a blood relative who wants to donate a kidney to a family member.
- A **living unrelated donor** (LURD) is a spouse, in-law, friend, co-worker, or anyone else who wants to donate a kidney to a recipient.

UWMC Transplant Services has a Living Donor Program that teaches and assesses potential living kidney donors for our transplant patients.

People who want to be a living kidney donor must:

- Be over the age of 21, unless *first degree* relative (either a parent, sibling, or child)
- Be under the age of 70
- Be in good health
- Have a body mass index (BMI) of 30 or lower
- Not have diabetes
- Have normal kidney function

What is the benefit of having a living kidney donor?

With a living donor, the surgery can be done at a time that is best for the recipient. Most times, the wait time is shorter than it is with a deceased donor. This means the recipient is likely to be healthier at the time of transplant.



A living donor can be a relative or someone who is not related to you.

From a living transplant donor:

“My sister was on dialysis. I was watching her get sicker. I was glad I could do something to help her get better.”

What is the success rate of living kidney donation?

- The 1-year success rate for a kidney transplant from a living donor is over 97% (more than 97 out of 100 transplant patients are alive 1 year after transplant).
- The 1-year success rate for a patient who receives a kidney from a deceased donor is about 94% (about 94 out of 100 transplant patients are alive 1 year after transplant).
- We expect that a kidney transplant from a living donor will work for about 15 to 20 years.

How do I talk with someone about being a donor?

- You may want to talk about living kidney donation with your family, spouse or partner, friends, or co-workers who may be interested in donating. Start by giving them basic information and the living donor website (www.uwmedicine.org/donor) or Living Donor Phone Line (206.598.3627) so they can learn more.
- You or someone who knows you can tell your story to others who might be able to donate. If talking about living kidney donation is hard for you, ask a close friend or family member to be your advocate.
- Bring family and friends with you to your transplant evaluation visit so that we can explain living donor transplant to them. Even if they cannot donate, they may be able to talk with others about living donation.

Tips on Talking about Living Kidney Donation

- **Choose a place and time that feels right.** Your family member or friend needs to feel comfortable. Leave plenty of time for the two of you to talk.
- **Speak from your heart and listen with your heart.** Take the time to listen to their feelings and concerns.
- **Be careful not to pressure others.** Donation is a major surgery and a serious decision. People who feel pressured to donate may not be eligible.
- **Give it time.** Don't expect an answer right away. People will need information, time, and support to decide. They may need time to talk with their own family, employer, or others involved in their daily lives.

What else do potential donors need to know?

Time off Work

Kidney donation is major surgery. The donor should allow 4 to 8 weeks for recovery after the surgery. A donor's time off work may be covered with sick leave, vacation pay, or donated time from other employees.

Donors who live in the U.S. may qualify for special leave under the Family and Medical Leave Act (FMLA). Federal employees receive paid leave to be a living kidney donor. Some other employers and state governments also offer paid leave for living donors.

Family History

Some kidney diseases may be inherited. A family member who wants to donate a kidney should talk with their primary care provider about their own risk for kidney disease. The UWMC Living Donor Program team will also talk with potential donors about this concern.

Pregnancy

If a woman has been a living kidney donor and then becomes pregnant, her remaining kidney should not have any problems.

But, she may have a higher risk of:

- *Preeclampsia* (high blood pressure and protein in the urine)
- Having a pre-term birth (early delivery).

The risk for preeclampsia in all women is 2.5% (2.5 out of 100 women). For a female kidney donor, the risk is 4% to 5% (4 to 5 out of 100 women).

If the donor does become pregnant, she should tell her obstetrician that she has only 1 kidney.

Smoking

Potential kidney donors must stop smoking tobacco at least 60 days before the day of surgery. For their recovery and health, we also strongly advise not smoking after kidney donation.

What if I have more than 1 donor?

If more than 1 person wants to be considered for donating a kidney to you, please ask them to call the Living Donor Phone line at 206.598.3627 or visit www.uwmedicine.org/donor and click on “Potential Living Kidney Donor Screening.” The Living Donor Team will review every potential donor for you. Based on our review, we will choose 1 donor at a time to be fully evaluated. Other donors will be considered as back-up.

What risks are involved in being a donor?

Kidney donation is major surgery. There is always risk involved with major surgery.

Potential kidney donors must be in excellent health, not have diabetes, and have kidneys that are healthy and working well. Evaluating a potential kidney donor usually takes about 3 to 6 months. This evaluation is done to make sure that the potential donor is in good health.

The Living Donor Team will review the potential donor's health and test results. At any point, a potential living donor may be found ineligible based on the results of their evaluation.

Is there a risk of death from donor surgery?

The risk of death from donor surgery is very low. Overall, death occurs only 3 times out of 10,000 donor operations. UWMC has had no donor deaths. We have done more than 500 living donor surgeries.

Are there increased health risks after donation?

In a healthy donor, the remaining kidney usually grows in size and is able to provide all the kidney function needed for the rest of the donor's life. The risk of kidney failure, also called *end stage renal disease* (ESRD), for living donors is about the same as it is for other people of the same age, gender, and health who have not donated a kidney.

But, there is a long-term risk of developing ESRD after donating a kidney. The exact level of risk is not known, but it can be as high as 0.5% (1 out of 200 donors).

What if my donor is healthy but is not a match for me?

A positive cross-match or an incompatible blood type means that your potential donor cannot donate to you (see the chapter on "Tissue Matching"). If this occurs, you may be interested in learning about UWMC's Donor Exchange Program.

This program matches donors with recipients through a national exchange program. The program searches through their list of donors and recipients until they find a match. To learn more, visit the National Kidney Registry website at kidneyregistry.org.

What about organ donation from people in the community or anonymous donation?

Some people have a sincere desire to be a living kidney donor, even if they do not have a relative or friend who needs a kidney transplant. These people are called *non-directed kidney donors*.

UWMC has a non-directed donor program. Non-directed donors can donate either to someone on UWMC's wait list or to someone on the National Kidney Registry's wait list.

Non-directed donors are usually matched to the person on the list who:

- Has a compatible blood type
- Has been waiting the longest for a transplant

From a living unrelated donor:

"I am already signed up as an organ donor, and being able to help someone when I am alive would be terrific."

From a potential transplant recipient:

"I asked my grandmother to spread the word for me to the rest of the family. I knew my grandmother would not be the donor, but she was a great intermediary. It took the spotlight off me."

Does someone advocate for the donor?

Every transplant program has an *independent donor advocate* (IDA). Donors can talk with the IDA about their concerns. The IDA advises donors and helps guide them through the process of deciding if donating is in their best interest.

What can a potential donor expect?

- Potential living donors should either:
 - Visit www.uwmedicine.org/donor and click on "Potential Living Kidney Donor Screening."
 - Or:
 - Call the Living Donor Program (LDP) at 206.598.3627. The IDA will ask them some basic questions and explain the donor process to them.
- If the person is interested, we will send them a donor information packet.
- Before a potential donor can begin the donor evaluation, the transplant recipient must be medically and financially cleared for transplant.
- The potential donor may stop the evaluation at any time if they decide they do not want to donate.
- The LDP will contact your donor at 6 months, 1 year, and 2 years after their donor surgery to check on their health. LDP will give the results of their kidney tests to United Network for Organ Sharing (UNOS).

Can I find out how a donor's evaluation is going?

Federal law requires that we keep all health records private. This federal law is called the Health Insurance Portability and Accountability Act (HIPAA).

This means that the transplant team cannot give you or your nephrologist any information about your donor's evaluation. It is up to your donor to tell you about the evaluation process, if they wish.

Who pays for living donor evaluations?

- Sale of human organs is prohibited by the National Organ Transplant Act of 1984. But it is legal to pay for expenses related to living kidney donation such as travel costs and lost wages.
- The potential living donor must get a health history and physical exam before we begin their evaluation. These costs should be covered by the donor's health insurance. The LDP does not cover these costs. If your

potential donor does not have health insurance, they should call the LDP at 206.598.3627.

- The LDP will pay only for the potential donor's medical expenses that are directly related to the required medical workup. If the testing finds health problems that need more evaluation or treatment, the LDP will not cover those costs.
- The expenses for the evaluation surgery, hospital stay, and complications for the potential living kidney donor should be paid by the transplant recipient's insurance. Most recipients have insurance coverage that will pay these donor expenses. If you are not sure if your insurance will cover this, contact your insurance company.

What if my donor needs help with travel or housing costs?

If your potential donor cannot afford to travel to UWMC, they may be able to get help with travel costs.

Receiving this financial help is based on your family size and income. Talk with your social worker about how to apply for this help.

How can potential donors learn more?

To learn more about living kidney donation, the Donor Exchange Program, or non-directed donation, potential donors can call The Living Donor Program at 206.598.3627 or visit www.uwmedicine.org/donor.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Deceased Donors

For a kidney transplant

This chapter explains the different types of deceased kidney donors. Read this chapter before you are called for surgery so that you know what to expect.

The Kidney Donor Profile Index

During your team visit, the transplant team will talk with you about the different types of deceased donors. They will also explain the *Kidney Donor Profile Index* (KDPI).

The KDPI is used to rate a donor's kidney health. The KDPI score is based on the donor's age, height, weight, ethnicity, history of high blood pressure (*hypertension*), history of diabetes, whether stroke was the cause of death, serum creatinine levels, hepatitis C status, and Donor After Cardiac Death (DCD) status (see "Donor After Cardiac Death" on page 4).

A donor's KDPI score tells how long their kidney is likely to work after transplant. The score is given as a percent (%). It can be as low as 0% and as high as 100%. A lower KDPI score means that the kidney is expected to last longer. For example:

- A KDPI score of 20% means the kidney is likely to work longer than 80% of other deceased donor kidneys.
- A KDPI score of 60% means the kidney is likely to work longer than 40% of other deceased donor kidneys.
- Kidneys with KDPI above 85% are expected to work longer than 5½ years. These transplants tend to happen more quickly than transplants of kidneys with KDPI below 85%.



Learn about the different types of deceased donors so that you are ready to make decisions when you get the call for transplant.

Types of Donors

Standard Criteria Donors

When you are placed on the deceased donor kidney transplant wait list, you are added to the list of people who are waiting for a kidney from a *standard criteria donor* (SCD).

An SCD:

- Has a KDPI score below 85%
- Does not have known risks for hepatitis or HIV infection

At the time of this writing (December 2016), the wait time for an SCD kidney transplant is about 3 to 5 years.

Other Types of Donors

You can also choose to accept a kidney from a donor who does not meet the standard criteria. These donors may have:

- A KDPI score above 85%
- Known risks of infection (see “Higher-Than-Standard-Risk Donors” on page 5)

Most times, making this choice means you have a shorter wait for kidney transplant. If you are on dialysis, you are likely live longer after transplant if you receive your kidney earlier.

If you have type B blood, you may choose to accept a kidney from a donor who has type A or AB blood (see “A2 and A2B Donors” on page 6). We do these types of transplants because the wait list for type B transplant patients is much longer than the wait list for type A and AB patients.

Deciding on Donor Type

We may call you at any time of day or night for a deceased donor transplant. The kidney we offer you may be from:

- An SCD
- A donor with KDPI above 85%
- A higher-than-standard-risk donor
- A donor who has had cardiac death (see “Donation After Cardiac Death” on page 4)
- An A2 or A2B donor

You will need to know what these terms mean so that you can quickly make the best decision for you when we call.

You do not need to accept a kidney from any donor who does not meet the standard criteria. But, your wait for a kidney from an SCD might be months or years longer than your wait for a kidney from a donor who has a higher KDPI score or with known risks of infection.

Estimated Post-Transplant Survival (EPTS)

All people on the deceased donor kidney transplant wait list are given an *Estimated Post-Transplant Survival* (EPTS) score. This score is used to match kidneys that are likely to last longer with the people who will likely need working kidneys longer. The score is given as a percent (%).

Your EPTS score is based on factors that affect how long you will need a kidney to work after transplant:

- Your age
- How long you have been on dialysis
- How many transplants you have already had
- Whether you have a history of diabetes

If you have a higher EPTS score, you may choose to receive a kidney from a KDPI above 85% donor. This kidney may not last as long as one from a KDPI below 85% donor, but your wait time for transplant will likely be shorter.

Here are 2 examples of how the EPTS score works:

- Someone with an EPTS score of 20% is often a young person who will likely need a kidney transplant to last longer than 80% of other candidates.
- Someone with an EPTS score of 60% will likely need a kidney transplant to last longer than 40% of other candidates.

How to Find Your EPTS Score

We will tell you your EPTS score, but you can also figure it out yourself. To do this, visit the Organ Procurement and Transplantation Network website:

<https://optn.transplant.hrsa.gov/resources/allocation-calculators/epts-calculator/>

Kidney Life and Donor KDPI Scores

This chart shows how long we expect a kidney to last based on the donor's KDPI score:

Deceased Donor's KDPI Score	Kidney Expected to Last
Higher than 85%	5.60 years
Between 21 and 85%	8.90 years
Between 0 and 20%	11.44 years

Please note that these numbers are *medians*. This means that half (50%) of the kidneys will work longer than the number of years in the "Kidney Expected to Last" column and half (50%) will work a shorter time. Your health and how well you take your medicines will be the main factors that affect how long the transplant will work.

Kidneys from donors with a KDPI score above 85% often do not last as long as kidneys from donors with a KDPI score below 85%. We usually offer kidneys from donors with KDPI above 85% to people on the wait list who are:

- Over age 60 and do not have diabetes
- Over age 50 and have diabetes

Donation After Cardiac Death

One of the factors in the donor's KDPI score is their *donation after cardiac death* (DCD) status. You may be offered a kidney from a DCD donor, so it is important to understand what this means and how it may affect you.

- Most organ transplants come from donors who are pronounced *brain dead*. But, some organs come from donors who donate after cardiac death. This means that their heart stopped beating before they were pronounced dead.
- When the DCD donor's heart stopped beating, their kidney stopped receiving oxygen. Because of this, a DCD kidney may take longer to start working in your body. This is called *delayed graft function* (DGF). It is common to need dialysis after a DCD kidney transplant.
- Most DCD kidney transplants start working very well after they have some time to heal.

KDPI-above-85% donors may also be DCD donors.

Higher-Than-Standard-Risk Donors

Sometimes we find out that a deceased donor was involved in “high-risk behaviors.” These behaviors are defined by Public Health Services (PHS). They include:

- Drug use
- Time in jail
- Prostitution

For a full list of high-risk behaviors, read “Behavioral Risk Factors for Recent HIV, HBV, or HCV Infection” at optn.transplant.hrsa.gov/media/1163/2013_phs_guideline.pdf.

If we offer you a kidney transplant from a deceased donor with known risks, we will tell you that it is from a “higher-than-standard-risk donor.”

A kidney from this type of donor works just as long as a kidney from an SCD. Accepting a kidney from a higher-than-standard-risk donor may shorten your wait time for transplant.

Infection Risk After Transplant

We test every deceased donor for hepatitis B, hepatitis C, and *human immunodeficiency virus* (HIV). But, there is a very small chance that the test result will be a *false negative*. This means that even though the result looks negative, the donor did have the hepatitis or HIV virus.

The risk of an infection, and a false negative test result, is higher in donors who were involved in high-risk behaviors. **We will always get your consent before giving you a kidney from a higher-than-standard-risk donor.**

There is only a small risk that hepatitis or HIV will be passed to you through your kidney transplant. If you receive a kidney from a higher-than-standard-risk donor, your risk of getting an infection is:

- For hepatitis B virus: About 1 in 300 transplants (0.33%)
- For hepatitis C virus: About 1 in 5,000 transplants (0.02%)
- For HIV: About 1 in 16,000 transplants (0.006%)

In comparison, your risk of dying in a plane crash is 1 in 5,000 (0.02%).

The risk of getting hepatitis B is higher than the other infections. We will ask you to get a hepatitis B vaccine series before transplant. This will lower your risk of this infection.

If you decide to accept a kidney from a higher-than-standard-risk donor, you will meet with an infectious disease specialist before your surgery. This specialist will clearly explain the risks involved.

We will keep testing you for hepatitis and HIV for 1 year after your transplant. The risk of getting these infections through kidney transplant is never 0%, even if the organ is from an SCD.

A2 and A2B Donors

Some donors with type A blood have different proteins on their red blood cells. These proteins make their blood look like type O blood to your immune system. This means your body may accept their organ more easily.

This blood type is called “A2 subtype” or “non-A1 subtype.” Some people with type AB blood have the “A2B subtype” or “non-A1B subtype.”

Donors with A2 or A2B subtype blood can safely donate to some type B recipients. A2 donors can also safely donate to some type O recipients, but this match is only done with living donors, not deceased donors.

If You Have Type B Blood

If you have type B blood, your wait time for a deceased donor kidney is often longer than it is for other blood types. If you are able to receive a kidney from a type A2 or A2B donor, your wait time is likely to be much shorter.

We will do a blood test to see how strongly you react to type A blood. This test checks for *anti-A antibody titers*.

- If you have a strong reaction, we will **not** give you a kidney from a type A2 or A2B donor.
- If your reaction is not very strong, we can safely give you a kidney from a type A2 or A2B donor. If we offer you an A2 or A2B kidney, it means that your blood test showed that your anti-A antibodies are not too high.

A kidney from a type A2 or A2B donor can work just as well as a kidney from a type B donor. The outcome and long-term patient and graft survival rates are the same.

There are very small risks involved in transplanting an A2 or A2B kidney into a type B recipient. There may be a slightly higher risk of early rejection. Your doctor will monitor your kidney closely after your transplant. If needed, your doctor may do a kidney biopsy.

You may choose not to receive a kidney from a type A2 or A2B donor. This choice will not affect your place on the wait list for a type B kidney transplant.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Waiting for Transplant

For a kidney/pancreas transplant

After you are done with your evaluation and you have been accepted for transplant, you can be added to the wait list. This chapter explains about the wait list and things you can do until you get called for your transplant.

What is the wait list?

The wait list for organ transplants is a national computer database managed by the United Network for Organ Sharing (UNOS). UNOS is a nonprofit, federally-funded organization. It maintains the transplant list for the entire country. This list contains the name of everyone in the U.S. and Puerto Rico who is waiting for an organ transplant.



The wait list for organ transplants is run by the United Network for Organ Sharing (UNOS).

If you want a kidney or pancreas transplant from a deceased donor, you must be placed on this list.

How do I get on the list?

We will enter your information – your name, blood type, and tissue type – into the UNOS computer system to add you to the wait list.

How does the list work?

When a kidney or pancreas from a deceased donor becomes available, all patients on the list who are waiting for a kidney or pancreas are compared to that donor. The computer makes a list of patients who best match that kidney or pancreas. It also considers how long you have been waiting for a transplant, your age, and *sensitization* (see page 2).

Who gets the transplant?

Who gets the transplant depends on:

- If their blood and tissue type (HLA) matches the donor's.
- How long they have been on the wait list (people who have been waiting longer for transplant have priority).

