

## 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

#### **Improved Health**

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



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

- **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](http://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.

