



Health Facts for You



Waiting for your
kidney/pancreas transplant

UWHealth

Welcome to the UW Health Kidney and Pancreas Transplant Program. The team takes pride in building a care plan tailored to your needs. We are committed to your success. UW Health is a national and international leader in the field of transplantation. Our program provides care for both adult and pediatric patients. We offer both deceased and living donor transplantation along with options for paired kidney exchange.

The Kidney and Pancreas

To best understand the transplant process, it is good to have basic knowledge of how the kidneys and pancreas work.

What do my kidneys do?

- Filter blood and send it back to the heart
- Balance fluid levels in the body by making urine
- Filter and balance minerals in the blood
- Control blood pressure
- Help to make red blood cells

What are my options if my kidneys stop working?

- Dialysis (Peritoneal or Hemodialysis)
- Transplant (Living donor or Deceased donor)
- Medical management

What does my pancreas do?

- It makes enzymes that your body uses to digest food.
- It makes glucagon and insulin to control blood sugars.

What are my options if my pancreas stops working?

- Transplant
- Management using insulin

Waiting for Your Transplant

The Waitlist

UNOS manages the waiting list, matching donor organs to recipients, 24 hours a day, 365 days a year. Priority is given to patients according to the following:

- Blood type
- How well the 6 antigens (genetic markers) match with those of the donor
- The length of time on dialysis or on the waiting list with a GFR of < 20 mL/min.
- Age. Pediatric patients (under age 18) receive more points
- Panel Reactive Antibody (PRA) level. This is a blood level that shows how easy or hard it may be to find a suitable donor for a patient based on antibodies a recipient may have.
- EPTS (Expected Post Transplant Score). This is based on your: your age, a history of transplant, a history of diabetes, and if you are on dialysis. A score of less than 20 gives you an opportunity for kidneys from a donor with a KDPI (Kidney Donor Profile Index) score of less than 20.

The patient who has the most points and is found healthy enough for transplant at this time will be called in to receive the transplant. A new list is made for every donor and changes according to the UNOS point system. This is why there is no way to predict how long someone may wait.

Multiple Listings and Transferring of Waiting Time

Multiple listing is when you are listed for transplant at two (2) or more transplant centers. Multiple listing can increase your

chances of getting an organ offer. It does not assure that you will have a shorter wait time.

UW Health allows multiple listing. You need an evaluation at each transplant center. Each transplant center then decides whether to accept you on their waiting list. You should check with your insurance to see if they cover more than one evaluation. You will need to keep current health information and contact information at each transplant center where you are listed.

There are many reasons that affect how long you wait for transplant. You can transfer your primary waiting time to another transplant center, or switch time between transplant centers. You cannot split your total waiting time among multiple transplant centers. Your transplant care will be done at the center where you have your transplant. To learn more about multiple listing or transferring waiting times, contact the transplant center where you are listed or want to be listed. For more information: https://unos.org/wp-content/uploads/unos/Multiple_Listing.pdf

When to Call

Waiting for your transplant may take a many months or years. You may go through many health changes during this time. It is vital to keep the transplant team informed of any changes in your health status. Examples of things that you should call about include:

- Taking antibiotics or have an active infection.
- Getting a blood transfusion.
- Being hospitalized.
- An increase or decrease in your weight (5 pounds or more).
- Having a significant change in your health status.
- Having a change in insurance coverage.

- Changes in contact information (such as phone number or address).
- Changes in your support person or plan.
- Planning to travel away from home.

The transplant team needs to know about these changes. This will help to ensure that you are in the best condition for your transplant. Some medicine changes or hospitalizations could change your status on the wait list. It is vital that you contact the team with any health changes.

Re-evaluation While Waiting for Transplant

In order to remain active on the UNOS waiting list or while planning for a living donor, some of your tests need to be updated on a regular basis. Most of these tests can be done by your local doctor and sent to us. Your transplant coordinator will provide you with the proper orders. We expect that the tests will be done quickly. We want you to be ready if an organ becomes available. If these tests are not done, you may be made inactive on the waitlist until they are done.