- **If you started dialysis before you were added to the wait list:** Your wait time goes back to *the day you started dialysis*. If you started dialysis 2 years ago and are listed today, you already have 2 years of wait time.
- **If you were not on dialysis before you were added to the wait list:** Your wait time begins when your estimated glomerular filtration rate (GFR) is 20 mL/min or less. This is measured either by a blood test or urine test.
- **If your GFR is above 20 mL/minute:** You can be added to the kidney transplant wait list, but you will be “on hold.” This means your wait time will not start to add up until your GFR reaches 20 mL/minute or less. Please tell your nurse coordinator when your GFR reaches 20 mL/minute or less. We will take you off “hold” so that you can start gaining wait time.
- Their age (younger patients have priority).
- Whether or not they are *sensitized*. A person who is sensitized has a high score on their *panel reactive antibody* (PRA) test.
 - Being sensitized means you have antibodies in your blood that could fight against many potential organ donors. You can be sensitized through pregnancy, blood transfusions, or other transplants.
 - If you are sensitized, you could have a harder time finding a kidney or pancreas that your body will accept. Because of this, you are given priority on the wait list over those who are not sensitized.
 - Patients with a PRA of 99% may receive transplants from donors all across the region.
 - Patients with a PRA of 100% may receive transplants from donors all across the country, rather than just our local area.
 - Please see the chapter on “Tissue Matching” for more information on PRA and Human Leukocyte Antigens (HLAs).

Where am I on the wait list?

People are not ranked in an order such as 1st, 2nd, or 3rd on the wait list. The decision about who will receive a transplant is made when a donor organ becomes available. You are given priority based on compatible tissue and blood types between you and the donor, as well as how long you have been on the wait list.

You may end up waiting longer than someone else on the list, simply because a certain kidney or pancreas matches best with that other person. You might also receive a transplant sooner than someone who has waited longer than you because the organ matches best with you.

You will never be removed from the list without receiving written notice from the United Network for Organ Sharing (UNOS).

How long will I wait?

We cannot predict how long your wait for transplant will be. But, your transplant team can give you an “average” wait-list time based on your blood type. (Please see the chapter on “Tissue Matching” for other things that may affect your wait time.)

Remember, once you are active on the wait list, you can be called for transplant at any time, day or night.

Can I be on more than 1 wait list?

All transplant programs in Washington state use the same wait list. Getting on a wait list at another center in the Seattle or Spokane area would not change your wait time. In fact, once you are on UWMC’s wait list, you cannot be listed at another transplant center in this area.

But, being listed with transplant programs in other areas of the U.S. may change your wait time. Visit the UNOS website at www.unos.org to see the wait times for different areas of the country. If you list with other programs, you may need to go to these centers to be evaluated for transplant, even if you have already been evaluated at UWMC.

What to Do While Waiting

- Call your transplant nurse coordinator at least once a year. It’s easiest to do this on a day that you will clearly remember, such as your birthday. Also call if there is a big change in your health status or lifestyle.
- Keep your transplant coordinator updated on:
 - Your phone numbers
 - Address
 - Health status (recent hospital stays or infections)
 - Financial status (including insurance changes)
 - Times when you plan to be out of town
 - *Elective* (planned) surgeries
- Make sure that your personal affairs are in order:
 - Fill out an advance directive and write your will.
 - Complete forms for medical leave or loan deferment, if needed.
 - Arrange caretakers for your children and pets.

Please let us know if you need help with these concerns.

- Have yearly medical checkups. These may include a cardiac stress test, heart evaluation, Pap smear, mammogram, colonoscopy, and other tests that the transplant team has asked you to have.

- **Important:** Keep up to date with your monthly blood samples for deceased donor cross-matching. If the HLA lab does not have your current blood samples, you may miss a chance to have a transplant.
 - Tubes for this testing will be mailed to you.
 - Take the package to dialysis if you are on dialysis, or to a local lab if you are not on dialysis, for your monthly blood sample.
- Follow the healthcare plan you created with your referring doctor. For example, attend dialysis, have regular doctor visits, and take your medicines as prescribed.
- Watch your fluid gains and phosphorus levels. This will help you keep your active status on the list.
- Maintain a healthy lifestyle:
 - Eat healthy foods.
 - Get good rest.
 - Manage your stress.
 - Lose weight if you need to.
 - Follow a regular exercise program to keep your body strong.

Staying in great mental and physical shape is very important. The medicines you take may weaken your muscles. You will want to be as healthy and strong as possible if and when you have your transplant. A dietitian or physical therapist may be able to help you with your goals.

- Do not smoke cigarettes and do not abuse alcohol or drugs. If you need help managing your alcohol, cigarette, or drug use, please tell us. We can help you find a program to quit.
- If you are a woman, create a birth control plan that you will use after transplant surgery. There are 2 very important reasons you must avoid becoming pregnant for at least 1 year after surgery:
 - A pregnancy will impact the success of your transplant.
 - Transplant medicine can cause birth defects in the baby.
- Learn more about kidney or kidney/pancreas transplants. Ask questions. Read the handouts you receive (see the chapter on “Resources”).
- Decide what pharmacy you will use to get all your medicines. You may want to look into mail order options, since they may save you money.
- Assess your insurance coverage and personal finances:
 - Learn about all the costs of having a transplant.
 - Find out exactly what your plan covers, including how your plan works when you are outside your hometown area.

- If you live outside the Puget Sound region, make a plan for coming to Seattle. Your plan should cover how you will get to Seattle and where you will stay. Plan to stay in the area for at least 3 to 4 weeks after transplant. You will need to come to the hospital at 7:30 a.m. for follow-up visits on many days.
- **Set up a support system in Seattle.**
 - If you are from out of town, make plans for family and friends to stay with you in Seattle. Ask our staff for help, if needed.
 - If you are from Seattle, you will still need a plan for support if and when you have your transplant.
- Get ready for the day when you are called for transplant. It may happen quickly. Find ways to cope if it takes longer. Ask for help if you are having problems coping while you wait (see the chapter on “Coping”).

For Caregivers Who Wait

If you are the caregiver for a transplant patient, this can be a stressful time for you, too. You may be able to find other friends or family members who will step in for you in the weeks after transplant, so that you can take some time for yourself. Looking after someone 24 hours a day is a tough job!

Keep in mind that there are many ways to help your loved one:

- Talk with friends and family about living donation
- Update your vaccinations
- Take care of the pets
- Wash your hands often after your loved one’s transplant

Getting Called for Transplant

We will call you when there is an organ that will work for your transplant. This can happen at any time of the day or night, on any day of the week.

We must be able to reach you within 1 hour of an organ becoming available. Even if you are out of town, at a party, or at a conference, **we must be able to reach you at ALL times.**

If there is someone who will always know where you are, make sure you give us that person’s phone number, too.

We have many stories about patients who could not be reached when we called them for transplant. Do not be one of these stories! Make sure we are able to reach you **AT ALL TIMES.**

Since each patient is unique, what happens after the phone call will vary. You may be called in as a primary or backup recipient. We will tell you of the plan as soon as the cross-match results are final.

When the coordinator calls you in for transplant:

- We will tell you when and where to arrive at the hospital.
- If you have diabetes and take insulin, and you are told not to eat, ask the coordinator how much insulin you should take. Your dose will depend on the expected time of your surgery. Most times, the coordinator will tell you to take only ½ of your usual dose.

After you receive this call:

- Do **NOT** eat or drink anything, unless we tell you otherwise. Your stomach needs to be as empty as possible when you have surgery.
- We will give you enough time to gather the belongings you will need and make important phone calls, but please try to get to the hospital quickly and safely.

Have Your Bag Packed

Have your bag packed and ready to go at all times. Include personal items you will need for a hospital stay.

Please also bring:

- Your copy of *Your Kidney/Pancreas Transplant Guide*
- Your UWMC clinic card
- Information about your insurance plan
- Photo ID
- A list of emergency contact phone numbers
- All your medicines
- An extra exchange (if you are on peritoneal dialysis)
- Reading glasses, if needed
- Credit card, if you think you will need money during your hospital stay

You can ask to put your photo ID and credit card in the hospital safe.

We also ask that you bring these items with you to the hospital, to make sure they are working well:

- Blood pressure cuff
- Thermometer
- Blood glucose meter, if you use one

Do **not** bring:

- Jewelry
- Valuables

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Coping

Before, during, and after kidney/pancreas transplant

The transplant process can be very stressful before, during, and after your surgery. This chapter offers tips on coping that you may find helpful.

Coping with the Medical Workup

With so many tests and medical visits, the workup time can be stressful. You will see many UWMC staff and make many trips to the hospital or clinic before your transplant.

Use this time to:

- Learn as much as you can about what happens during the transplant journey. Many people feel more in control when they know what to expect. Feeling more in control may help you cope better.
- Explore all of your options. Weigh the risks and benefits of each choice you are given. **You** are the one who will decide what form of treatment you will have for your kidney disease.
- Take charge of your pre-transplant workup. Make sure all the tests you need to have are scheduled.

Finding Balance

Your wait for transplant may be long, but life cannot go “on hold” while you are waiting. Even after you are approved for transplant and put on the wait list, do your best to keep your life in balance. Here are some tips:

Physical Needs

- Keep active. Exercise helps maintain your health. If you have a physical disability, ask your doctor about special exercise programs.
- Work or volunteer if you can. People who work while waiting tend to have better outcomes after transplant.



Being active will help you cope while you are waiting for transplant.

Social Needs

- Stay in touch with your family and friends. Keep from getting isolated or lonely.
- Do your usual activities and hobbies, or try something new.

Emotional Needs

- Make sure you have a safe place where you can express your feelings, both the good and the bad.
- It is OK to feel sad, frustrated, and anxious. Share your feelings with a person or group you trust.

Intellectual Needs

- Keep your mind active. Try reading more instead of watching TV.
- Exercise your mind with a class, games, puzzles, or a book group.

Spiritual Needs

- If you are part of a spiritual community, stay involved.
- Rely on your beliefs for comfort and strength.
- Read, meditate, and do other things to increase your feeling of spiritual well-being.

Other Ways to Cope While Waiting

Adjust Your Attitude

- Stay positive. Positive thinking, humor, and leading a normal life all help people cope during a stressful time.

Receive and Give Support

- Be patient and gentle with yourself. You will likely need support more than ever at this time.
- You may need to rely on your support system in ways you never have before. Your personal support group can be very helpful as you go through your transplant. Involve those who will care for you all along the way so they will know what you will be going through. Use their support when you need it
- Know that transplant affects the whole family. It can change a family's lifestyle as well as your own.
- It can be easy to direct your anxiety and frustration at your caregivers. Reassure them that they are not the cause of your anxiety and frustration. Always thank them for their support.

Relax

- There are many healthy ways to relax when you feel anxious or stressed. Check out your local bookstore for books and tapes that may help.
- Ask your social worker for help finding a way to release tension.
- If you are having a hard time coping or feel you cannot handle it on your own, ask your doctor or social worker for a referral for counseling.

Social Work and Care Coordination Services

Your social worker is a member of your transplant team. Talk with your social worker at any time in your transplant journey, starting from your first visit.

Social Work and Care Coordination services include:

- **Psychosocial assessment:** At this visit, your social worker will meet with you and your support team to help you get ready for the transplant process. The social worker will ask questions about your lifestyle, support system, and financial and insurance resources. The social worker will also ask what you expect from your transplant experience.
- **Supportive counseling and referrals:** Counseling is available for you and your family or support person(s) during the entire transplant process. Your social worker can help with issues such as depression, anxiety, fear, stress, family problems, lifestyle changes, reactions to treatment, and stress from being in the hospital. If needed, your social worker will provide referrals to agencies, resources, or therapists.
- **Education:** Your social worker can teach you about or provide information about all personal and social aspects of transplant.
- **Casework services:** Your social worker can help you find local housing and assist with transportation and other issues after you are discharged from the hospital. They can also supply information about fundraising, getting insurance coverage, and working through problems with forms and complex health systems.
- **Information and referral to resources:** Ask your social worker for information and referral to resources such as Social Security, Washington State Department of Social and Health Services (DSHS), vocational rehabilitation, and local subsidized housing organizations.

Coping After Transplant

In the Hospital

Do your best to be patient while you are in the hospital after surgery. Focus on going home. Your transplant team will tell you what you need to do to be able to go home and when it is safe to do so.

After Discharge

Mood changes and strong emotions are normal after transplant. They may be caused by side effects of medicines. They can also be caused by the stress of surgery. Be sure to tell your caregivers that these ups and downs are common.

Some feelings you may have are:

- **Anxiety and depression:** You have had medical and nursing care 24 hours a day in the hospital. When you go home, you will have to do things on your own at home, with help from your caregivers. Use your caregivers, ask for support, read your discharge instructions, and ask questions. Always know that you can talk with someone 24 hours a day by phone, if needed.
- **Guilt:** Some patients have “survivor’s guilt.” This is a feeling of regret that someone had to die for them to receive an organ. Some patients feel guilty that because they got an organ, it means someone else did not. Others feel they did not deserve the suffering that led to the need for a transplant. These are all normal feelings. If you are bothered by these feelings, please talk with someone on your transplant team.
- **Stress:** The weeks after transplant can be stressful. Your life revolves around medicines, clinic visits, lab tests, and worries over organ rejection and infection. Most patients say that it gets much easier over time. Ask for help if you have concerns about how you are doing.

Give yourself time to recover from surgery and the changes you have gone through. Returning to a “normal” lifestyle will take time and patience.

It may also take friends and family time to adjust to the “new” you as a healthier, more independent person. You can help them by getting better and taking great care of yourself.

Writing to the Donor’s Family

Many transplant patients want to write to the family of their donor. Most donor families welcome hearing from the transplant recipient.

It is your choice whether to write to the donor family. If you do write, it is helpful to talk about yourself, your family situation, your job or volunteer work, and your hobbies and interests. Share how your transplant experience has changed and improved your life. And of course, thank the donor family for their gift.

To maintain privacy, please include only your first name in your letter to the donor family. Do **not** include your address, phone number, email address, Facebook page, or other personal information.

When you are ready, give your letter to your social worker or transplant coordinator. We will forward it to the donor family.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Transplant Surgery

For a kidney/pancreas transplant

By the time you have your transplant surgery, you may have been waiting a long time. This chapter covers the basics about what happens just before and during surgery. Reading this chapter before surgery will help you know what to expect.

The Phone Call

A UWMC transplant team member will call you when we accept an organ that is a good match for you. **When we call, the phone number we call from could be from any area code.**

When you receive this important call, we will tell you:

- When to arrive at the hospital and where to check in.
- If you are the primary recipient, which means you are 1st in line, or the backup recipient, which means you are 2nd in line.
- Only basic information about your donor.

Even while we are planning for your surgery, be prepared that it might be cancelled. This could happen if you have a new health problem, if the kidney is not good quality, or if the final cross-match shows that the kidney is not a good match for you.

If this happens, try not to be discouraged. The fact that we called you may be a good sign that you are moving up on the wait list.

Before Surgery

Before we can go ahead with your transplant surgery:

- You will have more blood tests, a chest X-ray, and other tests. These tests include a final cross-match to find out if your immune system will accept the kidney and/or pancreas.



When you receive the call for transplant surgery, we will tell you about your next steps.

- If you are on dialysis, you may be asked to go to your regular dialysis session or come to UWMC and have dialysis here.
- Your surgeon, nephrologist, and anesthesiologist will examine you. They will review your health records to make sure you have everything you need for a safe operation. They will also decide what your transplant medicines will be. You may see other doctors, too.
- The transplant team may ask if you want to be part of a research study. This choice is up to you. Ask questions to help you decide if it is a good idea for you.
- The nurse will tell you what to do. If there is time, you will be asked to take a shower. You may also be given an enema. You may be given medicines by mouth or through an *intravenous* (IV) line in your arm to prepare you for your surgery.

The final decision to proceed with the transplant depends on your health and the results of your cross-match. When you are cleared for transplant, you will be taken to the operating room (OR).

Your Family and Support Team

During your surgery, your family and support team may stay in the waiting area near the OR or in your hospital room. They need to tell us where they will be so we can stay in touch with them during your surgery. They can use the phone in the waiting area to talk with someone on the team in the OR.

We will tell your support team when your surgery starts. The lead surgeon will talk with your family or other members of your support team when your surgery is over. Other surgery staff will still be working with you at this time to prepare you to leave the OR.

Your support team must be prepared to wait a little while longer to see you after they talk with the surgeon. A nurse will often be the one who tells your support team when they can see you.

Your Surgery

There will be many people in the operating room with you: the surgeon, the anesthesiologist, nurses, and other members of your surgical care team. These providers will work together to prepare you for surgery.

- Your anesthesiologist will:
 - Give you *general anesthesia* to make you sleep. You will receive this medicine by IV and through a mask over your nose and mouth.
 - Place a breathing tube to help you breathe during surgery.
 - Monitor you during the entire surgery to make sure you are asleep and not feeling pain.

- While you are asleep:
 - You may have a large IV placed in your neck vein. You will receive powerful *immunosuppression* medicines through this IV. The IV will still be in place when you wake up from surgery.
 - You will have a *catheter* (thin tube) placed in your bladder to drain urine from the new kidney. The catheter will still be in place when you wake up from surgery.
 - You will be connected to equipment that monitors your body functions and systems.
 - A *nasogastric* (NG) tube may also be placed to empty your stomach. This tube goes through your nose and into your stomach. If you are having a pancreas transplant, you will have an NG tube in place when you wake up from surgery.
- Your incision will be on your right or left lower abdomen, or in the middle. Your surgeon will tell you before surgery where your incision will be.
- A kidney transplant takes about 2 to 4 hours. A kidney/pancreas transplant takes about 4 to 6 hours.
- After surgery you will go to the recovery room. You may wake up there or in your hospital room. You will have a bandage over your incision.

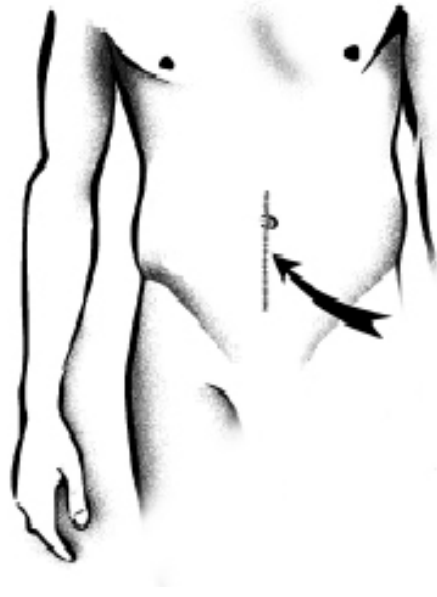
The drawings below and on the next page show where the incisions are made and how your new organ(s) is placed. You will have one of these incisions for your pancreas or kidney/pancreas transplant.

Abdominal Incision for a Kidney Transplant



This drawing shows an incision for a right kidney transplant. Your incision could also be on the left.

Abdominal Midline Incision for Pancreas or Kidney/Pancreas Transplant



This drawing shows the incision for a kidney/pancreas transplant.

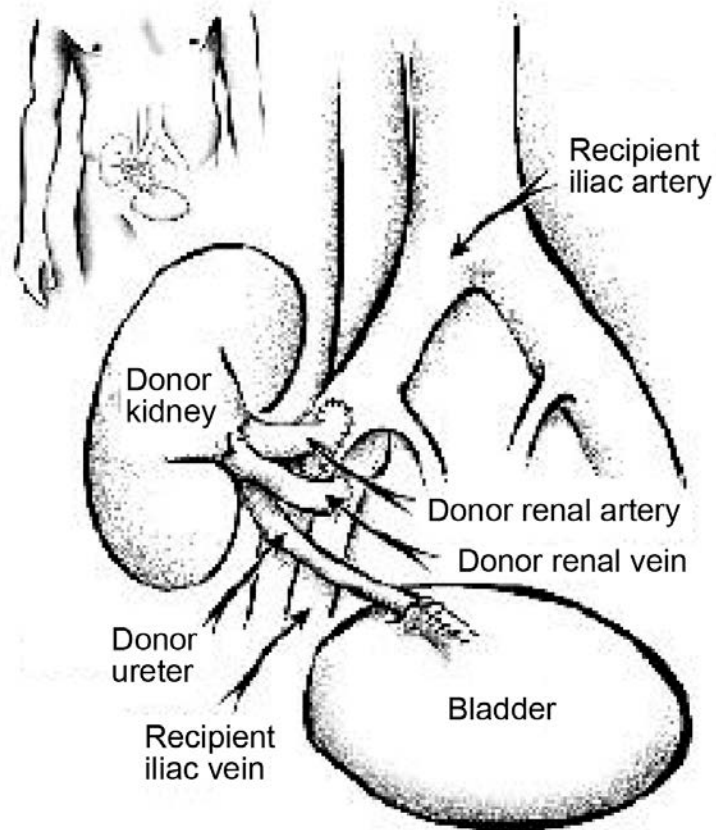
Surgery for a Kidney Transplant

Your new kidney will not be placed where your own kidneys are. Your own kidneys will not be removed during kidney transplant.