All patients must have a formal re-evaluation every 1-2 years while on the waiting list or while waiting for living kidney donor. Patients come to UW Health for this re-evaluation visit. The doctor does a physical exam, reviews records, and discusses any new issues related to transplant.

Our goal is that when we have an organ for you, you will be ready for transplant. Knowing about changes in your health helps to assure us that it is safe for you to have surgery when the time comes.

Waiting on the transplant list can be stressful for you, your family and friends. Be sure that you talk with your support

people about your appointments, your health status, and your plans.

Caring for Yourself While Waiting

Taking care of your health is very important while waiting for a transplant. It is expected that you will take all you are told to by your doctor, attend all doctor's appointments and, if on dialysis, attend all sessions. You must also follow your care team's plan for diet and exercise.

Getting the Call

When on the list, the transplant team should be able to reach you at any time of the day, any day of the week. If the transplant team contacts you and you cannot return the call within one hour, the team will call the next potential recipient.

You need to have a plan ready for when the call comes.

- How will you get to UW Health?
- Who will come with you?
- Who will take care of things at home while you are in the hospital, such as your children, pets, etc.?

Getting to the Hospital Quickly

When you get the call, you have a short amount of time to gather your things and make final arrangements. As a rule, the sooner you can get to the hospital, the better. Your safety when traveling is important, so be careful on your way here. The transplant is often done within 24 hours of the call.

The Organ Allocation Specialist will call you if an organ that may be a match for you becomes available. At this time you will be asked:

- To stop eating and drinking.
- About your current health status.
- To come to UW Health **OR** keep a phone line available, but to wait at home until you are called again.

It is vital that family and friends are involved in the planning process. Be sure that they are aware of the need for you to be reached at all times. They should also know the plans for you to be transported to the hospital when the call arrives. You will need to make plans for the care of your pets, children, work duties, and other responsibilities ahead of time. Being prepared will help you feel less stressed during your hospital stay.

There may be times when the donor organ becomes unsuitable for transplant. In an event of one of these "dry runs" you will be discharged home to wait until another donor becomes available.

What to Bring to the Hospital

Be prepared when you get the call. This call can come anytime, day or night.

Plan to bring these items:

- Advance Directive (Durable Power of Attorney for Health Care or Living Will)
- **ALL** medicine bottles **and** list of medicines, one day supply of medicines, and your insurance/Medicare/Medicaid cards.
- Local doctor/specialist contact information
- Local pharmacy phone number
- Loose clothing (sweat pants or something with elastic or drawstring waist bands), T-shirts, socks and supportive shoes for walking and therapy.
- Hygiene items, glasses, pajamas, slippers, robes etc.
- Personal comfort items (electronic devices, phone, chargers, and blanket or pillow)
- **NOT** a lot of money, but enough to pay for 1 month's supply of

medicines after hospital discharge (or credit card/check book)

- Blood pressure cuff (if applicable)
- If you have diabetes, your glucose meter with supplies
- Cell phone on and ready to call in case of delay or questions (608-263-6400 or 1-800-323-8942)

Please do not bring large amounts of cash, credit cards, jewelry or valuable items.

Where My New Kidney Will Come From

The Organ Shortage

There is a severe shortage of organs for transplant. This means that the wait for a kidney transplant can be many years. The UW Transplant Program has long been a leader in trying to find new ways to increase the number of good organs that can be used for transplant. When you are told you need a kidney transplant, you have options as to where your new kidney will come from. It is very important that you explore these options fully.

Live Donor Kidney Donation

In a living donor transplant, a healthy person's kidney is transplanted into the recipient. Living donors can be related or un-related.

Patient survival statistics after a living donor kidney transplant are better than those who have had a deceased donor transplant. Other benefits include being able to have a planned surgery and knowing the donor.

Deceased Donor Kidney Donation

Some patients may not have a living donor. They will need to go on the list to wait for a deceased donor transplant. Deceased donor kidneys are offered to recipients according

to the United Network for Organ Sharing (UNOS) guidelines. The Organ Procurement Organization (OPO) contacts the UW Transplant Program when a kidney is found and tells them who is first on the UNOS list to get the kidney. Below are the types of deceased donor kidneys that patients may be offered.