These are the usual steps for a kidney transplant (see drawing on page 5):

- Your surgeon will make an incision in your abdomen and expose blood vessels in your pelvis.
- Next, the donor kidney will be placed in your abdomen. The donor kidney blood vessels will be sewn into your blood vessels.
- After blood starts flowing to the new kidney, your surgeon will connect the donor ureter into your bladder.
- Next, the surgeon will place a stent to support the connection of the new ureter to the bladder.

Kidney Transplant



Placement of the donor kidney and ureter and blood vessel connections.

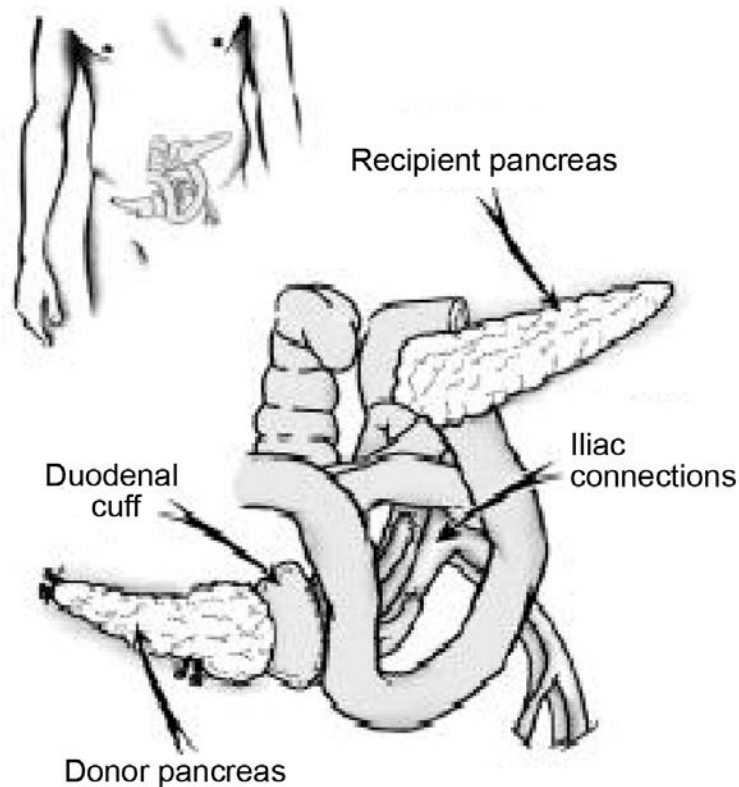
Surgery for a Kidney/Pancreas Transplant

Your own pancreas will not be removed during surgery. These are the usual steps for a transplant of both a kidney and a pancreas:

- Your surgeon will make a midline abdominal incision (see drawing on page 4) and expose the blood vessels in your pelvis.
- The donor pancreas will be placed in your pelvis (see drawing on page 6). Most times, this is on the right side. The donor pancreas blood vessels will be sewn into your blood vessels.
- After blood starts flowing to the pancreas, a connection is made to from the pancreas to your bowel.
 - Because your bowels are involved in this surgery, they may “fall asleep” or slow down after surgery. It may be hard for you to pass gas or have a bowel movement. The nasogastric tube will help relieve pressure in your bowels until they “wake up” and you are able to pass gas. When your bowels start moving again, the nasogastric tube can be removed.

- After the pancreas transplant is done, your surgeon will place the donor kidney on the left side of your pelvis. (See “Surgery for a Kidney Transplant” on page 4.)

Pancreas Transplant: Enteric Drainage (Bowel Drained)



The duodenum collects pancreas secretions, which drain into the bowel (enteric drainage).

After Kidney or Pancreas Transplant Surgery

- You will be taken to the recovery room after surgery. When you are ready, you will be taken to a care unit in the hospital.
- In the recovery room, you will have an ultrasound exam to check how the blood is flowing into your transplanted organ(s).
 - If you received a pancreas transplant, you will spend the first night after your surgery in the intensive care unit (ICU). Nurses will watch you closely and check your blood sugars often.
- If you have heart problems:
 - You will be connected to a heart monitor.
 - You may spend the first night after your surgery in the intensive care unit (ICU).

Insulin After Surgery

- If you have diabetes:
 - And you received **only a kidney transplant**, you will receive insulin through your IV after surgery. You will also return to self-injected insulin after the IV is stopped. You may need a higher dose of insulin than you needed before transplant. The transplant team will watch your blood sugar levels closely, to see if your insulin dose needs change over time.
 - And you received **a kidney/pancreas transplant**, you will no longer need insulin after your surgery.
- If you do not have diabetes and receive only a kidney transplant, you may need IV insulin after surgery to control your blood sugar levels.

Tubes and Devices

You may have **some or all** of these devices in place after your surgery:

- An **intravenous tube (IV)** for giving you fluids and medicines. The IV is usually removed on your day of discharge.
- **Nasal prongs** to give you oxygen, until your oxygen level is normal.
- A **bladder catheter** (Foley catheter). This tube drains urine from your bladder. This allows the sutures in this area time to heal before you start urinating normally. The catheter will stay in place for about 3 to 4 days.
- **Surgical staples** to close your incision. These will be removed about 2 to 3 weeks after your surgery.
- A **ureteral stent**, which will be removed about 4 to 6 weeks after your surgery, either during your hospital stay or in the clinic. Plan to be in the hospital for half a day for this visit.
- A **drainage tube** (also called a JP drain) to drain fluid from your abdomen. Most times, this is removed several days after surgery, when the amount of fluid has decreased.
- A **nasogastric (NG) tube** (after a kidney/pancreas transplant). This will stay in place until you pass gas.
- A **peritoneal dialysis catheter**. This is usually removed during the transplant surgery or 4 to 8 weeks after a kidney transplant.
- **Sequential compression devices (SCDs)**. These wraps on your legs inflate from time to time to improve blood flow. They help keep blood clots from forming. Keep these wraps on. Your nurse will remove them when it is safe to do so.



Sequential compression devices (SCDs) help keep blood flowing through your legs while you are lying in bed.

Self-care to Speed Your Recovery

- After you are awake, your nurse will teach you to:
 - **Do deep-breathing and coughing exercises.** Do these exercises about once every hour to help lower your risk of breathing (*respiratory*) problems and lung infection (*pneumonia*).
 - **Use your patient-controlled analgesia (PCA) pump.** This device allows you to give yourself pain medicine when needed.
- You also need to **start walking** as soon as you are able. Walking will reduce your risk for getting blood clots, pneumonia, constipation, and bloating. It will also help speed your recovery.

Like all major surgeries, this surgery involves risks. Please talk with your surgeon about these risks and carefully read the chapter on “Benefits and Risks” in this guide.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Recovery in the Hospital

After a kidney/pancreas transplant

This chapter reviews what to expect after your surgery.

After surgery, you will recover in the hospital for about 3 to 7 days. Just as before your transplant, a team of healthcare professionals will be working with you while you recover. Be an active participant in your recovery so that you learn how to take care of yourself.

Your Care Team

Medical Staff

Your care team while you are in the hospital includes:

- Your attending surgeon, transplant fellow, transplant nephrologists, physician's assistant (PA), and surgical resident
- Transplant nurse coordinator, bedside nurses, and patient care techs
- Pharmacist, dietitian, social worker, and physical or occupational therapists

The transplant unit nurses provide your daily nursing care. They are also your link with the rest of the transplant team. These nurses will tell other members of the transplant team about your needs and concerns.



We encourage your personal support team to visit you often while you are in the hospital, and learn about your recovery needs.

Your Personal Team

We strongly encourage your personal support team to visit often and to be an active part of your recovery care. There will be a cot in your room if one of your caregivers wants to stay overnight.

Rounds

The transplant resident doctors (doctors who are in special training) visit transplant patients every morning. These visits are called “rounds.”

The entire transplant team makes rounds every day in the afternoon. This is the best time for you and your family to talk with the team. Write down any questions you have, so that you can ask them at afternoon rounds.

Interpreters

Tell your nurse or social worker if you or your family members need an interpreter to help you understand all the information you will receive during your recovery in the hospital. You may also ask for an interpreter to be present for your scheduled team visits.

Your English-speaking family or friends can help with communication **only** about issues that are not related to your healthcare.

Also, please let us know if you have hearing or vision problems so that we can fully meet your needs.

To Support Your Care

Bring these items to the hospital to support your care:

- *Your Kidney/Pancreas Transplant Guide*. Re-read the chapters “Recovery in the Hospital” through “Discharge.”
- Your home blood pressure cuff, thermometer, and blood glucose meter. While you are in the hospital, we will check them to make sure they are working well.

Tubes After Surgery

After surgery, you may have these tubes in place:

- A *catheter* in your bladder to drain and collect urine. This catheter is usually removed in 3 to 4 days. If you have had bladder problems, the tube may stay in place for up to 10 to 14 days.
- An *intravenous tube* (IV) for giving you fluids and medicines. The IV is usually removed on your day of discharge.
- A *nasogastric* (NG) tube to keep your stomach empty, if you had a pancreas transplant. This tube is removed when you have passed gas, which is a sign that your bowel is working again.

- *Nasal prongs* to give you oxygen, until your oxygen level is normal.
- If you have a *peritoneal dialysis tube*, it will be removed either during surgery or when your kidneys are stable, in about 4 to 8 weeks.
- A *stent* (plastic tube) to keep your ureter open where it goes into your bladder. As your ureter heals, this stent will be removed, usually 4 to 8 weeks after surgery.

You will also have wraps on your legs called *sequential compression devices* (SCDs). These wraps inflate with air from time to time. This motion squeezes your legs, which helps prevent blood clots. Always wear your SCDs when you are in bed or sitting in a chair.

As you recover, your doctor or nurse can give you a better idea about when each tube is likely to be removed.

Pain Control

At first, you will give yourself pain medicine through a *patient-controlled analgesia* (PCA) pump. This pump gives pain medicine through your IV line until you can take medicine by mouth.

Your nurse will explain how to control pain once you are taking oral medicines. Keep your pain at a level where you are comfortable enough to take part in your own care.

Physical Activity

We will expect you to become active as soon as possible after surgery. It may be hard at first, but there are many benefits to getting up and moving around right after your surgery:

- Better healing and overall physical recovery
- Better pain control
- Relief of bloating and increased recovery of bowel function
- Lower risk of blood clots
- Lower risk of lung infection (*pneumonia*)

Your first goals after surgery will be to:

- Begin doing breathing exercises using the *incentive spirometer* (IS). You will start doing this before you leave the recovery room.
- Get up and stand by your bed the evening after your surgery.
- Walk in your room and the hallway by the next morning.

Preventing Falls

While you are in the hospital, it is important for you to work with nurses and other caregivers to prevent falls. Being in the hospital increases your risk of falls. This is because you may:

- Be weak after surgery
- Be attached to strange equipment
- Have side effects from your pain medicine
- Try to get out of bed in the hospital without help

Even if you do not need help to get out of bed at home, you can fall in the hospital when getting up without help. **Please ask for help to get out of bed to prevent falls and keep yourself safe.** Your physical therapist will tell you when it is OK for you to get out of bed on your own.

Dialysis

If your kidney has *delayed graft function*, you may need dialysis for many days to weeks after your transplant. About 30% to 40% of patients (30 to 40 out of 100 patients) who receive a deceased donor kidney need dialysis after their transplant surgery.

This is a common. It does not mean your kidney will not work.

Eating

- Your diet may be limited to sips of water or liquids at first. This is to keep you from being nauseated.
- As your bowel starts working again, you will add solid foods and eat a more normal diet.
- Some patients, including those with diabetes, may take longer to be able to eat solid food after surgery. If you cannot eat solid food, you may receive IV nutrition for several days. Your dietitian will help you decide which foods and snacks are right for you when you start eating again.

Bathing

You may take a sponge bath or a shower about 48 hours after surgery.

Self-Care After Transplant

Your care team will teach you about self-care while you are in the hospital. You will learn:

- How to take your medicines. This is a good time to review the chapter on “Medicines.” A pharmacist will meet with you to go over the details of your medicines and your dosing schedule. You will start taking your medicines yourself during your hospital stay.

- How to take care of your incision.
- About the transplant diet. Your dietitian will talk with you about your diet and give you the handout “Nutrition After Your Transplant.” Also read the chapter “Nutrition” in this guide.
- How to keep track of the fluid you drink and the amount of urine you make.
- Which labs and vital signs to check and record.
- About the signs of rejection and infection.
- About general self-care after transplant.

Visitors

We welcome your family and friends to visit you in the hospital. Please ask them to follow these hospital policies:

- Only children over age 6 may visit.
- To prevent infection:
 - Do not bring pets, live plants, or flowers to the hospital.
 - If visitors have a viral or bacterial infection such as a cold or the flu, we will ask them to return when they are well.

Personal Items

Feel free to bring personal items with you to increase your comfort. You can also have your family or support person bring them for you after surgery.

Here are some items you may want to bring from home:

- Robe
- Pictures of loved ones
- Books, handicrafts, and puzzles
- Music player
- Loose, comfortable clothes to go home in

Discharge

The transplant team will not discharge you until it is medically safe to send you home. If you are ready to go home, but you need more IV medicine or dialysis, it will be arranged for you as an outpatient.

Nutrition

Before and after a kidney/pancreas transplant

In this chapter, you will learn about the importance of watching your diet before and after your transplant.

Before Transplant

Assess your diet, lifestyle, and exercise before transplant surgery. Make a plan, decide what you want to change, and take small steps.

Everything you do to stay healthy and strong before transplant will help your recovery. This includes:

- Following all the dietary guidelines your providers have given you.
- Eating less salt and fewer processed foods.
- Reaching and maintaining your target weight.
- Staying active and keeping your muscles strong. Exercise will keep your weight on target and reduce weakness after surgery.



Good nutrition is very important, both before and after transplant.

If you have diabetes, also work with your team to maintain good blood sugar and A1C levels.

After Transplant

Your first few weeks after transplant surgery will be full of changes. You will start new medicines and your diet will change in many ways.

Once you have recovered from surgery, you will learn to make long-term lifestyle changes to keep your new kidney healthy.

Right after Surgery

- **Drink plenty of fluids.** Your team will give you a fluid target, usually between 2 to 3 liters (68 to 100 ounces) a day.

- **Eat protein-rich foods to help healing.** Some examples of these are:

- Nuts, nut butters, and seeds
- Beans and legumes
- Dairy products and eggs
- Fish, poultry, and red meat

Check with your transplant dietitian if you want to use nutrition drinks or protein powder.

- **Eat as desired.** You may have a low appetite, feel full quickly, and be constipated. These symptoms will ease over time.
- **Eat a regular diet.** You do not need to follow a renal diet after transplant. Your team will tell you if any diet restrictions are needed.

Special Concerns

Your dietitian will give you a handout called “Nutrition After Your Transplant.” It gives more details on everything in this chapter and will help guide your food choices after your transplant surgery.

Here is a basic overview of some special dietary concerns you may have:

- **Blood sugar levels.** Your blood sugar levels may rise due to new medicines and stress of surgery. If you have diabetes, your blood sugars will likely need fine tuning. You may need to make changes in your insulin or diabetes medicines. Good blood sugar control helps with wound healing and limits infections.
- **Potassium levels.** You may have high levels of potassium in your blood while your body adjusts to new medicines and your new kidney slowly starts working. If your potassium levels are above normal, avoid high-potassium foods and beverages until your team says it is OK.
- **Phosphate levels.** Phosphate levels are usually low after transplant. We will ask you to eat dairy products and whole grains to raise your phosphorus levels.
- **Magnesium levels.** The drug tacrolimus changes your magnesium levels. Your team will ask you to increase the amount of high-magnesium foods you eat. We will give you a list of these foods. Report any muscle cramping to your providers and take all supplements that are prescribed.
- **Food safety.** Make safe food choices after transplant to reduce the risk of infection and illness. You will receive detailed guidelines about preparing and storing food, and what to do when eating in a restaurant.

You will see your dietitian in the hospital after transplant and also in clinic after discharge. We will make sure you have contact information for your providers so you can call or email with questions about your diet and food choices.

After 3 Months

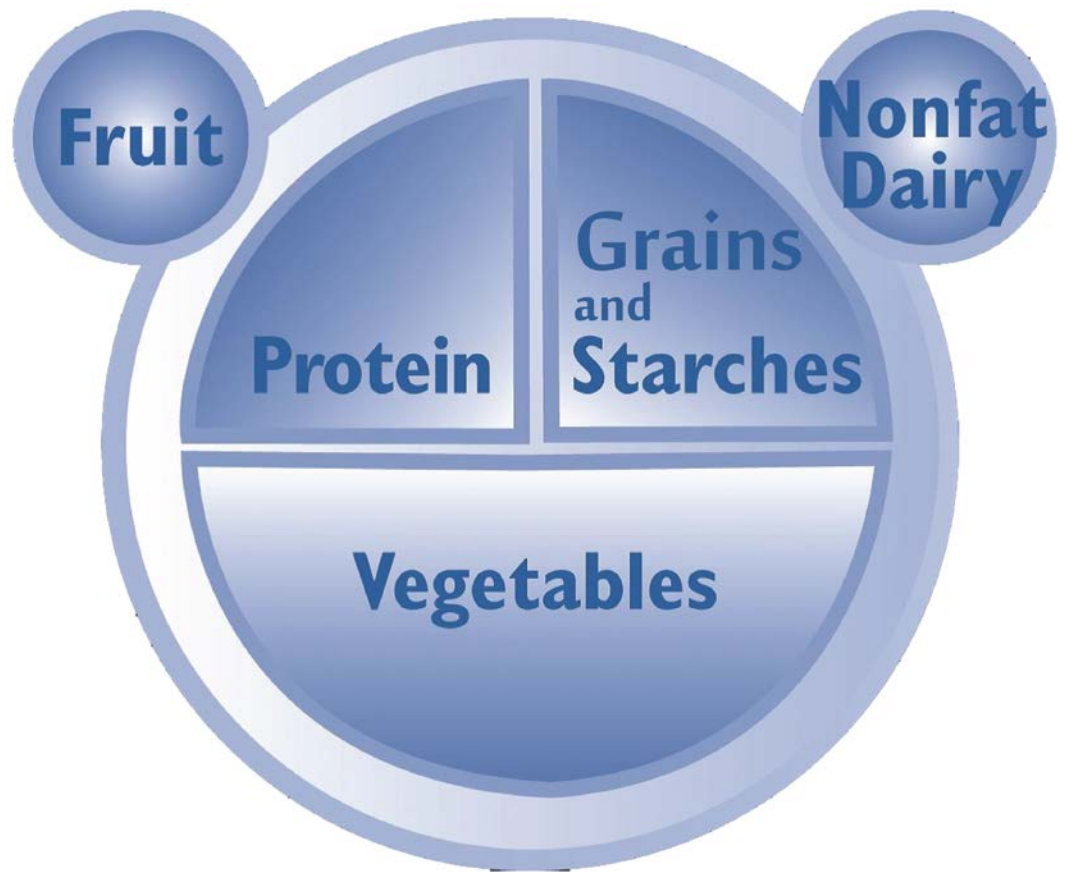
By 3 months after transplant surgery, you should see these milestones:

- Incision is healed from the inside out
- Blood levels are stable
- Medicines have been reduced
- Energy has improved

You are now ready to set long-term dietary goals to keep you and your new organ healthy:

- **Limit sodium.** The American Heart Association suggests 2,000 mg sodium a day to keep your blood pressure in the healthy range and to prevent fluid retention. Watch your intake of table salt, condiments, processed foods, and frozen meals, as these items contain a lot of sodium.
- **Keep your food choices heart-healthy.** Transplant drugs can raise your cholesterol and other blood fats. To keep these in control:
 - Eat brightly colored fruit and vegetables
 - Eat high-fiber foods such as whole grains and fresh produce
 - Use healthy oils such as peanut, olive, and canola oil
 - Limit saturated animal fats
 - Include fish weekly
- **Maintain a healthy weight.** Prednisone can increase your appetite and desire for sweets. It also breaks down muscle. It's easy to gain weight after transplant if you are not careful. To keep your weight in balance, make exercise a part of your daily life and make healthy food choices.
- **Eat a balanced diet.** Use the graphic on page 4 to guide your food choices:
 - Fill $\frac{1}{2}$ of your plate with fresh or cooked vegetables.
 - Fill $\frac{1}{4}$ of your plate with protein foods.
 - Fill $\frac{1}{4}$ of your plate with grains or other starches.