Donation After Brain Death (Deceased Donor)

The most common type of organ donor is a person who has suffered a head injury causing brain death. "Brain death" occurs when someone does not get enough oxygen to the brain and the brain then stops working. This is often due to trauma or a stroke. Doctors can do tests to tell when someone is brain dead.

The brain controls breathing. People in a hospital who are brain dead are on a breathing machine. The breathing tube and medicines keep the heart beating and supply the kidney and other organs with blood and oxygen until a transplant team arrives. Once the kidney is removed, it should be transplanted within 24 hours. Kidneys from these types of donors are called "standard donor" kidneys.

Donation After Circulatory Death (DCD)

There may be times that a patient's trauma is so bad that doctors can't save their life; but, they are not "brain dead." The doctor meets with the family to decide if life support should be stopped. If the family chooses to remove life support, the machines are turned off. Patients may or may not be able to donate.

Transplant teams are on site when the life support is turned off. When the patient's heart stops beating, they are declared dead by the doctor. The transplant teams can remove the organs. This is called donation

after circulatory death (DCD).

The kidney may have some damage due to lack of blood flow when organs are removed. Because of this, kidneys from DCD donors may sometimes take a few days to start working after the transplant. Success rates for patients who get a kidney from a DCD donor are the same as with a brain death donor.

Donor Scoring - KDPI

KDPI is a score that ranges from 0 to 100%. This score is based on transplant research. It relates to how long a kidney is likely to function. Kidneys with high KDPI scores are expected to function for a shorter amount of time than others.

KDPI scores are calculated based on facts about the donor. This includes:

- Age, height, weight, and ethnicity
- Cause of death due to loss of heart function, loss of brain function, or stroke
- History of high blood pressure
- History of diabetes
- Exposure to the Hepatitis C virus
- Kidney function (serum creatinine levels)

The KDPI score is calculated when a deceased donor kidney becomes available.

Risks If KDPI More Than 85%

Kidneys with KDPI more than 85% come from donors who may have one or more of the above medical factors (advanced age, obesity, diabetes, low kidney function, etc.). Possible risks if getting this type of kidney may include:

- a delay in the kidney working right away after transplant. This may last from a couple of days to a couple of weeks. This is called delayed graft function. Since the kidney(s) may

not work right away, patients may need dialysis after transplant. Only about 1-2% of kidneys may never work adequately after transplant.

- The kidney may not last as long as kidneys with KDPI less than 85%. How long a kidney continues to work is called graft survival. Your provider will explain how outcomes vary between kidneys with lower and higher KDPI scores.

Benefits If KDPI More Than 85%

Your chances of getting a transplant sooner increases if you agree to receive a kidney with KDPI more than 85%. This may extend your life. This could most benefit those who have many health concerns and those having trouble with dialysis. Your waiting time may be less by accepting a kidney with a KDPI score of 85% or higher.

If I agree to be listed for a kidney with KDPI >85%, will I still be listed for other kidneys?

Yes. All patients on the list are eligible to get a kidney from a donor with a KDPI score less than 85%. Only patients who sign a consent to accept a kidney with a KDPI score of 85% or higher will be on the list for this type of donor kidney. Those who consent would receive the first available kidney with any KDPI score from 0% to 100%. Patients who do not sign the consent form are only eligible for a kidney with a KDPI score less than 85%.

Do you ever transplant two kidneys?

Yes. National data as well as our experience has shown that if you get two kidneys from a donor with a KDPI score of more than 85%, the function is similar to that of one kidney from a donor with a KDPI score of less than 85%. Therefore, you may be offered two kidneys with KDPI scores more than 85% **even if you did not consent to**

one kidney with KDPI more than 85%.

The two kidneys are placed on one side of the body. Your incision is the same as if you were getting one kidney.

Two kidneys might also be used when the donor is younger or very small. This is called “en bloc” transplant. The kidneys are put in together on one side of your body. Studies have shown that two younger/smaller kidneys have similar outcomes of one adult-sized kidney.

Organs Meeting Risk Criteria for possible transmission of HIV, Hepatitis B and Hepatitis C

You may be offered an organ from a deceased donor thought to be at more risk for spreading certain infections.