Always include vegetables, fruit, and dairy to keep your bones strong and blood pressure under control.



Healthy Plate Food Model

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Medicines

After a kidney/pancreas transplant

After a transplant, you will take medicines every day for the rest of your life. This chapter describes many of the drugs and supplements you will be taking. It includes common side effects, doses, and costs.

Getting Started

You will take many medicines after transplant. Before your surgery, learn as much as you can about:

- How each medicine works
- What its side effects are
- When and how to take it
- How you will pay for it

It will be helpful to learn ways to organize your medicines. Before your surgery, set up a system that will help you remember to take each medicine at the right time and in the right way.



You will take many medicines after your transplant.

What medicines will I take after transplant?

After transplant, you will take:

- **Immunosuppressants** to suppress your immune system. These drugs help prevent or treat rejection of your new organ(s). You will take these drugs as long as you have your graft.
- **Antibiotics** to fight infection. The drugs you take to suppress your immune system will increase your risk of infection. You will take antibiotics for 3 to 6 months after your transplant surgery.
- **Antacids** to help prevent upset or excess acid in your stomach. You will take antacids for 2 to 3 months after transplant.
- **Laxatives** and **stool softeners** to help avoid constipation. You will take these for 2 to 3 months after transplant.

You may also need to take:

- **Pain medicines**, usually for about 1 week after surgery.
- **Aspirin** in small doses to prevent blood clotting.
- **Antihypertensive drugs** to treat high blood pressure.
- **Diuretics** (water pills) to help treat swelling.
- **Iron** to help prevent anemia.
- A **multivitamin** to supplement your diet.
- **Calcium** and **vitamin D** to prevent *osteoporosis* (thin, weak bones).
- **Magnesium** and **phosphate supplements** to make up for the loss of these minerals through urine after transplant.

What about side effects?

Many of the drugs you will take after surgery have side effects. **Keep all of your doctor and clinic appointments.** At your visit, tell us about any side effects you have. We can adjust your medicines and doses as needed.

What will my medicines cost?

Your medicines can cost \$1,000 or more a month. These costs may go down over time, when you no longer need to take some drugs or your doctor lowers the doses.

Medicare, Medicaid, and private health insurance may cover some drug costs. But even with insurance, you may need to pay \$500 to \$2,000 out of your own pocket for drugs every month for the rest of your life.

Before your surgery, talk about transplant medicines with your health insurance company, your local pharmacist, and the social worker or financial counselor who are on your follow-up care team. Find out:

- What transplant medicines are covered by your healthcare plan
- What your co-pays or deductibles will be

Be sure to keep your insurance coverage after transplant. Your medicine costs can be \$12,000 to \$24,000 a year.

Where can I get my prescriptions filled?

Right After Transplant

- If you live in the Seattle area, you can fill your prescriptions at your local or home pharmacy.
- Most patients may be able to fill their prescriptions at the UWMC Pharmacy during the 3 months after transplant.

Long Term

In the long term, you can fill your prescriptions at your local pharmacy or use a mail order pharmacy. Some insurance plans require that transplant patients buy some of their medicines from “specialty pharmacies.”

Tell your health insurance company and local pharmacy that you will be a transplant patient, so they will know your medicine needs. They can help you arrange for buying and refilling your prescriptions.

Always carry your prescription insurance cards in your wallet or purse. Your pharmacy needs to see these cards for billing purposes.

What medical equipment will I need?

You will need some medical equipment to monitor the effects of your medicines. You may need to buy:

- A blood pressure machine that also measures your pulse
- A thermometer
- A scale
- A blood glucose meter

Before your surgery, buy both the blood pressure machine and thermometer and learn how to use them. That way, you can start to use them right after surgery.

At the Hospital

What to Bring

When you come to the hospital for transplant, bring with you:

- **Your current medicines** and a list of their names and doses. Your transplant team needs to know **all** of the medicines and supplements that you are taking.
- **This manual** (*Your Kidney/Pancreas Transplant Guide*)
- Any **equipment** you were asked to buy (see above)

Learning About Your New Medicines

After surgery, you and your caregiver will learn your medicine schedule. You will need to know the names, strengths, doses, purposes, and side effects of each medicine you take.

The hospital pharmacist will teach you about your medicines 1 to 2 days after surgery. It is a good idea for family members and caregivers to learn about your medicines along with you.

At first, taking so many medicines can be overwhelming. But, the number you take will decrease over the next few months. Transplant patients tell us that the best way to learn everything you need to know is to start taking the medicines yourself while you are still in the hospital.

Tips to Help You Keep Track

- Your pharmacist will give you a box called a *mediset*. Use it to keep track of your pills. Store it at room temperature, away from direct light.
- Work with your pharmacist to set up a medicine schedule that will work for you. Try to schedule your medicines so that you take them only 4 times a day, at breakfast, lunch, dinner, and bedtime. This will make it easier to remember to take your pills.
- Carry a 1-day mediset with you during the day to make it easy to take your medicines on time.
- Use your cell phone or get a watch with an alarm. Set the alarm to remind you when it is time to take your medicines.

After Discharge

- **You will receive medicines to last 3 to 5 days when you leave the hospital.** You will also be given prescriptions. Fill these as soon as you can at the pharmacy you have chosen. Make sure you do not run out of your medicines.
- **Keep an up-to-date list of all of your medicines with you. Include the directions for taking them.**
 - Update this list when your drugs change. Use it to refill your mediset.
 - Ask your doctors to print out a current list at your clinic visits.
 - You may want to keep your list on your computer, tablet, or cell phone so that you can update it easily and always have it with you.
- **When you come for clinic visits, bring:**
 - Your mediset
 - Medicine bottles you had filled at your pharmacy
 - Your medicine list
- **If you have problems or questions about your medicines, call your transplant nurse coordinator.**
- **Refill your medicines early.** Do not let your supplies run out.
- **Keep your follow-up appointments** so that your medicines can be checked and adjusted.

- **After 3 months**, you will need to get your prescriptions renewed. This can be done by your primary care provider (PCP) or your nephrologist.

Taking Your Medicines

Here are some basic rules for taking medicines:

- **Take ONLY the medicines your doctor prescribes for you.**
- **Take your medicines exactly as they were prescribed.**
 - Do **not** take more or less than your prescribed dose.
 - Do **not** stop taking a medicine without talking with your doctor or transplant nurse coordinator.
- **Do not take any new medicines or supplements** without first talking with your doctor, transplant nurse coordinator, or pharmacist.
- **If you miss taking a dose:**
 - Do **not** take more than a single dose at a time. Wait until it is time to take your next dose and take your usual amount.
 - Call your transplant nurse coordinator or doctor for instructions.
- **Know the side effects of your drugs.** Tell your doctor or transplant nurse coordinator about any side effects you have. If symptoms bother you too much, your doctor may be able to prescribe a different drug.
- **Tell all of your healthcare providers that you are a transplant patient** and are taking drugs that suppress your immune system. Tell your dentist, optometrist, and all other providers.
- **Keep all medicines out of reach of children and pets.**
- **Do not let anyone else take your medicines.**
- **Do not take herbal, natural, or nutritional supplements** without first talking with your transplant providers (doctors, nurses, pharmacists, and dietitian). This is because these products:
 - May have hidden ingredients that can cause side effects
 - Might interact with your transplant medicines and harm you
 - Can make managing your medicines even more complex
- **Avoid these (if possible) while taking immunosuppressants:**
 - Grapefruit, pomegranate, and star fruit
 - *Non-steroidal anti-inflammatory drugs* (NSAIDs) such as ibuprofen (Advil, Motrin) and naproxen (Aleve, Naprosyn)
 - Aspirin (unless prescribed by your doctor)
 - Herbal or “natural” medicines

- Acetaminophin (Tylenol) – do not take more than 2,000 mg a day (total from all sources)
- Nutritional supplements, unless prescribed by your transplant team

Drugs to Prevent Rejection

These medicines are called *anti-rejection drugs* or *immunosuppressants*.

Why do I have to take these drugs?

After transplant, your immune system will try to protect your body. It will see the new organ as a threat and try to destroy (reject) it.

How do they work?

These drugs weaken (suppress) your immune system by decreasing the effects of *T lymphocytes*, a type of white blood cell.

How many immunosuppressants will I take?

The transplant team will prescribe 3 different anti-rejection drugs for you. Each one affects the immune system in a different way. When these drugs are taken together:

- They are more effective at stopping rejection.
- You can take smaller doses of each drug.
- You will have fewer side effects, and less severe side effects.

Your transplant team will explain the specific drugs you will take.

How long will I need to take them?

You will take anti-rejection drugs for as long as you have your graft.

How well do these drugs work?

Even when you take your anti-rejection drugs as prescribed, rejection may still occur. Rejection most often occurs within 1 year after your transplant. Sometimes it can be reversed by using IV medicines.

Your blood test results will tell us if your body is rejecting your new organ. Be sure to keep all appointments for blood tests.

What should I do if I forget a dose?

It is important that you remember to take these medicines every day as prescribed. **If you forget whether you took your dose:**

- Do **not** double your dose.
- Call your doctor or transplant nurse coordinator for instructions.

What kind of side effects do they cause?

- **Infections:** These drugs may make it easier for you to get colds, flu, and other viral and fungal infections. You can also get infections from germs that usually would not cause illness. These are called *opportunistic* infections.
- **Cancers:** They may cause a higher risk of skin and other cancers.

Immunosuppressant Drugs for Induction

You will receive IV immunosuppressants while you are in the hospital. This process, called *induction*, rapidly lowers your immune system right after transplant surgery.

Costs are not listed for these induction drugs. They are only given while you are in the hospital. You will not need to pay for them long term.

Antithymocyte Globulin

Brand names: *ATG, Thymoglobulin*

Purpose: Antithymocyte globulin (ATG) is a strong anti-rejection drug. It destroys T-lymphocytes. Some patients receive ATG to treat acute rejection episodes.

If you receive ATG:

- It will be given to you by IV infusion over 12 hours, starting right after your transplant surgery.
- You will then have infusions every day or every other day, for a total of at least 3 doses.

Possible side effects: T-lymphocytes release chemicals as they are destroyed. These chemicals can cause allergic or flu-like symptoms. These are more common after the first few doses. You will most likely be given acetaminophen (Tylenol), an *antihistamine* (Benadryl), and a *corticosteroid* (methylprednisolone) before your first 3 doses to prevent some of these side effects.

Side effects of ATG include:

- Flu-like symptoms, such as fever and chills
- Nausea
- Headache
- Shortness of breath
- Low or high blood pressure
- Low counts of white blood cells, platelets, and red blood cells
- Greater risk of infection

Basiliximab

Brand name: *Simulect*

Purpose: Basiliximab is an antibody. It blocks the action of *interleukin-2* (IL-2), a substance in the body that helps activate T-lymphocytes. Blocking IL-2 helps keep your immune system from trying to destroy your transplanted organ(s).

An IV infusion of basiliximab is given right after transplant. A 2nd dose is given 4 days later. Some patients may receive this drug instead of ATG.

Possible side effects: This drug has a very low risk of side effects. Allergy or flu-like symptoms, such as fever or chills, are possible.

Methylprednisolone

Brand name: *Solumedrol*

Purpose: This drug, also known as a steroid or corticosteroid, blocks many types of immune cells. You will receive a large IV dose of methylprednisolone during your transplant surgery. You will receive another IV dose every day for up to 3 more days after surgery. This drug is also used to treat rejection episodes.

Possible side effects: High doses of steroid drugs can cause:

- Higher blood sugar
- Slower wound healing
- Blurred vision
- Muscle aches
- Mood swings
- Insomnia
- Swelling

Long-Term Immunosuppressant Drugs

You will take anti-rejection drugs by mouth for as long as you have your graft. These are called *maintenance* medicines.

Tacrolimus

Brand names: *Prograf, FK-506*

Purpose: Tacrolimus keeps T-lymphocytes from trying to reject the transplanted organ. Most transplant patients start taking tacrolimus about 1 to 3 days after surgery and keep taking it long term.

Forms: Capsules come in 3 sizes: 0.5 mg, 1 mg, and 5 mg. You can combine sizes to make your full dose. The brand name is Prograf, but there are also generic forms.

Usual dose: Your dose of tacrolimus will be between 1 mg to 10 mg taken every 12 hours, usually at 8 a.m. and 8 p.m. You may take it with meals. Your doctor may adjust your dose based on the result of a blood level test.

On clinic days, do not take your dose of tacrolimus until after your blood is drawn.

Possible side effects: The most serious side effects of tacrolimus are injury to the kidney and the nervous system, causing tremor and headache. Your doctor may adjust your dose to reduce these side effects. Tacrolimus interacts with many drugs and some foods (grapefruit, pomegranate, and star fruit). Eating these foods can increase side effects.

Some side effects include:

- Lower kidney function
- Higher blood sugar
- Higher blood pressure
- Higher blood potassium
- Lower blood magnesium
- Shakiness or tremor
- Headache
- Convulsions (seizures)
- Nausea or vomiting
- Hair loss
- Higher cholesterol
- Greater chance of infection

Cost: Tacrolimus costs \$300 to \$500 a month for generic forms. You will take it long-term. Most insurance plans, including Medicare Part B, cover the cost for eligible transplant recipients.

Mycophenolate Mofetil

Brand names: *CellCept, Myfortic*

Purpose: Mycophenolate (MMF) lowers the production of lymphocytes. Patients take this drug while they are also taking tacrolimus.

Forms: MMF comes in 2 different forms:

- CellCept comes as a 250 mg capsule and a 500 mg tablet. It also comes as an oral suspension (liquid).
- Myfortic is enteric-coated and comes in 180 mg and 360 mg tablets.

Usual dose:

- CellCept: 1,000 mg (1 gram) taken by mouth 2 times a day
- Myfortic: 720 mg taken by mouth 2 times a day.

MMF is best taken on an empty stomach, but can be taken with food, if needed, to avoid stomach upset.

Take your doses at the same time every day. Your doctor may adjust your dose based on the result of a blood level test.

Possible side effects:

More common:

- *Leukopenia* (low white blood cell count)
- Nausea or vomiting
- Abdominal pain
- Diarrhea
- Greater risk of infection

Less common:

- *Anemia* (low red blood cell count)
- *Thrombocytopenia* (low platelet count)
- **May cause birth defects, so should not be taken by pregnant women or women who plan to become pregnant**

Cost: Mycophenolate costs \$300 to \$500 a month for generic forms. You will need to take it long term. Most insurance plans, including Medicare Part B, cover the cost for eligible transplant recipients.

Prednisone and Methylprednisolone

(Types of steroids)

Purpose: Prednisone (oral) and methylprednisolone (IV) are also called *steroids* or *corticosteroids*. These drugs lower the function and activity of lymphocytes. They are used to prevent or treat rejection of the graft.

You may receive methylprednisolone in large IV doses (*pulse therapy*) to treat acute rejection of your transplant. If your doctors prescribe this drug to you, you will receive it by IV for several days after your surgery. You will then start taking prednisone by mouth.

Forms: Prednisone tablets come in 6 sizes: 1 mg, 2.5 mg, 5 mg, 10 mg, 20 mg, and 50 mg. The tablets are usually white and scored, so that they break in half more easily.

Usual dose: 5 to 10 mg a day as a single dose every day. Always take prednisone with food or a snack to avoid stomach upset.

Possible side effects: Higher doses of these drugs cause more side effects. These usually lessen when the doses are reduced.

Other side effects can occur after many months or years of taking the drug at lower doses. It is important to get plenty of exercise and good nutrition to keep your body strong (especially bones and muscles) while you are taking prednisone.

Some patients may need to take insulin to control their blood sugar while taking prednisone. If you have diabetes, you might need higher doses of insulin at first, right after your surgery.

Short-term side effects (at high doses):

- Stomach upset, heartburn, stomach ulcers
- Emotional changes, mood swings, problems sleeping
- Night sweats
- Weight gain and swelling
- Slower wound healing
- Increased appetite, feeling hungry
- Higher blood sugar
- Face swelling (“moon face”)
- Acne
- Blurred vision
- Greater chance of infection
- Muscle aches

Long-term side effects:

- Muscle weakness
- Bone and joint weakness and pain
- *Osteoporosis* (bones become brittle and can break more easily)
- High blood sugar (*diabetes*)
- Stretch marks and weak, dry, thin skin
- Increased or unwanted hair growth
- Rounded shoulders (“buffalo hump”)
- Easy bruising
- Vision changes, cataracts
- Higher cholesterol

- Greater chance of getting certain cancers
- Greater chance of infection

Cost: Prednisone costs \$5 to \$10 a month. You will need to take it long term. There are generic forms.

Other Immunosuppressant Drugs

Cyclosporine

Brand names: *Neoral, Gengraf, Sandimmune*

Purpose: Cyclosporine keeps the T-lymphocytes from trying to reject the transplanted organ. If your doctor prescribes this drug for you, you will take it instead of tacrolimus. Both drugs work the same way on the immune system.

Dose: There are many forms of cyclosporine. Capsules come in 3 sizes: 25 mg, 50 mg, and 100 mg. You may need to mix different sizes of capsules to make your dose. The liquid formula strength is 100 mg/ml.

Special instructions: Cyclosporine capsules are affected by air. Keep them sealed in their package until you are ready to take your dose. The capsules are stable for 7 days after you open the package.

Usual dose: 100 mg to 500 mg taken every 12 hours, usually at 8 a.m. and 8 p.m. Take it at the same time every day, with or without food. Your doctor will adjust your dose based on the result of a blood level test.

Possible side effects: The most serious side effect of cyclosporine is kidney damage. This effect can be avoided by closely monitoring your kidneys. Your doctor will adjust your dose if there are any problems.

Side effects include:

- Lower kidney function
- Higher blood pressure
- Higher blood potassium
- Lower blood magnesium
- Shakiness or tremor
- Burning or tingling in your hands or feet
- Increased or unwanted hair growth
- Increased gum growth
- Mood changes
- Acne
- Lower liver function

- Convulsions (seizures)
- Headache
- Higher cholesterol
- Higher risk of infection

Cost: Cyclosporine costs \$300 to \$500 a month. You will take it long term. There are generic forms.

Sirolimus

Brand name: *Rapamune*

Purpose: Sirolimus keeps T-lymphocytes from destroying the graft. It also has anti-cancer or anti-tumor effects. If your doctor prescribes this drug, you will usually take it while you are also taking tacrolimus or prednisone (or both).

Forms: Sirolimus tablets come in 0.5 mg, 1 mg, and 2 mg. It also comes as a liquid in a strength of 1 mg/ml.

Usual dose: Between 1 mg to 10 mg taken once a day, with or without food. Take your dose at the same time every day. Your doctor may adjust your dose based on the result of a blood level test.

Possible side effects:

- Higher blood cholesterol and triglyceride levels
- Decreased wound healing
- Lower blood platelets, red blood cells, and white blood cells
- Mouth ulcers or sores
- Acne
- Tingling in your hands or feet
- Joint pain
- Higher risk of infection
- **May cause birth defects** – do **not** take if you are pregnant or planning to become pregnant

Cost: Sirolimus costs \$500 to \$1,000 a month. You will take it long-term. There are no generic forms.

Azathioprine

Brand name: *Imuran*

Purpose: Azathioprine affects your bone marrow so that your body produces fewer white blood cells. You may take azathioprine instead of mycophenolate. You will take it long term along with tacrolimus or cyclosporine and steroids.

Forms: Azathioprine comes as a 50 mg tablet. The tablets are scored so they can be broken in half more easily.

Usual dose: 25 mg to 175 mg taken every day in 1 dose, usually in the evening at bedtime.

Possible side effects: Azathioprine affects cells that grow rapidly, such as white and red blood cells, platelets, and hair cells. The effects on blood cells can be reversed by lowering your dose.

Side effects include:

- Low white blood cell count
- Anemia (low red blood cell count)
- Bleeding (from low platelet count)
- Hair loss
- Nausea
- Jaundice (yellow skin caused by effects on the liver)

Cost: Azathioprine costs \$15 to \$100 a month. You will take it long-term. There are generic forms.

Drugs to Prevent Infections

When your immune system is suppressed, you can get infections more easily and they can be harder to treat. Infections can be caused by germs that:

- Come from your environment
- Come from another person
- Normally live in or on you but usually do not cause infection (*opportunistic* infections)

For the first 3 months after transplant surgery, it is easier to get infections because of the large doses of anti-rejection drugs you are taking.

You will need to take several antibiotics during the first 3 months to prevent infection. The antibiotics you make take include:

Clotrimazole Troche and Fluconazole

Brand names: *Mycelex* and *Diflucan*

Purpose: You will take an *antifungal* (anti-yeast) drug for 3 months after transplant. These drugs help prevent *thrush* (yeast growing in your mouth).

Usual doses:

- Clotrimazole troche (Mycelex) is a 10 mg lozenge that you dissolve in your mouth. Do not eat or drink for at least 30 minutes after each dose.

- Fluconazole (Diflucan) is taken by mouth once a day or once a week. It may be taken with food.

Possible side effects:

- Clotrimazole troche:
 - Bad taste in your mouth
 - Dry or chalky mouth
 - Nausea
- Fluconazole:
 - Nausea
 - Rash
 - Diarrhea
 - Abdominal pain

Cost: Clotrimazole troche costs \$50 a month. Fluconazole costs \$20 a month. There are generic forms of both.

Valganciclovir, Ganciclovir, and Acyclovir

Brand names: *Valcyte, Cytovene, and Zovirax*

Purpose: These are antiviral drugs. Some viruses that cause infection, such as *herpes* virus, do not leave the body after an infection has healed. These viruses stay *dormant* (not active) until a weakened immune system “wakes them up.”

Viral infections can be severe and life-threatening for people who are immunosuppressed. Valganciclovir, ganciclovir, and acyclovir are used to treat and prevent simple herpes virus infections (such as cold sores) and a more resistant herpes virus called *cytomegalovirus* (CMV).

You will take these drugs for 3 to 6 months after transplant. They do not treat other viruses like cold, flu, or hepatitis.

Usual doses:

- Valganciclovir (Valcyte) is taken by mouth to prevent or treat CMV infections. It can be taken with food. The usual dose:
 - To **prevent** CMV is 450 to 900 mg, taken once a day.
 - To **treat** CMV is 900 mg, taken twice a day.
- Ganciclovir (Cytovene) is a form of valganciclovir. It is given by IV to treat CMV infections, either in the hospital or through home infusion.
- Acyclovir (Zovirax) is used to prevent herpes infections such as cold sores. It is not used to prevent CMV. The usual dose is 400 mg twice a day. It can be taken with food.

Possible side effects:

- Nausea
- Lower kidney function
- Headache
- Low white blood cell count

Costs:

- Valganciclovir can cost up to \$2,000 a month. There is a generic form.
- Ganciclovir cost varies depending on your insurance coverage.
- Acyclovir usually costs less than \$20 a month. There is a generic form.

Trimethoprim/Sulfamethoxazole

Brand names: *Bactrim*, *Septra*, *Cotrimoxazole*, *Trim/Sulfa*, *TMP/SMX*

Alternate non-sulfa drugs: Dapsone and Pentamidine

Purpose: These are *anti-pneumocystis* drugs. Pneumocystis is a fungus that is found in the lungs of healthy people. It usually does not cause illness. But, the fungus can cause a lung infection in someone who has a weak immune system.

These drugs stop this fungus from infecting the lungs. Most transplant patients take Bactrim or Septra, sulfa-based drugs. If you have a sulfa allergy, you may take Dapsone or Pentamidine instead. These drugs are usually taken for 6 months after transplant.

Usual dose:

- Bactrim or Septra are single-strength (SS) tablets (80/400 mg). Take it every day at bedtime with a full glass of water.
- Dapsone is usually taken as 100 mg once a day by mouth.
- Pentamidine is usually taken once a month in an inhaled form (*aerosol*) at the hospital or clinic. The usual dose is 300 mg a month.

Possible side effects:

- Rash (report any rashes to your doctor)
- Nausea
- Lowered white blood cell count
- Lowered red blood cell count (with Dapsone)
- Sensitivity to the sun
- Cough, wheezing (with Pentamidine)

Cost: Bactrim, Septra, and Dapsone cost \$5 to \$25 a month. There are generic forms. Pentamidine cost varies depending on your insurance plan.

Drugs to Prevent Heartburn

Ranitidine, Pantoprazole, Omeprazole, and Lansoprazole

Brand names: *Zantac, Protonix, Prilosec, and Prevacid*

Purpose: Antacids either neutralize stomach acid or stop acid from being secreted. They are taken for about 3 months after transplant to prevent stomach upset, heartburn, or stomach problems caused by other medicines or stress. Take antacids on an empty stomach for the best effect.

Usual doses:

- Ranitidine (Zantac) is taken in a 150 mg dose at bedtime.
- Pantoprazole (Protonix) is taken in a 40 mg dose once a day.
- Omeprazole (Prilosec) is taken in a 20 mg dose once a day.
- Lansoprazole (Prevacid) is taken in a 30 mg dose once a day.

Possible side effects:

- Rash
- Headache
- Dizziness

Cost:

- Ranitidine costs \$10 a month. There are generic forms.
- Omeprazole, pantoprazole, and lansoprazole cost from \$10 to \$100 a month. There are generic forms. You do not need a prescription for these.

Drugs to Prevent Constipation

Laxatives stimulate your intestines to help stool move through your bowel. *Stool softeners* make hard stool softer, so that it is easier to pass.

Docusate, Senna, Polyethylene Glycol, and Bisacodyl

Brand names: *Colace, Senakot, Miralax, and Dulcolax*

Purpose: Straining to have a bowel movement after surgery can keep your incision from healing. Avoid constipation and hard stools after transplant, and keep your stools soft for 3 months after your surgery.

To avoid constipation:

- Reduce your use of prescription pain medicines as soon as you can after surgery. These drugs can cause constipation.
- Drink plenty of fluids.
- Increase your physical activity.
- Eat more foods with fiber.

How they work:

- Docusate (Colace) is a mild stool softener. It is prescribed most often after transplant.
- Polyethylene glycol (PEG or Miralax) helps your stool hold more water, which makes it softer.
- Senna (Senakot) and Bisacodyl (Dulcolax) are stimulant laxatives.

If you have diarrhea while you are taking these medicines, ask your doctor about taking less.

Cost: Laxatives and stool softeners cost \$5 to \$10 a month. There are generic forms. You can buy them without a prescription.

Drugs to Control Blood Pressure

Amlodipine and Metoprolol

Brand names: *Norvasc* and *Lopressor* or *Toprol XL*

Purpose: It is important to control your blood pressure. High blood pressure can harm your new organ. It can also cause stroke, heart disease, and other problems. Some people have high blood pressure before transplant, and it is very common to have high blood pressure after transplant surgery. Some of the anti-rejection drugs can also raise your blood pressure.

To control blood pressure, the transplant team often prescribes both:

- A *calcium-channel blocker* drug such as amlodipine (Norvasc)
- A *beta-blocker* drug such as metoprolol (Lopressor or Toprol XL)

Special instructions:

- Do **not** stop taking your blood pressure medicines unless your doctor tells you it is OK to do so.
- Take your blood pressure and pulse and record the numbers 2 times a day:
 - **Before** your morning dose of blood pressure medicine
 - **Before** your bedtime dose of blood pressure medicine

Bring your record with you to your follow-up clinic visits. Over time, we may adjust your dose of blood pressure medicine to make sure it is at the best level for you.

- Get up slowly after lying or sitting to keep from feeling dizzy or lightheaded.

Possible side effects:

- Dizziness
- Rapid fall in blood pressure
- High or low heart rate
- Flushing
- Headache
- Feeling tired

Cost: Blood pressure medicines cost \$20 to \$50 a month. Many of these drugs have generic forms.

Drugs to Prevent Blood Clots

Aspirin

Purpose: A small dose of aspirin can help keep clots from forming in the blood vessels leading to a new organ. Aspirin may also prevent heart attacks and strokes. It is prescribed for some patients, but not all.

Usual dose: 1 tablet (81 mg or baby aspirin) taken once a day.

Possible side effects:

- Bleeding in your *gastrointestinal* (digestive) tract
- Blood in your urine
- Ringing in your ears

Cost: Aspirin costs \$5 a month. You will take it long term. There are generic forms. You can buy it without a prescription.

Drugs to Treat Swelling

Furosemide and Torsemide

Brand names: *Lasix* and *Demadex*

Purpose: Some of your transplant medicines can cause swelling (*edema*). Drugs called *diuretics* (water pills) help your body excrete the excess water and sodium that cause the swelling. This fluid comes out in your urine.

Diuretics also lower blood pressure and remove potassium and magnesium from the body. You may need supplements if you lose too much of these minerals.

Possible side effects:

- Low blood potassium or magnesium
- Too much water loss (dehydration)

- Dizziness
- The need to urinate more often
- Headache
- Not feeling hungry
- Leg cramps
- Higher heart rate

Drugs to Lower Cholesterol

Atorvastatin, Simvastatin, Pravastatin, Rosuvastatin, and Lovastatin

Brand names: *Lipitor, Zocor, Pravachol, Crestor, and Lovastatin*

Purpose: Most anti-rejection drugs raise cholesterol. High cholesterol is linked to heart disease, blood vessel disease, and damage to your new organ. Some transplant patients need drugs to lower their cholesterol.

Special instructions: Tell your doctor if you have any muscle weakness or pain.

Possible side effects:

- Dizziness
- Headache
- Rash
- Nausea
- Abdominal cramps
- Muscle aches

Vitamins and Minerals

Iron

Forms of iron: *ferrous sulfate* or *ferrous gluconate*

Purpose: After transplant, you may need extra iron to prevent *anemia*. Anemia occurs when there are not enough healthy red blood cells to carry oxygen to your tissues. Blood loss is the most common cause of anemia.

Having anemia may make you feel tired and weak. Iron treats anemia by helping your body build new red blood cells.

Usual dose: 324 mg, taken 1 to 3 times a day. You can buy most iron supplements without a prescription.

Special instructions: Vitamin C helps your body absorb iron. Take your iron supplement at the same time that you eat foods that are high in vitamin C, such as oranges, broccoli, and dark leafy greens.

Multivitamins

Brand names: *Centrum, One a Day, Nature Meds, Theragra, others*

Purpose: We suggest you take a multivitamin with minerals every day after transplant to make sure your body has all the nutrients needed for healing and recovery. You can buy multivitamins without a prescription.

Calcium

Forms of calcium: *Calcium carbonate (Tums, Oscal) and calcium citrate (Citracal)*

Purpose: Most transplant patients have a higher risk of *osteoporosis* (bone weakness) after surgery, especially if they already had bone disease before transplant. This risk is from taking anti-rejection drugs, and from having low levels of vitamin D and sex hormones (estrogen and testosterone) before transplant.

Calcium helps build strong bones. Taking calcium after transplant can help prevent bone disease, bone loss, and fractures.

Your body needs vitamin D to absorb calcium, so you will also need to take a vitamin D supplement (see “Vitamin D” below).

Usual dose: Take 600 to 1,200 mg of calcium each day. The amount you need depends on how much calcium is in the foods you eat.

Dairy foods and dark leafy greens are good sources of calcium. See the “Nutrition” chapter of this guide or talk with your transplant dietitian to learn more about calcium-rich foods.

You can buy calcium supplements without a prescription. Calcium in chewable tablets is often in a form that your body can absorb most easily.

Read labels carefully. A product with 500 mg calcium carbonate, such as Tums 500, may contain only 200 mg calcium that your body can use.

Vitamin D

Forms of vitamin D: *Cholecalciferol (vitamin D3), ergocalciferol (vitamin D2), calcitriol (Rocaltrol), and others*

Purpose: Your body needs vitamin D to absorb calcium. Sunlight is the main source of vitamin D for most people. Transplant patients usually need to take a vitamin D supplement since they must avoid sun exposure to lessen their risk of skin cancer.

Usual dose:

- Most vitamin D in supplements is cholecalciferol (vitamin D3). Take about 1,000 units of cholecalciferol every day. This is in addition to the

vitamin D that is in your multivitamin. You can buy cholecalciferol without a prescription.

- Ergocalciferol and calcitriol are stronger forms of vitamin D. They must be prescribed by your doctor.

Magnesium

Types of magnesium: *Magnesium oxide (Mag-Ox)*, *magnesium amino acid chelate (Mag plus Protein)*, and others

Purpose: Your body needs the mineral magnesium for healthy muscles and nerves. Magnesium also helps some enzymes work. Enzymes are proteins that help speed up important chemical reactions in your body.

Many transplant patients develop low magnesium levels. This may be caused by anti-rejection drugs or from taking diuretics. Your magnesium levels can be measured with a blood test.

You may not be getting enough magnesium from the foods you eat. See the “Nutrition” chapter of this guide or talk with your transplant dietitian to learn more.

Usual dose: 400 to 800 mg, taken twice a day. Magnesium comes in tablet and liquid forms. You can buy it without a prescription.

Phosphate (Phosphorus)

Sodium phosphate (K-Phos Neutral, Phospha 250 Neutral)

Purpose: Your body needs the mineral phosphate for the growth and repair of body tissues, and for healthy bones. Transplant patients sometimes develop low blood phosphate levels. This may be because of a short-term change in how your body handles this mineral.

Fish and dairy products can be a good source of phosphate. See the “Nutrition” chapter of this guide or talk with your transplant dietitian to learn more.

Usual dose: 250 to 500 mg, taken twice a day. You will need a prescription for K Phos Neutral and Phospha 250 Neutral.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Discharge Checklist

After a kidney/pancreas transplant

Before you work through the checklist in this chapter, please review these chapters: “UWMC Clinic Care After Discharge” and “Life After Transplant Surgery.”

When can I leave the hospital?

Before you are ready to leave the hospital with your new kidney or pancreas, you will want to make sure you have done all the planning needed to make your transplant successful.

You will be able to leave the hospital when you can check off each of these items as true:



You will be able to leave the hospital when you can say “Yes!” to all the “I know” statements in this chapter.

Questions and Concerns:

I know when to call with questions and concerns.

You may have questions or need to report a problem after you arrive home. A transplant team member is on call 24 hours a day. Call the transplant team if you have:

- Fever
- Pain
- Signs of infection in your wound:
 - Redness
 - Tenderness
 - Swelling
 - Drainage from incision
- Nausea, vomiting, or diarrhea

- Urine changes:
 - Pain when you urinate
 - Bloody urine
 - A sudden decrease in the amount of urine you produce
 - Not able to pass urine
- High blood glucose
- Bowel changes
- Questions about your medicines

I know who to call for questions and concerns.

- For **life-threatening emergencies** at any time, call 911.
- For other questions and concerns:
 - Weekdays from 8 a.m. to 5 p.m., call your transplant coordinator.

Your transplant coordinator is: _____

Phone number: 206.598. _____

- After hours and on weekends and holidays, call the Community Careline at 206.744.2500 for help with your concerns.
- For help with housing, transportation, or emotional support:
 - Weekdays from 8 a.m. to 4:30 p.m., call the Transplant Social Worker at 206.598.4676.
 - After hours and on weekends and holidays, call 206.598.6190 and ask for the Social Worker on call to be paged.

Housing:

I know where I will stay.

- At your home
- Or, you will be staying with or at: _____
- Phone number: _____

Transportation:

I know who will drive me to and from my follow-up visits.

Follow-up Care:

I know how to get blood draws at the lab.

The lab is on the 3rd floor of the hospital. It is open weekdays from 6:30 a.m. to 6 p.m. You do not need to make an appointment for your lab visits.

You should have your blood drawn before you take your morning medicines and about 12 hours after your last dose of immunosuppressants. Since most patients take their medicines at 8 a.m. and 8 p.m., they usually have their blood draws between 7:30 a.m. and 8 a.m. The timing of your blood draws will depend on when you usually take your medicines.

Most times, you will have your blood drawn on clinic visit days. Clinic visit days are Mondays, Wednesdays, and Thursdays. Your transplant coordinator may ask you to have blood drawn at other times, too.

If you need to have blood drawn after hours, go to the Evening Blood Draw lab on the 2nd floor of the hospital.

I know how to set up follow-up visits at the clinic.

Your transplant coordinator will set up your first follow-up visit for you. After that, you will set up your return visits at the clinic reception desk or by calling your transplant coordinator.

Physical Signs:

I know the signs of kidney transplant rejection.

- Weight gain
- Fluid retention (swelling of your feet)
- Decrease in the amount of urine you are producing
- Fever, flu-like symptoms, or just feeling unwell (fatigue, aches)
- Pain or swelling over the transplant site
- Higher levels of creatinine in your blood

I know the signs of pancreas transplant rejection.

- Higher levels of serum amylase or lipase
- Flu-like symptoms: fatigue, aches, and fever
- Higher blood glucose levels

I know the signs of infection.

- Fever and chills
- Sore throat
- Burning or pain when you urinate
- Being short of breath or coughing
- Nausea or vomiting
- Fatigue
- Congestion
- Areas of red skin

Self-care:

I know how to care for my physical needs.