Donors are deemed to meet risk criteria for possible transmission of HIV, Hepatitis B and Hepatitis C based on national guidelines. This may include risk factors such as prostitution, intravenous (IV) drug use, or those with same sex partners. Potential donors have blood tests done to look for viruses such as HIV, Hepatitis B and Hepatitis C. You will also be tested for HIV, Hepatitis B and Hepatitis C before your transplant. No test is perfect, and false negative results can happen.

There is a small chance (at most, 1 organ in 10,000) that an infection could be passed on. After your transplant you will be tested for HIV, Hepatitis B and Hepatitis C. These infections all have good treatment options. We believe that the risks of getting this type of kidney are very small.

Hepatitis C Positive Donors

Hepatitis C is a virus that can damage the liver. We now have medicines to treat this virus, so we can often use kidneys from donors who have had or have hepatitis C.

Donors who have had hepatitis C and do not have an active infection are very low risk. If you receive a kidney from a donor who has had hepatitis C, we will do tests to check for signs of this virus. You likely would not need other medicines.

Organs from donors with an active hepatitis C infection can be safely used. Patients who receive a kidney from a donor with an active hepatitis C infection will take medicine to treat the virus. When placed on the waiting list, the transplant team asks if you are willing to accept a hepatitis C donor kidney. If you agree, you will be required to sign a consent. If you choose not to accept this kidney, you will not lose your place on the waiting list.

What will I be told about my donor?

Privacy laws limit how much we can tell you about your donor. We can't tell you the donor's age, gender, or personal health history. The United Network for Organ Sharing (UNOS) distributes the organs. The Organ Procurement Organization (OPO) informs the UW Transplant Program when a kidney is found and who is first on the UNOS list to get the kidney.

The OPO carefully screens all would-be donors for any illness that could affect the transplant organ or the patient who gets it. This screening can be limited by time constraints between the time that the donor was injured and when the organ is obtained. Your specific donor's assessment and screening results may impact your care after transplant. This may include the need for other tests or medicines. We believe the risk of these treatments outweighs the risk of waiting for another organ. We use our best knowledge and judgment to make sure every organ we transplant will work and will not harm the person who gets it.

How do I choose?

There are risks and benefits for each type of kidney transplant. Members of the transplant team can tell you more about this topic. They can help you choose the option that may be best for you.

Where My New Pancreas Will Come From

The Organ Shortage

There is also a severe shortage for this organ. We do not know how long it will take for a pancreas to become available. Patients may die while they wait. You have options about where your new pancreas will come from. It is vital that you explore these options fully.

Donation After Brain Death (Deceased Donor)

The most common type of organ donor is a person who has suffered a head injury causing brain death. “Brain death” occurs when someone does not get enough oxygen to the brain and the brain then stops working. This is often due to trauma or a stroke. Doctors can do tests to tell when someone is brain dead.

The brain controls breathing. People in a hospital that are brain dead are on a breathing machine. The breathing tube and medicines keep the heart beating and supply the pancreas and other organs with blood and oxygen until a transplant team arrives. Once the pancreas is removed, it should be transplanted within 12 hours. Pancreas from these types of donors are called “standard donor” pancreases.

Donation After Circulatory Death (Deceased Donor)

There may be times that a patient’s trauma is so bad that doctors can’t save their life; but, they are not “brain dead.” The doctor meets

with the patient’s family to decide if life support should be stopped. If the family chooses to remove life support, the machines are turned off. Patients may or may not be able to donate.

Transplant teams are on site when the life support is turned off. Once the heart stops beating, the person is declared dead by the doctor. The transplant teams can remove the organs. This is called donation after circulatory death (DCD).

The pancreas may have some damage due to lack of blood flow when the organs are removed. This can cause problems for the patient who gets this pancreas. Most of the time these problems can be treated. A pancreas from a DCD donor may sometimes take a few days to make enough insulin to control glucose levels. The blood pancreas enzyme level may also rise in the first few days after transplant. Despite this, the outcomes are the same whether the pancreas comes from a DCD donor or from a brain death donor.

Organs Meeting Risk Criteria for possible transmission of HIV, Hepatitis B and Hepatitis C

You may be offered an organ from a deceased donor thought to be at more risk for spreading certain infections.

Donors are deemed to meet risk criteria for possible transmission of HIV, Hepatitis B and Hepatitis C based on national guidelines. This may include risk factors such as prostitution, intravenous (IV) drug use, or those with same sex partners. Potential donors have blood tests done to look for viruses such as HIV, Hepatitis B and Hepatitis C. You will also be tested for HIV, Hepatitis B and Hepatitis C before your transplant. No test is perfect, and false negative results can happen.

There is a small chance (at most, 1 organ in 10,000) that an infection could be passed on. After your transplant you will be tested for HIV, Hepatitis B and Hepatitis C. These infections all have good treatment options. We believe that the risks of getting this type of kidney are very small.

What will I be told about my donor?

Privacy laws limit how much we can tell you about your donor. We can't tell you the donor's age, gender, or personal health history. The United Network for Organ Sharing (UNOS) distributes the organs. The Organ Procurement Organization (OPO) informs the UW Transplant Program when a pancreas is found and who is first on the UNOS list to get the pancreas.

The OPO carefully screens all would-be donors for any illness that could affect the transplant organ or the patient who gets it. This screening can be limited by time constraints between the time that the donor was injured and when the organ is obtained. The donor's evaluation and screening results may impact your care after transplant. This may include the need for more tests or medicines. We believe the risk of more treatment outweighs the risk of waiting for another organ. We use our best knowledge and judgment to make sure every organ we transplant will work and will not harm the person who gets it.

How do I choose?

There are risks and benefits of each type of pancreas transplant. Members of the transplant team can tell you more about this topic. They can help you choose the option that may be best for you.

Tips to Prepare

Make sure your transplant team knows how to reach you.

When an organ becomes available, we need to be able to contact you within an hour. If we cannot reach you, we have to move on to the next patient.

- Keep your cell phone ringer on and next to your bed.
- Put ringers on the loudest setting.
- Keep your cell phone charged.
- Take your cell phone everywhere (church, grocery, doctor appointments, etc.).
- Give your transplant coordinator contact numbers of close family or friends. We will call someone you have listed to help us find you if we can't reach you at your main numbers.

Have your support persons in place. This is often a family member or close friend.

- Choose 1 to 2 people you feel close with who have the time, health and flexibility to be your caregiver. Your support person must be an adult.
- Be clear with your support person about what you are asking them to do for you. Allow them to say "no" if they cannot make this commitment.
- A support person will need to be available for rides, coming to appointments, and helping you at home. You may need 24-hour care after transplant. Please make sure your support system can do this. Your transplant social worker will review your support expectations.
- When you are in the hospital, you must have someone with you who can learn about post-transplant care. Your primary support person is required to attend transplant classes.

- If your support person will not be driving from home, think about where your support persons will stay while you are in the hospital. UW Housing offers discounts at local hotels as well as the Restoring Hope Transplant House. Many area hotels have shuttles available. The housing number to assist to make arrangements is (608) 263-0315.
- Depending on the distance and time it takes to get to Madison, you may need to stay in the Madison area for a period of time after discharge from the hospital. Your support person will need to stay with you.
- You will need your support person(s) to help you after you return home from transplant. The amount of time needed is organ specific. The transplant social worker and your coordinator will discuss how long you will need this extra support.

Allow others to help you when you need it. Sometimes it is important to let go of pride and desire to be independent and allow others to help. Think about how you have felt when someone has had an illness, a death or even a new baby in the family. People are usually quite happy to help out but need to know best ways to help you. It could be helpful for others to pick up a few things at the store, deliver a meal to your door, or help with raking and lawn mowing, or household chores. When you are back to full speed, you can offer to help them if you wish.

Organize personal affairs. This includes completing advance directives. The Transplant Social Work Team can answer questions you may have about these forms.

Consider a plan for your bill payments, mail and email while you are not able to do these

things. Having a plan will make it easier for someone to take over for you at any time.

Think about child and pet care arrangements for when you are in the hospital and while you are recovering.

Know your options and have phone numbers and supplies ready to go.

Arrange for your transportation needs.