- Have a bowel movement (must have 1 before discharge)
- Empty your bladder (if not on dialysis)
- Properly care for your wound
- Properly care for your vascular access site
- *If you have diabetes or high blood glucose levels:* Show that you know how to manage your blood glucose and give yourself insulin shots

I know how to exercise responsibly.

- Walk in the hallway 3 to 4 times a day
- *If you have stairs at home:* Go up and down stairs
- Know your physical activity limits

I know the equipment I need and how to monitor my progress.

- Have a scale to check your weight
- Have a thermometer to take your body temperature
- Have a blood pressure machine/cuff to measure your blood pressure (may also measure pulse)
- *If you have diabetes or high blood glucose levels:* Have a blood glucose meter to measure your blood sugar

I know how to keep records.

- Take and record your blood pressure, temperature, and pulse 2 times every day
- Weigh yourself every morning and record your weight
- Record any times you vomit or have diarrhea
- Measure and record your intake of fluids and how much you are urinating (total for each day):
 - 30 cc = 1 ounce
 - 240 cc = 8 ounces (1 cup)
 - 1,000 cc = 32 ounces (1 quart)
- Record your labs:
 - Creatinine (Cr)
 - Potassium (K)
 - *For pancreas transplant patients:* Amylase and lipase
 - Anti-rejection drug levels

If You Have Diabetes or High Blood Glucose:

I know how to monitor my blood glucose and adjust my insulin dose.

- Check and record your blood glucose at least 2 times a day
- Give yourself insulin injections
- Record insulin doses and adjust them if needed
- Know the signs and symptoms of *hyperglycemia* (high blood glucose) and *hypoglycemia* (low blood glucose)

Diet and Medicines:

I know how to manage my diet.

- Keep food and liquids down without vomiting
- Eat enough food to help your body heal after surgery
- Talk with your dietitian about your dietary needs and foods to avoid or limit
- Make a diet plan

I know how to manage my medicines

- State the name and doses of the anti-rejection medicines you are taking
- Adjust the doses of your medicines as directed by your doctor
- Fill your pill box (mediset) and take medicines on your own
- Receive your discharge medicine prescriptions
- Have a plan for filling your discharge medicine prescriptions

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Care After Discharge

After a kidney/pancreas transplant

This chapter explains the follow-up care you will receive after your transplant surgery.

What can I expect after I leave the hospital?

After you are discharged from the hospital, you will be starting your *outpatient* care. As part of this care, you will have many visits with your transplant team at the Transplant Clinic. We will set up your first visit for you before you leave the hospital.

At first, you will visit the clinic 2 to 3 times a week. This will decrease over time, until you come to the clinic only 1 time a week or every other week.

You must arrive at the hospital at 7:30 a.m. for labs before every clinic visit. You need to come in at that time even if your appointment is much later in the day.

Why do I need follow-up visits?

You will need to see the UWMC transplant team often for about 3 months after your transplant. This is the most common time for problems and rejection to occur. At these visits, the transplant team will check you closely and can diagnose and promptly treat any problems.



You will come to the clinic often for the first 3 months after transplant.

What should I do to prepare for these visits?

- Fill your discharge prescriptions** at the pharmacy of your choice as soon as you can after leaving the hospital.
- Take your medicines as prescribed.** Keep learning their names, what they do, and doses. Update your mediset and medicine list when changes are made.
- Refill your mediset** at least once a week.
- Do not take over-the-counter, herbal, or natural medicines or supplements** without your doctor's approval.
- Do not take non-steroidal anti-inflammatory drugs (NSAIDs).** Some of these are ibuprofen (Motrin, Advil, Nuprin), naproxen (Aleve, Naprosyn), indomethacin (Indocin), large doses of aspirin, and menstrual cramp medicines. You may use acetaminophen (Tylenol) for headache, fever, or pain.
- Watch for signs of rejection or infection.** See the chapter "Discharge Checklist" for a list of what to watch for.
- Take your blood pressure, pulse, and temperature** 2 times a day, and record these numbers.
- Weigh yourself once a day** and record these numbers.
- If you have diabetes or are a pancreas transplant patient:**
 - **Check your blood glucose** at least 2 times a day. Record your results.
 - If you can, check your blood sugars more often. It is best to check before each meal and at bedtime.
- Measure your daily fluid intake and the amount you are urinating.** Record these amounts.
- Record any times you vomit or have diarrhea.**
- Collect urine** (if asked to do so).
- Change the dressings on your wound** (if asked to do so).
 - After showering, make sure your wound is dry.
 - Use a clean towel and blot dry.

- ❑ **Care for your wound.** Wear loose clothing to keep from irritating your incision. If you see any signs of infection, please call your transplant coordinator **right away**.
- ❑ **For kidney transplant patients:**
 - **Try to empty your bladder at least every 3 to 4 hours.** You will urinate more often and in larger amounts, especially at night.
 - Within the next few weeks, your bladder will get bigger and you will not have to urinate so often.
- ❑ **Never go longer than 48 hours without a bowel movement.** Constipation can be serious. To help avoid constipation:
 - Get more physical activity
 - Drink enough fluids
 - Reduce your pain medicine as you are able
 - Add fiber (fruits, vegetables, and grains) to your diet
- ❑ **Keep monitoring your peritoneal catheter for infection.** Do not flush your peritoneal dialysis catheter. Peritoneal dialysis catheters are usually removed 4 to 8 weeks after transplant. This will be done in the operating room. You will be given general anesthesia.
- ❑ **Arrange transportation to and from clinic.**
- ❑ **Slowly increase your activity at home.**
 - Do not lift or carry anything heavy:
 - For 6 weeks after surgery, do **not** lift or carry anything that weighs more than 10 pounds. A gallon of milk weighs almost 9 pounds.
 - For 6 weeks after that, do **not** lift or carry anything that weighs more than 15 pounds. A bowling ball weighs about 15 pounds.
 - You may shower every day.
 - For about 4 weeks after surgery, until your incisions are healed, do **not** take a bath, sit in a hot tub, or swim.
 - For 4 to 6 weeks after surgery, do **not** drive. Ask your doctor if it is OK before you start driving again.
 - It will help your recovery if you walk every day and take part in basic activities such as cooking and doing light household chores.
 - For 3 months after surgery, do **not** do any exercise that twists your body, such as golf or tennis.

- For 6 months after surgery, do **not** do any high-impact exercise such as jogging, aerobics, dancing, hiking with a heavy pack, or playing basketball.
 - Avoid contact sports such as boxing or football after your kidney transplant.
 - Transplant patients can usually return to work part-time after about 4 weeks. If you have to be physically active to do your job, you should probably wait about 3 months before you go back to work. Talk with your doctor about the best plan for you based on your recovery and your job.
 - It is OK to resume sexual activity slowly, as you desire.
 - Use birth control. This is **not** a good time to get pregnant. We advise women to wait 1 year after transplant before getting pregnant. See the chapter on “Life After Transplant Surgery.”
 - For 12 weeks after surgery, we advise that you not travel very far from home.
- Avoid the risk of infection.**
- For about 3 months after surgery, avoid large crowds.
 - Do **not** let your pets lick your incision, or bite or scratch you. If your pet does bite or scratch you, wash the area right away.
 - Do not empty litter boxes.
 - Wash your hands often to lower your risk of infection.
 - You do not need to wear a mask all the time, but we advise wearing one if you must be around dust or anyone who is sick.
- Talk with your surgeon about your peritoneal dialysis catheter.** Your *fistula* or *graft* will not be removed. If it clotted during or after surgery, it may need to be opened up.
- Eat healthy foods.** Keep a food log if your dietitian asks you to. There are usually very few diet or fluid restrictions after transplant surgery. Sometimes you may need to keep watching your potassium or fluid intake. See the chapter on “Nutrition” and the handout “Nutrition After Your Transplant.”
- Do NOT eat grapefruit, pomegranate, or starfruit (or their juices).** These fruits affect how your immunosuppressant drugs work.
- Call 911 right away if you have a life-threatening emergency.**

Who do I call for help?

- On weekdays, call your transplant coordinator:
_____, 206.598. _____
- After hours and on weekends and holidays, call the Community Care Line at 206.744.2500.

When should I call the transplant coordinator?

Call if you have:

- **Fever** higher than 100°F (37.8°C)
- Growing **pain**, especially in your abdomen or over your kidney area
- **Signs of infection in your wound:**
 - Redness
 - Tenderness
 - Swelling
 - Drainage from your incision
- **Nausea, vomiting, or diarrhea**
- **Urine changes:**
 - Pain when you urinate
 - Bloody urine
 - A sudden decrease in how much you are urinating
 - Not able to pass urine
- **High blood glucose:**
 - Blood glucose higher than 300 mg/dL
 - *If you had a pancreas transplant:* Blood glucose higher than 250 mg/dL
- **Bowel changes:**
 - No bowel movement for over 48 hours
 - Blood in your bowel movements
- **Questions about your medicines:**
 - Dose instructions
 - What to do about missed doses
 - Other concerns

What do I bring to my clinic visits?

- Your vital sign log booklet. We will give you this booklet during your hospital stay after transplant.
- All other records you have been keeping at home.
- Urine collections (take these to the lab), if you were asked to do so.
- Your medicine list and mediset, filled with your pills. We will give you all of these during your hospital stay after transplant.
- Your filled prescriptions in their original containers.
- Family member or friend.
- Something to do while you wait.
- Your questions for the transplant team.

What will the clinic day be like?

Before You Arrive

- Do **not** take your morning medicines until after your blood draw.
- You may eat breakfast before your clinic visit unless you were told not to do so. You may be asked to fast on some days.
- Plan to arrive at the lab for your blood draw at **7:30 a.m.**
- Allow 4 to 5 hours for your visit. Clinic visits usually start at 8:30 a.m. and can last until 1 p.m.

At the Hospital

- First, go to the lab for your blood draw.
- After your blood draw, take your morning immunosuppressant medicines with a snack or beverage.
- Check in at the front desk of the Transplant Clinic at your scheduled appointment time.
- How long you spend at the hospital will depend on:
 - How early your clinic visit is
 - How many care providers you need to see
 - Whether you need any other procedures, such as removal of surgical staples or stent, or an IV infusion
- Your transplant coordinator will tell you of any changes in your medicine doses. Stay on your current doses and schedules unless you are told to change them.

- Be sure to tell your transplant coordinator how to reach you. We may want to call you at home to talk about your lab results (drug blood levels) that came in after you left.

What will happen at these clinic visits?

You can expect these things to happen at your clinic visits:

- Blood draws to check medicine levels
- Blood draws to check how your kidney or pancreas is working
- Visits with the transplant doctors and coordinators that include:
 - Checking your incision to make sure it is healing well
 - A physical exam to find out how well you are recovering from surgery, including taking your vital signs (blood pressure, weight, temperature) and checking you for signs of rejection or infection
- A review of your medicines
- A review of your lab results
- Possible visits with other transplant team members such as your social worker, dietitian, nurse practitioner, and pharmacist
- Procedures such as stent removal, wound staple removal, and biopsies
- Possible admission to the hospital if you need inpatient treatment

How long will I visit the clinic?

You will have regular visits at the Transplant Clinic for about 3 months after your transplant surgery. After that, you will be cleared by the transplant team to return to the care of your primary nephrologist. This is called a “transfer of care.”

From time to time after your care is transferred, you will still return to UWMC’s Transplant Clinic for follow-up visits.

When will transfer of care occur?

When we transfer your care to your primary nephrologist depends on:

- How well your new kidney or pancreas is working
- Whether you have any problems that must be watched closely

After transfer of care occurs, your primary nephrologist will manage your general transplant issues. But, you are always welcome to return to our clinic for specific questions about your transplant or immunosuppression.

Life After Transplant Surgery

After a kidney/pancreas transplant

This chapter explains what to expect in the months after your transplant surgery.

In time, you will start to receive your ongoing care from the nephrologist who referred you for your transplant. This usually happens after 3 months.

Even after this change occurs, you will still visit the Transplant Clinic during the first year after your transplant. But, these visits will be less often than before. After the first year, you will be seen once a year in the Long-Term Follow-up Clinic.

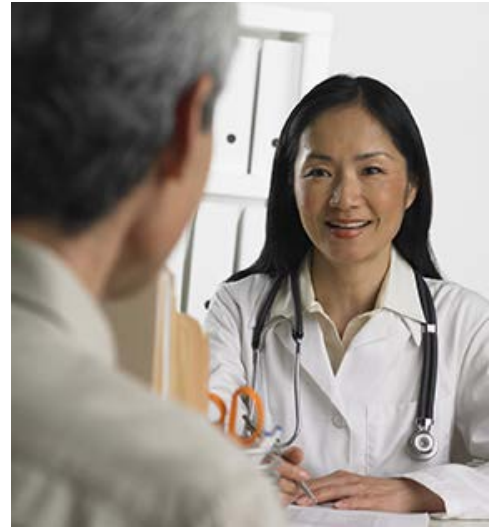
Long-term Self-care and Follow-up

The goals of a kidney or pancreas transplant are a better quality of life and a more normal lifestyle. But, a transplant is only a treatment for renal failure or diabetes, not a cure. This means that you will have some new lifelong responsibilities in caring for your new kidney or pancreas. After a while, your new routines and lifestyle will start to feel normal.

Here are some things you will be responsible for after transplant:

Take Charge of Your Ongoing Healthcare

- Report a fever or illnesses to your nephrologist **right away**. If your doctor is out of town, ask to talk with the doctor who is covering for your doctor. You must talk with your regular doctor or the doctor who is on call before you call the transplant center.
- See your nephrologist as instructed to check how your new kidney or pancreas is working.
- Report any health problems to your nephrologist. Be open and honest with your nephrologist when talking about your health issues.



After about 3 months, we will transfer your care to the nephrologist who referred you for transplant.

- As instructed, have blood draws to check how your kidney and pancreas are working and to check your anti-rejection medicine levels.
- Keep your vaccinations up to date. This includes getting a yearly flu shot and a tetanus booster every 10 years.
- **Never** get live virus vaccine, such as a measles, mumps, rubella vaccine, nasal flu vaccine, or shingles vaccine.
- Have your body systems checked as instructed. This includes eye exams and dental exams. Ask for tests to check your bone density, heart health, and skin (for skin cancer).
- Visit your dentist for a checkup twice a year.
- Women: Have screening tests for breast cancer (*mammogram*) and cervical cancer (*Pap smear*).
- Have screening tests for colon cancer (*colonoscopy*).
- If you plan to travel outside the country, go to a travel medicine clinic before your trip. Tell clinic staff that you have had a transplant.

Take Your Medicines

You will take anti-rejection drugs on a strict schedule for the rest of your life. Missing a dose can lead to rejection.

- Take all your medicines as prescribed.
- Plan ahead to get refills of your medicines so you do not run out.
- If any of your medicines make you ill, **keep taking them as prescribed**, but call your doctor right away.
- Do **not** take any medicines prescribed for other family members or friends, or any medicines you were taking before transplant.
- Check with your doctor **before** taking herbal products or other medicines.

Rejection

Rejection of the *graft* (organ) is a natural response of your body. Your immune system tries to destroy the new organ because it does not see it as being a part of you. Anti-rejection medicines interfere with your body's rejection process. They block *lymphocytes*, the white blood cells that "fight" your graft. The immune system is so strong that rejection can still occur even when you are taking strong anti-rejection medicines.

Types of Rejection

Most rejections occur in the first 6 months after transplant. These are called *acute rejections*. Acute rejections can often be reversed by taking *intravenous* (IV) medicines.

Late rejections are called *chronic rejections*. They may be caused by infections, not taking medicines as prescribed, or a change in drug levels for some other reason. This type of rejection:

- Occurs 1 or more years after transplant
- Happens more slowly than acute rejections
- Can cause damage that cannot be repaired, leading to graft loss

Signs of chronic rejection are usually subtle, such as a slow rise in *creatinine*. Late rejections are hard to treat.

Rejection does not mean for sure that you have lost your kidney or pancreas graft, but it is an emergency that needs treatment right away. A treated and reversed rejection is known as a *rejection episode*.

When a rejection episode starts, you may feel fine or you may have symptoms such as fever, muscle aches, fluid retention, or pain or swelling over your kidney or pancreas. Your serum creatinine or other lab results may or may not change. Regular doctor visits and lab tests are important to help watch for signs of rejection.

Preventing Rejection

The best defense against rejection is prevention. To prevent rejection:

- Take your anti-rejection medicines as prescribed by your nephrologist, in the right amounts and at the right times.
- Tell your nephrologist or the transplant team if you run out of your medicines or if you cannot buy them for any reason.
- Have your lab tests done on schedule.
- Tell your nephrologist right away if you notice a change in how you are feeling or there is a change in your lab results.
- Keep all of your routine nephrology visits, even if you feel fine.

Diagnosing Rejection

If your doctor suspects a rejection, a *biopsy* may be the only way to diagnose the problem. Biopsy results will tell:

- The type of rejection (acute or chronic)
- The grade of rejection (mild, moderate, or severe)

To do the biopsy, the doctor will inject a local anesthetic into your skin above your graft. A needle is quickly passed in and out of your transplanted organ to take a small tissue sample. This is done 2 to 4 times.

The tissue taken during the biopsy is sent to the pathology lab. It will be checked under a microscope for signs of rejection or other problems. Your doctor will receive your biopsy test results in 1 to 5 days.

Based on the type of rejection and how severe it is, your doctor will plan your treatment. You may need a hospital stay or a series of outpatient visits. After your treatment is done, you may have a follow-up biopsy to check on your progress.

Read the chapter “Transplant Renal Biopsy” to learn more about biopsies.

Graft Loss

Sometimes, a transplanted organ cannot be saved from rejection, infection, or recurrent disease. Graft loss is hard emotionally, and it is normal to feel angry if it happens.

The transplant team will help you. It may be possible to get another transplant. This will take some time and planning. In the meantime, you will return to dialysis for kidney loss and to insulin for pancreas loss.

Kidney Retransplant

If you lose your new kidney, you may be able to have another transplant. This is called *retransplantation*. But, you will need to meet the eligibility requirements to be listed for retransplant.

If you request retransplant, the transplant team will review your actions after your first transplant. We will check to see if you have taken your medicines as prescribed, had the required lab tests, gone to healthcare visits, and done dialysis as needed.

If the transplant team decides you have not followed your care plan or if you are actively smoking, you will be denied retransplant at our center.

Insurance Coverage

Keep your insurance coverage for medicines up to date. Anti-rejection drugs usually cost over \$1,000 a month and must be taken regularly. If paying for them is an issue, the transplant social worker can help you.

The medicines your insurance covers can change often. Check your plan every year for changes.

Medicare coverage for medicines ends at 3 years after transplant if you do not qualify for Medicare, either because of your age or because of other health problems besides kidney failure.

Call a member of your transplant team if you cannot find insurance coverage for your medicines.

Your New Lifestyle

Stay Healthy and Active

- When your doctor says it is OK, return to your usual activities. This will help your recovery and improve your mental and physical health.

- Take good care of yourself. Stay active, get regular exercise, eat a healthy diet, and limit how much alcohol you drink.
- Remember, smoking or using tobacco in any form means you are not eligible for a retransplant. Tobacco raises your risk for heart attack, infection, and cancer.
- Get yearly flu shots and keep other vaccinations up to date.

Rethink Your Self Image

Start thinking of yourself as a healthy person again, not as a “patient.” Although you will always need doctor visits and medicines, you can lead a normal life that includes work, school, volunteer work, family, and friends.