When you get the call that an organ is available, you need a plan to get to the UW Hospital.

- Have gas in the car.
- Have cash available at all times.
- Have a driver and a backup driver available.
- Have printed directions to UW Hospital ready for your driver and/or a GPS unit available to use.

After transplant you will have many planned clinic visits, but some will be unplanned.

Pack your bags. You will need to be ready to go quickly after you get the call. Review the list in the “What to Bring to the Hospital” section.

Think about setting up a phone/email tree, blog or a key contact person. This will cut down on your phone calls in the hospital. Your hospital time is for rest and recovery, learning, procedures, etc. Sleep patterns change in the hospital. Getting as much rest as you can is very important.

Learn about transplant and what to expect. As you learn about what to expect you will feel more comfortable with the process.

- Review your transplant materials.
- Do this once a month while you wait for your call.
- Do internet research.

- Join a transplant support group in person or online.
- If you have questions, contact your transplant coordinator.

Take time each day to get exercise. Find an activity that you enjoy doing. Fresh air is good for the mind, body and soul. Sometimes it is hard to make yourself walk or be active when you do not feel good. But the more you use your muscles before transplant, the quicker you will recover.

Transplant Team Members

Transplant Surgeons

Transplant surgeons meet with you and your family during the evaluation. They review your record and test results and explain the surgery. They review the risks and benefits of transplant. The surgeon does the surgery and works with other doctors to manage your care after the transplant.

Medical Specialists

These doctors help to decide if a transplant is the best option for you. They stay involved while you are on the waiting list and after the transplant.

Pre-transplant Nurse Coordinators

These nurses coordinate your care before transplant. They are involved from the time of the first referral until a transplant is received. They arrange any tests needed to get you placed on the waitlist. This nurse helps you through the evaluation process. These nurses contact your local doctors and other healthcare facilities as needed.

Post-transplant Nurse Coordinators

These nurses coordinate your care after transplant. They are involved from the time of transplant through long-term, post-transplant care. They serve as your link to the rest of the transplant team after surgery.

They work with the doctors to coordinate your medical needs. They teach you and your family and advocate for you. These nurses contact your local doctors and other healthcare facilities as needed.

Clinical Social Workers

Social workers talk with you about your emotional health and social situation. They will discuss community resources and help with financial matters. They help support you during the transplant process. Social workers can answer your questions about advance directives. They can help you complete them if needed. They can also help to find support groups.

Clinical Dietitians

Clinical dietitians assess your nutritional status. They help you to make a plan for good nutrition.

Physician Assistants and Nurse Practitioners

These advanced practice providers care for you before and after your transplant. They check on you as you recover and help to manage your medicines. They also help to plan for your discharge needs. You will see them in transplant clinic before and after your surgery.

Surgical Residents and Transplant Fellows

These doctors mainly assist with hospital care. This includes getting you ready for and assisting with surgery. They help to manage issues after surgery and prepare you for discharge. You may also see transplant fellows at transplant clinic visits.

Financial Counselors

These staff work with you and your insurance company before and after transplant. They help to work through matters such as billing, deductibles, and

drug coverage. They teach you about the financial aspects of transplant. They are the best resource for any questions about insurance.

Transplant Pharmacists

Pharmacists work with the team to make sure the medicines are used correctly. They watch for side effects and try to minimize them. They also help to manage the timing of the medicines.

Inpatient Transplant Nurses

These nurses care for you in the hospital. You will have a primary nurse. This nurse works with the rest of the team to get you ready for discharge.

Case Managers

Case managers focus on the plan for leaving the hospital. Some patients need skilled nursing care or other services. The case managers can help arrange this care.

Transplant Clinic Nurses

These nurses care for you during clinic visits. They provide care and support for you after procedures. They arrange follow-up care and provide education

Office Support Staff

Support staff answer your phone calls and work with the coordinators and other staff. They help coordinators to manage lab results and patient issues and concerns.

Spiritual Care

Chaplains help people find comfort and meaning from their faith during illness recovery. Our chaplains provide spiritual and emotional support. They also perform sacraments. Faith and medicine offerings are provided in the hospital chapel. Catholic and Protestant services are held on Sundays.

Other Expert Doctors

Other doctors may be involved either during the evaluation or after transplant. UW Health has many specialized doctors who work with the rest of your team. Infectious disease, dental, endocrine, cardiology, hepatology, and urology are just a few of the teams that can assist in your care if needed.

Other Services

Other services are available to help you and your family. For example, Interpreter Services help those who need translation. Housing assistance can help if you need short-term housing.

The Transplant Surgery

What to Expect Before Surgery

When you get the call to come for transplant, you should not eat or drink anything from that point on.

You will be admitted to the Transplant Surgery Unit (B4/6) to be prepared for surgery. This unit staff cares for people who have received or are receiving a kidney, pancreas, or liver transplant.

When you reach the Transplant Surgery Unit you will meet your nurse and be taken to your room. Depending on the situation, surgery may happen quickly after you arrive, or you may wait several hours before having surgery. Several things need to be done before you go to surgery. These include:

- blood samples
- skin cleaning
- urine sample (if you make urine)
- bowel prep
- physical exam
- medicines
- chest x-ray
- post-operative teaching

- electrocardiogram (ECG)
- special preparations for those with diabetes
- dialysis (if needed)
- pre-surgical medicine

Blood samples will be drawn as soon as you arrive.

A urine sample will be done (if you are making urine) to check for infection.

A chest x-ray and electrocardiogram (ECG) are done to assure your health before the transplant.

You may have a **bowel prep** to clean out your bowels. If your transplant is from a living donor, you will be on a liquid diet the day before surgery and will not be able to eat or drink anything after midnight.

Your skin will be cleaned using a special soap. During surgery, hair may be removed from your abdomen. Both of these things help lower your risk for infection.

Dialysis may be done. Your provider will decide if this is needed. The doctor will look at your blood tests, fluid status, and your dialysis schedule and decide.

A physical exam and consent will be done by one of your doctors. At this time, they will explain the transplant to you and ask you to sign a consent form.

Hospital admission questions will be asked by your nurse.

Teaching will be started so you will know what to expect after surgery

Medicines used to prevent rejection will be given to you during surgery. Your doctor will decide which medicines you will

receive before and after your transplant. This may include

- Prednisone or dexamethasone (corticosteroids)
- Tacrolimus (Prograf[®], Astagraf XL[®], Envarsus XR[®])
- Mycophenolate (Myfortic[®] or Cellcept[®])

The Transplant Surgery

When you are taken to the surgery area, one support person may stay with you until you are taken to the operating room (OR). Other family members may stay in the surgical waiting area or go back to the inpatient unit (B46). The OR nurses will provide your family with updates. After surgery, the surgeon will talk with your support person and/or family.

Once you are in the operating room (OR), you will meet your nurse who will answer questions, make sure you are comfortable, and explain what is happening.

There will be ECG (electrocardiogram) patches on your chest, a blood pressure cuff on your arm, and a plastic clip on your finger to check your heartbeat and oxygen levels. The anesthesiologist will ask you to breathe oxygen through a soft plastic mask. Medicines will be given through your IV.

After you are asleep, a breathing tube (endotracheal or ET tube) will be placed in your windpipe to breathe for you. Other lines and monitors will be added after you are asleep. At least one intravenous catheter (IV) will be placed in your hand or arm. This will be used to give you fluids until you are able to eat or drink.

The surgery will take about 5-7 hours for a pancreas or kidney and pancreas transplant. You will go to the Recovery Room for about

1 hour before going back to your room on the transplant unit.

Your Incision

Your new kidney will be in a different place than your own kidneys. The incision will be 9-12 inches long. For a pancreas or kidney/pancreas transplant, the incision is made down the middle of your abdomen. Your muscle and skin will be closed with staples or stitches.

With a kidney transplant, a small tube called a **stent** is placed in the area where the new kidney's ureter is stitched to the bladder. The stent is inside the ureter and extends into the bladder. This tube helps keep this new connection straight while it heals and allows the urine to flow into the bladder. The stent must be removed later. This is most often done at your first or second clinic visit. This procedure called a cystogram.