Get Support

You will still need the support of your family and loved ones. As you get healthier after your transplant, your lifestyle and your relationships with others may change. Keep the people who care about you involved and use their support when you need it.

Talking with others who have had a transplant can be very helpful. Your transplant social worker has a list of patients you can talk with for support.

For Women

Menstrual Periods

It is common not to have your periods or to have them off and on during a chronic illness such as renal failure. After transplant, menstruation often returns. Your periods may be irregular, light or heavy, and short or long. Tell your doctor about any changes in your periods.

Pregnancy

It is possible to become pregnant at any time after transplant. You must have a plan for birth control in place before your transplant surgery. See a gynecologist to help you choose a birth control method.

- If you are planning to have a *tubal ligation*, it can be done at any time, but it is best to have it done before your transplant.
- If you are on birth control pills, tell your surgeon at the time of your transplant. You may or may not be able to keep taking them while you are in the hospital, because they may increase the risk of blood clots.
- Be aware that *intrauterine devices* (IUDs) may increase your risk of infection.

Please tell your transplant team if you plan to become pregnant, because some anti-rejection medicines can cause birth defects. We will change your medicines *before* you become pregnant.

We advise waiting at least 1 year after transplant surgery before getting pregnant. Waiting to get pregnant will lower your risk of kidney rejection. It also allows time to ensure that your new kidney is stable and that your ongoing immunosuppressive drugs are working well.

Pregnancy makes your new kidney work harder, and it also increases your risk of losing your graft. Pregnancies are “high risk” for transplant patients. This means it is common for the baby to be premature and need a hospital stay. See an obstetrician who specializes in high-risk pregnancies if you are planning to have children, or if you find out you are pregnant.

Sexually Transmitted Infections and Diseases (STIs and STDs)

Casual sexual activity – whether homosexual, heterosexual, or bisexual – can increase your risk of getting an infectious disease such as HIV/AIDS, hepatitis, genital herpes, gonorrhea, and others. Even if you are *monogamous* (have only 1 sexual partner), your partner may not be monogamous.

The best way to prevent these infections and diseases is to practice safe sex and use condoms in addition to your usual birth control. **Only condoms protect against STIs.** If you get an infection, tell your doctor right away.

Infections

The medicines you take to prevent rejection of your new organ weaken your body’s ability to fight infections caused by viruses and bacteria. These common infections may occur during the first several months after transplant:

- Respiratory infections such as colds and flu
- Urinary tract infections
- Wound infections
- Certain viral infections

Infections can show up in your bloodstream, or anywhere in your body. They can be spread from the environment, from sexual contact, from your donor organ, and from inactive viruses already in your body that become active.

You will take many antibacterial and antiviral medicines to help prevent infections. If you develop an infection, more medicines may be prescribed. Treatment for some infections requires a hospital stay. Sometimes, severe infections can lead to loss of your transplant.

Common Infections in Transplant Patients

Infection	Cause	How to Prevent	How to Treat
Colds and flu	<ul style="list-style-type: none"> • Virus • Being in contact with others who are ill • Spread by touching objects in the environment or by touching your hands to your eyes 	<ul style="list-style-type: none"> • Good hand washing • Yearly flu shot • Keep your hands away from your face 	<ul style="list-style-type: none"> • Rest and drink plenty of fluids • Take antihistamines or decongestants if your doctor says they are OK • Call your doctor if you have vomiting or diarrhea • Take acetaminophen, but avoid ibuprofen (Advil, Motrin) and products that contain aspirin
Urinary tract infections (UTIs)	<ul style="list-style-type: none"> • Bacteria entering the bladder (which is usually free of bacteria) • Catheterization, poor hygiene, or not emptying bladder all the way when you urinate 	<ul style="list-style-type: none"> • Shower every day • Wear clean underwear • Wipe from front to back • Avoid tub baths and hot tubs • Urinate after sexual intercourse 	<ul style="list-style-type: none"> • Drink plenty of fluids • Urinate often and empty your bladder all the way each time • Take antibiotics as prescribed • Take cranberry tablets to block bacteria growth in the urinary tract
Wound infections	<ul style="list-style-type: none"> • Bacterial contamination 	<ul style="list-style-type: none"> • Keep wounds clean • Keep wounds covered when bathing • Change dressing often 	<ul style="list-style-type: none"> • Take antibiotics as prescribed • Incision may need to be opened, and dressing applied
Pneumocystis	<ul style="list-style-type: none"> • Fungal infection • Environmental exposure 	<ul style="list-style-type: none"> • Trimethoprim/sulfa (Bactrim) 	<ul style="list-style-type: none"> • Trimethoprim/sulfa (Bactrim)
Cytomegalovirus	<ul style="list-style-type: none"> • Virus 	<ul style="list-style-type: none"> • Antiviral medicines such as valganciclovir 	<ul style="list-style-type: none"> • If severe, hospital stay and IV antiviral medicines
Chicken pox and shingles	<ul style="list-style-type: none"> • Virus • Droplets from direct contact with an infected person 	<ul style="list-style-type: none"> • Vaccine before transplant • Immunity against chicken pox from having it as a child • Antiviral medicines 	<ul style="list-style-type: none"> • Antiviral medicines • Tell your doctor if you have a fever, skin pain, or a rash or itching (avoid scratching) • If you had chickenpox as a child, you are at lower risk to have it as an adult
Other viruses and bacterial infections	<ul style="list-style-type: none"> • Environmental • Infections from resistance to antibiotics, a dormant virus, or donor 	<ul style="list-style-type: none"> • Keep your body clean • Avoid being around people who are ill • Avoid cat litter, and do not let your pets bite or scratch you 	<ul style="list-style-type: none"> • Antiviral medicines • Antibacterial medicines • Experimental medicines • Take entire prescription of antibiotics as directed

How to Protect Yourself from Infections

Keep Your Body Clean

- Wash your hands often.
- Shower every day.
- Avoid tub baths and hot tubs.

In Your Home

- Reduce dust and clutter in your home. Your house does not need to be sterile, but it should be clean.
- Wash your bed linens, towels, and clothes often and when soiled.
- Clean your computer keyboard and mouse, and the mouthpieces of your phones.

Food

- Do not eat food that has been sitting at room temperature or outside.
- Wash raw fruits and vegetables well before eating or cooking.
- Avoid raw meats and fish.

Outside Activities

- Do **not** work in the garden for at least 6 months after your transplant. After that, wear thick leather garden gloves and a facemask.
- Avoid construction sites and construction dust.
- Avoid crowded places during flu season. If you can, sit apart from most of the crowd.

Skin Cancer Risks

Immunosuppressive drugs and some antibiotics may make your skin more sensitive to the sun. Over time, being out in the sun for long times or often may cause permanent skin changes. It also raises your risk for skin and lip cancer.

Transplant recipients are more than 10 times more likely to have *non-melanoma* skin cancers, such as *squamous cell carcinoma* and *basal cell carcinoma*. This risk increases with time after transplant. Transplant recipients are about 3 times more likely to develop melanoma.

To reduce your risk of skin cancer, always protect your skin from the sun:

- Use sunscreen and lip balm with a sun protective factor (SPF) of **at least 30** every day, rain or shine. Reapply sun protection often, especially after swimming or sweating.

- Use sun protection on your:
 - Face, nose, and lips
 - Tops of your ears
 - Backs of your hands
 - Tops of your feet if you wear sandals
 - Hair part, and on top of your head if you are balding
- For extra protection, wear hats with brims, long-sleeve shirts, gloves, and long pants when you are outdoors.
- If you can, avoid being in the sun in the middle of the day (10 a.m. to 2 p.m.). *Ultraviolet rays* that damage the skin are strongest at that time.
- Check your skin once a month for changes in existing moles and lesions, and for new moles and lesions.
- Visit a *dermatologist* (skin doctor) every year to have your skin checked.

Travel

- Check with your doctor to make sure your travel plans are safe for your health.
- Pack your medicines in your carry-on bag.
- Carry your medicines in their original containers for safety. You can put them in a mediset when you get to your destination. Put them back in their original containers for your return trip.
- Be sure to bring enough supplies and medicines so that you do not run out during your trip. Do not plan on being able to buy extra supplies when you travel to other countries.
- When you get vaccinations for travel, make sure that they are **not** live virus vaccines (measles, smallpox, rubella, chickenpox, yellow fever, or Japanese encephalitis).
- If you have diabetes, before you travel:
 - Call the airlines or visit their website to learn about travel rules for supplies and equipment (needles, lancets).
 - You may need a letter from your doctor that says you have diabetes and that you need insulin shots.

Hair and Skin Care

Immunosuppressant drugs may affect the condition of your hair:

- Prednisone or cyclosporine may cause increased or unwanted hair growth. This may be troubling to women if facial hair increases.
- Perms, foils, dyes, and bleaching may make hair break. Wait for several months after your transplant before coloring or perming your hair.

Some other hair and skin care tips are:

- Use moisturizing soaps and shampoos. These will keep your skin moist without removing healthy oils.
- Do not use special skin products unless you have problems with acne or dry skin.
- Talk with your doctor about removing or bleaching excess hair.
 - Waxing or laser treatments done by a professional are the best way to remove unwanted hair.
 - Electrolysis is not advised because your skin may be weak and sensitive.

Dental Care

- Brush and floss your teeth 2 times every day.
- Get a dental checkup every 6 months.
- Wait 3 to 6 months after your transplant before your first dental checkup. Bacteria in your mouth may cause infection if dental work injures your mouth or gum tissue.

For **all** visits to the dentist:

- Tell your dentist that you are a transplant recipient. Your dentist may write a prescription for 2 gm Amoxicillin for you to take 1 hour before your procedure. Tell your dentist if you are allergic to penicillin.
- The dentist may take X-rays, if needed.
- Ask the dentist to check your mouth and teeth.
- If the dentist tells you that you need dental work, schedule that visit promptly.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Transplant Renal Biopsy

For a kidney/pancreas transplant

This chapter explains a transplant renal biopsy, an exam that shows what is going on inside your transplanted kidney.

Why do I need a kidney biopsy?

A biopsy is the best way to know what is going on inside your transplanted kidney. Your doctor may order a biopsy to:

- Find the cause of problems in how your kidney is working
- Check the status of your kidney before making any changes in your medicines

Biopsy results will show if you have rejection, infection, injury from medicines or other causes, or new kidney disease. These results may be used to change your medicines or your treatment plan.

How do I prepare?

Medicines

Before your biopsy, your doctor will review your medicines. If you are taking blood-thinning medicines, you will need to stop taking them a few days before the biopsy. Blood-thinning medicines include aspirin, Aggrastat, Agrylin, Angiomax, Argatroban, Arixtra, Coumadin (warfarin), Fragmin, Innohep, Integrillin, Iprivask, Lovenox, Orgaran, Persantine (dipyridamole), Plavix, Pletal, Refludan, Remodulin, ReoPro, Ticlid, Trental, and Ximelagatran.

Tell your doctor if you are allergic to iodine, lidocaine, or novacaine. These will be used during your biopsy.



Your doctor will review your medicines before your biopsy.

Eating

If you will **not** be taking a *sedative* (medicine to help you relax) for the biopsy, it is OK to eat before the procedure.

Most biopsies are done quickly and without sedation. The only medicine you will receive is an injection to numb the skin and tissues around your transplanted kidney.

If you need sedation to help you relax:

- Do **not** eat or drink after midnight the night before your biopsy.
- Sedation will increase the time you need to wait before you can go home.
- You will need to arrange for someone to drive or accompany you home after your procedure. You will not be allowed to drive yourself or travel alone in a bus or taxi.

Arriving at the Hospital

Blood and urine will be collected before your biopsy. When you arrive at the hospital, go to the lab on the 3rd floor for these lab tests unless you are told otherwise.

The Transplant Biopsy

After your tests, you will go to Radiology/Imaging Services. The *sonographer* (ultrasound technologist) will do an ultrasound of your transplant to check blood and urine flow. If no problems are found:

- Your abdomen will be cleaned with an antiseptic (Betadine or Chlorhexidine).
- Sterile paper drapes will be placed over the biopsy site.
- A numbing medicine (lidocaine or novacaine) will be injected into your skin and tissue near your transplanted kidney.
- When the area is numb, a very small cut will be made in your skin and the biopsy needle will be placed through this cut. Under ultrasound guidance, the needle is moved to your transplanted kidney.
- Once the needle is just outside your transplant, a biopsy is taken. You will hear a snapping sound when this is done.
- At least 2 passes with the needle may be needed to get enough tissue to make a diagnosis.

Sometimes the tissue around a kidney transplant gets very hard. You may feel pressure, but you should not feel any sharp pain.

After Your Biopsy

After your biopsy, nurses will monitor you for about 4 hours. You will be able to go home when you:

- Have no bleeding
- Have stable blood pressure
- Urinate at least once

At Home

- If your urine is red, drink plenty of fluids to help pass the blood.
- Call your doctor if you have:
 - Very red urine
 - Blood clots in your urine
 - Pain

Risks

All procedures involve risks. A transplant kidney biopsy has these risks:

- A *fistula* (an abnormal connection of an artery and a vein) inside the kidney may cause bleeding or higher blood pressure:
 - A fistula forms in 15% of patients (15 out of 100 patients)
 - Problems from a fistula occur for less than 1% of patients (fewer than 1 out of 100 patients)
- Blood in urine occurs for 10% of patients (10 out of 100 patients)
- Loss of blood that requires a blood transfusion occurs for 1% of patients (1 out of 100 patients)

Of patients who had a transplant kidney biopsy, less than 1% (fewer than 1 out of 100 patients) had:

- A blood clot that blocked urine flow
- The need for a *stent* (plastic tube) in the ureter to unblock the urine flow
- A blood clot that put pressure on the kidney, reducing kidney function and increasing blood pressure
- A hole in the kidney that caused bleeding and needed to be plugged

To treat a hole in the kidney, a *catheter* (a thin, flexible tube) is inserted into the groin and up to the kidney. A plug called a *coil* is then placed in the hole to stop the bleeding.

- Loss of kidney function
- Loss of the kidney
- Infection in the skin, muscles, or kidney
- Puncture of another organ in the abdomen
- Nerve injury between the skin and the kidney that causes pain or loss of feeling
- Nausea or vomiting
- Leaking of urine around the kidney
- Death

Ask your doctor if you have any questions or concerns about the risks of having a kidney biopsy.

Getting Your Biopsy Results

The first results of your biopsy will be ready:

- Within 48 hours if your biopsy is done early in the week
- Late on Monday if your biopsy is done on a Friday

Your nephrologist may call you with these first results.

Final results take at least 5 days because of special testing that is done on the tissue samples. Results may also take longer if more evaluation is needed.

Most times, you will meet with your nephrologist to talk about the final results. Your nephrologist will let you know if any changes in your treatment plan are needed.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Resources

For a kidney/pancreas transplant

This list of resources may be helpful to transplant patients, their families or support persons, and living donors.

The resources in this chapter are listed in alphabetical order. They include:

- Government agencies
- Community resources
- Printed resources
- Fundraising resources

If you want more resources, talk with someone on your transplant team. They will be happy to help you find more information on transplant topics.

Checking Online Health Information

When searching for health information online, please follow these guidelines:

- Find out who is providing the information. Make sure they are experts in their fields.
- Find out who owns the site. Consider if they might have a bias, such as a company that wants to sell a product.
- Look for sites with recent posts. Health information becomes outdated quickly.
- If you have questions about something you find online, ask your healthcare provider about it.



Follow the guidelines in this chapter when deciding what online information to trust.

Resource List

American Association of Kidney Patients

www.aakp.org

800.749.2257

3505 E. Frontage Rd., Suite 315, Tampa, FL 33607

Provides information, referral, and advocacy for people with chronic kidney disease.

American Kidney Fund

www.kidneyfund.org

800.638.8299

6110 Executive Blvd., Suite 1010, Rockville, MD 20852

Provides limited financial grants to needy transplant recipients and living kidney donors.

American Organ Transplant Association

www.aotaonline.org

832.930.2682

Provides transportation help to transplant patients.

Department of Social and Health Services (DSHS)

www.dshs.wa.gov

A state agency that runs programs such as Medicaid (medical coverage for the disabled and low-income), cash benefits for the disabled, and aid to low-income and single parents.

You can find information about your local DSHS office online:

- Go to *www.dshs.wa.gov*.
- Under “How Do I ... ?” click on “Find a local service office.”
- Under “How to Find an Economic Services Administration Office,” click on “Community Services Offices.”
- Enter your zip code and click on “Apply” for your local DSHS office address and phone number.

Financing Transplantation – What Every Patient Should Know By the United Network for Organ Sharing

A brochure from United Network for Organ Sharing (UNOS). See the UNOS listing on page 4 of this chapter.

Help Hope Live

www.helphopelive.org

A nonprofit group that helps transplant patients raise funds for unmet health and living expenses when having an organ transplant.

LifeOptions Rehabilitation Council

www.lifeoptions.org

A nonprofit agency that provides educational material for people who want to learn more about rehabilitation and returning to work, either while on dialysis or after a transplant.

Medicare

www.medicare.gov

800.MEDICARE

A federal agency that provides health insurance for senior citizens. It also runs the Medicare insurance program for End Stage Renal Disease.

National Family Caregivers Association

www.nfcacares.org

800.896.3650

10400 Connecticut Avenue, #500, Kensington, MD 20895-3944

Provides education, support, and advocacy for caregivers of people who have a chronic illness.

National Foundation for Transplants

www.transplants.org

800.489.3863

Helps patients raise funds to cover expenses of organ transplants.

National Kidney Foundation

www.kidney.org

800.622.9010

30 East 33rd Street, Suite 1100, New York, NY 10016

Provides educational materials on most aspects of kidney disease. Also provides information and advocacy for issues that are important to transplant recipients. Call the number for a list of materials, or visit the “Patients” section of their website.

National Living Donor Assistance Center

www.livingdonorassistance.org

Provides financial aid for costs of a living organ donation.

Organ Donor Information

www.organdonor.gov

Information about the need for both living and deceased organ donors.

Organ Procurement and Transplantation Network

<http://optn.transplant.hrsa.gov>

Up-to-date information on transplants in the U.S.

Renal Support Network

www.rsnhope.org

A nonprofit, patient-run organization that provides non-medical services to those affected by chronic kidney disease.

Social Security Administration

800.772.1213

www.ssa.gov

A federal agency that runs programs such as Social Security Disability, Supplemental Security Income (SSI), Social Security Retirement, and Medicare.

Team Transplant

Contact: Alysun Deckert, MSRD, CD, 206.598.6351, teamt@uw.edu

www.uwmcteamtransplant.com

A UWMC-affiliated running and walking group, open to all transplant recipients (any organ) and interested staff. Team Transplant promotes organ donation and is an informal support network. Special workshops are held on topics such as nutrition, stretching, and footwear. The group enters at least 1 half-marathon event each year, and other local events from time to time.

The Road Back to Life

www.theroadbacktolife.com

Offers mentoring, support, and advice to kidney patients.

Transplant Living

www.transplantliving.org

A service of the United Network for Organ Sharing organization.

Transplant Recipients International Organization

www.trioweb.org

Visit the website for contact numbers for your local chapter.

TransWeb

www.transweb.org

A web-based organization that provides information about transplants. This site can link you to an online chat list for transplant patients and those waiting for transplant.

United Network for Organ Sharing (UNOS)

www.unos.org

888.894.6361

A federally-chartered organization that sets policy and procedures for transplant organ distribution in the U.S. Their website has information on success rates for organ transplant listed by region and specific transplant centers. The site also has other information for transplant patients.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882

Financial Planning

For a kidney/pancreas transplant

This chapter covers financial concerns related to a kidney or kidney/pancreas transplant.

Transplant Costs

Transplants are costly. Planning your finances is a key part of planning for transplant. You need to find out what your insurance will cover and what you will need to pay yourself. You will decide how you will cover both short-term and long-term costs.

Short-term Costs

In the short term, you will need to plan for these expenses:

- Transplant surgery and your hospital stay
- Living costs while you are off work during recovery
- Lodging, food, and transportation in Seattle, if you live outside the area

Long-term Costs

In the long term, you will need to cover the costs of the medicines you will take for the rest of your life after transplant.

Paying for the Transplant

Health Insurance

Most health insurance plans will pay for a kidney or pancreas transplant. But, plans vary in what they cover. Some will cover many of the costs of transplant, but others may require that you pay many of the costs out of pocket.



Planning your finances is a key part of planning for transplant.

Check your healthcare plan carefully to find out:

- **If UWMC or University of Washington Physicians (UWP) is contracted:**

Call your insurance company to find out if UWMC and UWP are contracted. Give them these tax ID numbers:

- UWMC's tax ID number: 916001537
- UWP's tax ID number: 911220843

The contract status will determine whether you will use in-network or out-of-network benefits. Some plans do not have out-of-network benefits. If this is true for your plan, and UWMC or UWP is not contracted, you will need to pay out of pocket for all charges.

- **About coverage for your stay in the hospital:**

Does your health plan have a *deductible* you need to pay? A deductible is what you pay for covered healthcare services before your insurance plan starts to pay. This amount depends on your plan.

After you pay your deductible, you must pay either a *copayment* (copay) or *coinsurance* for covered services. Your insurance company pays the rest.

- **Copay:** If you have a copay for every day that you are in the hospital, you will pay a fixed amount for the services that are covered by your healthcare plan. The copay amount can vary for different services, such as drugs, lab tests, and visits to specialists. For example, your copay for a clinic visit might be \$20. Your copay for a hospital stay might be \$100 a day, up to a maximum of \$300.
- **Coinsurance:** If your policy pays a percent of the costs of your hospital stay (such as 80%), the portion you pay out of pocket (such as 20%) is your coinsurance. If you have coinsurance, it usually means you will be paying more than if you have a copay.

- **About waiting periods:**

A waiting period is the time that must pass before coverage takes effect for an employee or dependent covered by a job-based health plan. For example, some plans require that you have the plan for at least 1 year before it will cover transplant costs. Check these waiting periods any time you change insurance carriers.

- **About coordinating benefits:**

If you have more than 1 insurance plan, such as through your work and your spouse's work, check with the secondary policy to find out about *coordination of benefits*. Find out how and if the secondary policy will cover expenses that are left over after your primary insurance pays.

Medicare

Medicare is a health insurance plan that is run by the Social Security Administration. The plan is managed by Centers for Medicare and Medicaid Services (CMS). The plan covers people who have end-stage renal disease, have had a permanent disability for at least 2 years, or are at least 65 years old.

There are 2 basic parts of Medicare:

- **Part A** covers hospital stays, including a kidney transplant, skilled care, hospice, and some home healthcare. It also covers your doctor's fees while you are in the hospital.
- **Part B** covers doctor fees when you visit a clinic, but not while you are in the hospital; lab, radiology, durable medical equipment (DME), services at an ambulatory surgery center (ASC), and some home healthcare. It also covers approved costs related to your clinic visits.

Medicare has deductibles and copays. With a kidney transplant, these can add up to thousands of dollars. Most people cannot afford a kidney transplant if they have only Medicare. This means they also need other health insurance.

Medicare Supplements or “Medigap” Policies

These policies supplement your Medicare coverage. Most times, they pay Medicare copays and deductibles. They often cover things that Medicare won't cover. Having both Medicare and a supplement will likely cover most costs of a kidney transplant.

Medicare Part D

If you have Medicare Part A, or Parts A and B, you can sign up for Part D. This is the Medicare Prescription Drug Program. It covers some drugs, but not all.

If you want to add Part D, you will pay an extra monthly fee (*premium*). Part D has a range of premiums and benefit levels.

Part D can cover many of the medicines you will take after transplant. But, Part D does not pay for your immunosuppressive drugs. Those are covered under Part B of Medicare.

- If you have both Medicare and Medicaid, you also have Part D. You will not pay an extra monthly fee or deductibles for Part D. You might have to pay a small copay for some medicines.
- If you do not have Medicaid, you may have to pay a monthly fee, a yearly deductible, and copays for each prescription drug.

- If you are low-income and do not have Medicaid, Medicare can provide a subsidy that pays the monthly fee, deductibles, and copays. To apply for the low-income subsidy, call Social Security at 800.772.1213 or visit www.ssa.gov. You may have to wait until Medicare's open enrollment period at the end of every calendar year to apply for Part D.

Medicaid

Medicaid is a health insurance plan run by the state government and managed by CMS. It is paid for by the federal government and individual states.

Medicaid is for people who have very low incomes and are medically disabled. It will pay 100% of covered healthcare expenses. Talk with your social worker to see if you qualify.

In 2010, the Affordable Care Act expanded the Medicaid program to cover all adults with income below 138% of the federal poverty level. Washington state has expanded its Medicaid program since the Affordable Care Act was introduced. But, some states have not chosen to expand their Medicaid program. You can learn more at www.healthcare.gov.

Review Your Coverage

If you have not already done so, review your health insurance coverage with your transplant financial counselor. The financial counselor can make sure you have enough coverage for your transplant.

Paying for Medicines

Most times, transplant medicine costs are too high for people to afford without the help of health insurance. Check your prescription insurance coverage. Know what your expected copays or deductibles will be. You will be on many medicines after transplant, and each one will have a copay.

It is very important to keep your health insurance coverage after your transplant. Your medicines can cost \$12,000 to \$15,000 a year. Even with health insurance, you may have to pay part of these costs.

Here are some questions to ask about your prescription drug coverage:

- Does your insurance cover prescriptions at a certain percent, such as 50%, 80%, or 90%? Or, do you pay a copay per prescription, such as \$10 per prescription for a month's supply of the drug?
- Does your insurance provide different coverage based on whether the drug is a generic or a name brand? People with transplants are often prescribed name-brand medicines that do not have generic forms. Name-brand medicines can be very costly. Find out if your policy requires you to pay a higher copay or a percent for these medicines.

- Does your insurance offer a mail-order pharmacy? Some mail-order pharmacies allow you to get a 3-month supply of medicines for a lower copay than if you fill your prescriptions at a local pharmacy and get only a 1-month supply.

Medicaid

Medicaid covers the cost of most prescriptions. You might have a small copay for some medicines. If you have both Medicare and Medicaid, your prescriptions will be covered under Medicare Part D, not Medicaid.

Talk with your financial counselor if you are not sure if you qualify for Medicaid, or if you have questions about what program will pay for your medicines.

Medicare

If you have Medicare Part B, there are limits on what prescription drugs are covered after transplant. Here are some rules for how prescription coverage under Part B works:

- Medicare Part B covers immunosuppressive drugs at 80% for at least 3 years after a transplant. You (or your other insurance) will pay the 20% copayment. Medicare Part B will not cover any other outpatient medicines.
 - At 3 years after a transplant, your Medicare outpatient prescription drug coverage will end unless:
 - You are 65 years of age or older
- Or:
- You have been on Social Security Disability (SSD) for at least 2 years

If you meet either of these 2 conditions, your Medicare outpatient immunosuppressive drug coverage will continue beyond 3 years after your transplant. But, Medicare drug coverage will not continue more than 3 years after a transplant if you are on Supplemental Security Income (SSI), unless you are at least 65 years old. SSI is a different program than SSD (see the last page of this chapter).

- Medicare Part D will not cover your immunosuppressive drugs, unless you did not have Medicare at the time of your transplant. But, it will cover the many other medicines you will take after a kidney transplant. Part D will last only as long as you are eligible for Medicare. This means that if your Medicare Parts A and B end 3 years after a transplant, your drug coverage under Medicare Part D will also end at that time.

- If you have other insurance coverage through an employer or a spouse, Medicare will be your secondary insurance for the first 30 months of Medicare coverage. This means your other insurance pays first. If part of the medicine bill is still left after your insurance pays, that part can be billed to Medicare.
- Medicare is always your primary insurance if you have an individual health insurance policy.
- After 30 months of Medicare coverage, Medicare will become your primary coverage. This means all your medical bills will need to be billed to Medicare first. Any left-over parts of the bill can be sent to your other insurance.
- Some pharmacies will not bill Medicare Part B for prescription medicines. But, most pharmacies are able to bill Part D drug plans. If your pharmacy cannot bill Part B, please talk with your transplant social worker or pharmacist about different pharmacy options.
- Mail-order pharmacies that specialize in transplant medicines will do all your billing for you, including billing Medicare. If you have other insurance besides Medicare, the mail-order pharmacies will check to see if they can bill that insurance for you, too.
- If you do not have insurance coverage for some medicines, some drug companies have financial aid programs that may be able to help you. Ask your pharmacist or social worker about these programs.

Income While You Are Not Working

Some employers provide disability income insurance. There are 2 types of disability insurance: short-term and long-term.

Short-term Disability Insurance

This insurance pays part of your salary, often about 60%, while you are off work for a health reason. It usually covers your salary for 3 to 6 months.

Long-term Disability Insurance

This insurance pays part of your salary, often 60%, for as long as you are disabled and cannot work. But, you will usually need to be disabled for at least a certain amount of time, such as 90 days, before benefits will begin.

- **Social Security Disability (SSD)** – The Social Security Administration (SSA) has its own definition of disability for illnesses such as kidney disease or diabetes. To be eligible for SSD, your disabling condition must have lasted at least 1 year already, or be expected to last at least 1 year. Most transplant patients are not disabled for that long. This means they cannot rely on SSD to provide income while they are off work after a transplant.

Applying for disability can take many months. And, SSA must consider you disabled for at least 5 months before benefits begin.

If you are approved for SSD, the amount you receive each month is based on how much money you have paid into Social Security through payroll taxes.

- **Supplemental Security Income (SSI)** – This is a disability income program through the SSA. It is for disabled people who have not worked enough to pay much into the Social Security and are not eligible for SSD.

The SSI disability rules are the same as for SSD. But, SSI has strict income and financial limits.

If you are already on SSD or SSI before your transplant, there is a chance you will lose these benefits after your surgery. Depending on why you were first declared disabled, Social Security could decide you have recovered enough after your transplant to return to work. This would only happen after formal review by Social Security.

Contact your transplant social worker or primary care provider if Social Security starts an eligibility review.

If You Do Not Have Disability Insurance

If you do not have disability insurance, you will need to plan for the time you cannot work after transplant. Many people put aside money to help pay bills. Others borrow money from friends and family.

Fundraising is also an option. There are groups that help transplant patients raise money for expenses such as copays, travel, lodging, or lost income. If you want to try fundraising, talk with your social worker for ideas.

Medical Terms

For a kidney/pancreas transplant

This chapter defines many of the medical terms you may hear or read during your transplant journey.

You will hear and read many new terms as you learn about transplants. It will help to know what these words mean. Share this chapter with your family, your support team, and living donors.



You and your caregivers will learn many new words on your transplant journey.

Acute rejection

A rapid reaction against the transplanted organ. It often occurs about a week after transplant, due to a strong immune response to the new organ.

Allograft

A transplanted organ between two individuals who are the same species (such as human), but who have genetic differences.

Amylase

An enzyme made by the pancreas, normally found in the blood. Blood tests of amylase levels show how well a transplanted pancreas is working.

Antibody

A protein made by your immune system in response to a foreign substance (see “Antigen”). Antibodies help your body fight off antigens.

Antigen

A substance that your body sees as a threat, such as a virus, bacteria, or transplanted organ. Your immune system responds by making antibodies and also activates other cells to fight off the antigen.

Biopsy

A procedure that is done to find diseases or conditions such as rejection. In a biopsy, a very small sample of a tissue or organ is removed and examined under a microscope.

BK virus

A common virus that lives in the urinary system of most adults. In healthy people, it is harmless. In kidney transplant recipients, it can sometimes cause kidney damage. We will test your urine after transplant to make sure the BK virus levels are not too high.

Blood urea nitrogen (BUN)

A waste product excreted by a healthy kidney. The BUN level in your blood shows how well your kidney is working to keep your blood clean.

Caregiver

The support person or team who will help you through the transplant process. Caregivers must be able to provide you with both physical and emotional support before and after the transplant. A caregiver could be a family member, partner, or friend.

Catheter

A plastic or rubber tube. One type of catheter may be placed in your bladder to drain urine. Another type may be placed in a blood vessel to allow us to access your bloodstream (*circulatory system*).

Chronic allograft nephropathy

A slow decline in kidney function after transplant. There may be many reasons for this problem. It is also called *chronic rejection*.

Chronic kidney disease

Damage to both kidneys that cannot be reversed. It is also called *chronic renal failure*.

Creatinine

A waste product produced by muscles and removed from the blood by the kidneys. Your creatinine level can show how well your kidney is working to keep your blood clean. After transplant, we will closely watch the creatinine level in your blood.

Cross-matching

A blood test that shows whether a potential donor's blood is compatible with a prospective recipient's blood.

- A *positive cross-match* means that the donor and patient are **not** compatible. The recipient's body would reject the transplant.
- A *negative cross-match* means there is no reaction between the donor and the patient. The transplant may proceed.

Cytomegalovirus (CMV)

A common virus. Most adults who have been exposed to the virus do not develop CMV disease. The virus can become active if your ability to fight

infection is reduced (see “Immunosuppression”). CMV can cause fever, low white blood cell count, stomach problems, and other illnesses.

Deceased donor

A person who has died recently, whose family has agreed to donate their loved one’s organs for transplant. A deceased donor is also known as a *cadaveric donor*.

Delayed graft function (DGF)

A slow recovery (“waking-up”) of a transplanted organ. DGF may take days to weeks. A kidney transplant recipient may need dialysis to keep their blood clean while waiting for the kidney to “wake up.”

Desensitization

A treatment program to remove the antibodies in your blood that fight *human leukocyte antigens* (HLAs). If you have a very high *panel of reactive antibodies*, desensitization may allow you to receive a kidney from a greater number of donors. (See chapter on “Tissue Matching.”)

Diastolic

The bottom number of the two numbers in a blood pressure reading.

Donor-specific antibodies (DSAs)

Anti-HLA antibodies that can be in a transplant recipient’s blood. We screen for DSAs after transplant surgery. DSAs can be benign, or they can be an early sign of rejection of a transplanted organ. If we find DSAs in your blood after transplant, we will run more blood tests, or may do a kidney biopsy to find out if the DSAs are a problem.

Endocrinologist

A doctor who specializes in treating patients with diabetes and other hormonal diseases.

End stage renal disease (ESRD)

Chronic kidney disease that has worsened to the point where the kidneys cannot keep the blood clean enough on their own. Dialysis and kidney transplant are 2 ways to do the work that these kidneys can no longer do.

Glucose

The type of sugar that the body uses for energy. A high glucose level in the blood can be a sign of diabetes.

Graft

Transplanted tissue or organ, such as a kidney or pancreas.

Hematoma

A collection of blood near the transplanted organ or biopsy site.

Human leukocyte antigen (HLA)

Proteins found on the surface of all cells. They help your immune system know what substances are part of your body and what are foreign objects.

Hypertension

High blood pressure.

Immunosuppressants or immunosuppressives

The type of drugs used to suppress the body's immune system. They are also called *anti-rejection medicines*.

Immunosuppression

The process of reducing the body's immune system responses to foreign objects or antigens. We use immunosuppression to stop your immune system from attacking the transplanted kidney. But, immunosuppression also makes it harder for your immune system to fight foreign organisms such as bacteria or viruses.

Intravenous (IV)

Anything given to a patient through a needle or catheter placed into a vein. The word *intravenous* means "into a vein." Liquids, medicines, and nutrients may be given through an IV during and after surgery.

Living donor

A healthy adult who donates one of their kidneys to someone who is approved for kidney transplant.

Lymphocele

Lymph fluid that may collect near the transplanted organ. It is caused by lymph vessels that are damaged (usually from surgery) and cannot return lymph fluid back to the veins.

Lymphoma

A type of cancer of the lymph system.

Malignancy

Another term for cancer.

Mediset

A system that helps organize medicines. A mediset is usually a box that has a different compartment for each day. This box helps you sort your pills so that it is easier for you to remember to take them.

Nephrologist

A doctor who specializes in diagnosing and treating kidney disease.

Noncompliance

Failure to take medicines or follow healthcare instructions. It may shorten the time a graft is able to work. Noncompliance is also called *nonadherence*.

Panel of reactive antibodies (PRA)

A blood test done before transplant to test the recipient for “reactivity” to donor tissues. The test helps your doctors know if there might be a problem finding a transplant donor who is a match for you. Your PRA score will be between 0% and 100%. A high PRA means a high number of antibodies are in your blood, and it may take longer to find a donor.

Patient Care Coordinator (PCC)/Patient Services Specialist (PSS)/Program Coordinator

Transplant team members who schedule tests and appointments before and after transplant. They can answer questions about your evaluation.

Patient-controlled analgesia (PCA)

A way to control pain for a short time after surgery. PCA uses a hand-held control and a special IV pump that allows you to give yourself pain medicine as needed.

Post-transplant lymphoproliferative disease (PTLD)

Cancer of the lymph node or a lymphoma. This type of cancer is seen most often in transplant recipients.

Primary care provider (PCP)

Usually a non-specialist doctor who manages all your healthcare needs. A PCP may be a doctor, nurse practitioner, or physician assistant. Your PCP may refer you to specialists.

Recipient

A transplant patient who has received a transplanted organ.

Rejection

Injury to the graft caused by the recipient’s immune system.

Renal

Related to the kidneys.

Stenosis

A narrowing of a blood vessel or drainage tube in the body.

Stent

A tube or device placed in a vessel to keep it open or draining, such as a ureteral stent.

Systolic

The top number of the two numbers in a blood pressure reading.

Thrombosis

A blood clot.

Tissue typing

A blood test to determine which HLA proteins a possible organ donor or recipient has on their cells. This lets us know how close the match is between donor and recipient. See chapter on “Tissue Matching.”

Transplant attending surgeon

The doctor who is the main surgeon for your transplant surgery.

Transplant fellow

A doctor who is receiving special training in transplant surgery. This doctor will help with your care in the hospital after the surgery.

Transplant nurse coordinator

A nurse who has special training and skills in the health concerns of transplant patients. Your transplant coordinator is your resource for education, healthcare, and transplant care.

Transplant nephrologist

A doctor who specializes in treating kidney disease, with special training in kidney transplant. You will see this doctor often in the clinic after your transplant.

Transplant renal fellow

A doctor who specializes in treating kidney disease, who has finished medical residency and is getting extra training in transplant medicine.

Transplant surgery resident

A doctor who provides most of your day-to-day medical care in the hospital after surgery.

United Network for Organ Sharing (UNOS)

An organization that provides education about transplant and manages the waiting list for deceased donor organs. See “Resources” chapter for contact information.

Ureter

One of the two drainage tubes in your body that carry urine from your kidneys to your bladder.

Urethra

The drainage tube in your body that carries urine from your bladder out of your body.

Waiting List

The list of people in the U.S. who have been assessed for transplant and are waiting for deceased donor organs. This is also called the *wait list*.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882