You will have a **small rubber tube (Foley catheter)** placed in your bladder during surgery. The Foley will usually be in place for 2 days. The Foley helps us to closely watch your urine output and allows the stitches in your bladder to heal. After the Foley is taken out, we will still measure your urine each time you go to the bathroom. You will use a plastic collection "hat" in the toilet or a urinal while in the hospital so amounts can be measured easily.

What to Expect After Surgery

You can expect to wake up shortly after getting to the unit. Though you will likely feel drowsy, you may hear beeps, alarms, and voices. Your nurses will check your blood pressure, temperature, and measure your urine output often during the first 24 hours.

Because of the effects of anesthesia, the normal action of your bowels slows. Bowel

function can return faster if you walk. You will be encouraged to walk as soon as your doctors think it is safe. Once we hear bowel sounds or you pass gas, you will be able to start drinking liquids and will slowly advance to a regular diet.

The **incision** will have a dressing over it at first which will stay on for 48 hours after surgery. We will teach you how to clean and care for it. This will help you be more aware of any signs of infection or problems. The staples or stitches will likely be removed at your first clinic visit.

Your doctor will order **pain medicine** for you. During the time you are unable to eat or drink, you will receive it in your IV. Later, you will receive pain pills. Pain medicine should be taken to lessen incision pain. Your walking, coughing, and deep breathing will be easier when this is done.

You will be coughing, deep breathing and using the incentive spirometry device at least every 1-2 hours while awake. Your nurse will help you with this. Deep breathing helps air to reach your lower lungs. Coughing helps clear out secretions so pneumonia is less likely to occur. Coughing and deep breathing is an important part of recovery.

You will wear Sequential Compression Devices ("SCDs" or leg pumps) during surgery and for the first few days after surgery when you are in bed. This will aid in blood flow and help prevent blood clots. You will be expected to be up walking within the first 8-12 hours. You will then need to be out of bed to the chair and/or walking at least 3 times each day.

While in the hospital you will have blood samples drawn every day and more often if needed. The results of these tests keep you

and your health care team aware of how you are doing. You will become involved in tracking these tests and understanding their meaning.

Many patients will have their blood sugars checked during their hospital stay. If you have diabetes, you can expect to receive insulin through your IV. Your blood sugar levels will be checked often. You may continue to receive insulin over the next couple of days as you recover. Some patients who have not needed insulin in the past will be given insulin if their blood sugars are high.

As your condition improves, the nurses will watch you closely, but they will not be at your bedside as often. This is a good sign. You are on the road to recovery.

Education After Transplant

It is very important that you learn about the care of your new organ after your transplant. During your hospital stay, there are daily classes. You will be expected to attend class every day. This may start as early as your first day after transplant depending on how your recovery is going. It is the expectation that your primary support person will be involved in your education as well in order to assist you once you return home. The classes are daily at 10:00am.

- **Monday:** Medications & Honoring Your Donor
- **Tuesday:** Laboratory Tests
- **Wednesday:** Home Cares
- **Thursday:** Complications & Nutrition
- **Friday:** Medications
- **Saturday:** Home Cares 1
- **Sunday:** Home Cares 2

How Will I Know My Transplant Is Working?

Blood will be drawn daily to measure your creatinine (kidney function) and/or pancreas enzyme levels. These show us how well your new kidney and/or pancreas are working. The nurse will keep checking your urine output and blood sugar levels. The transplant team will talk with you daily to review your kidney and/or pancreas function. They will answer any questions you have about your progress.

Guidelines for Primary Supports and Visitors

Family and friends are welcome to visit often while their loved ones are in the hospital. Visiting hours in most units are from 8am-9pm, but those identified as primary support persons may stay with the patient at any time. (Staying overnight may be difficult; a very limited supply of cots is available.) Primary support persons are those who normally provide a patient with significant physical, psychological or emotional support. Examples might be a close family member, partner or best friend. Visitors should check at the information desk or nursing unit before visiting.

Commitment to Follow-Up Care

Your care after a transplant is for your entire lifetime. This long-term care includes:

- Biopsies
- Labs and other tests
- Medicines
- Transplant Clinic visits

Keeping the Commitment

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

- Follow the treatment plan.
- Call the transplant office about any new problems or symptoms related to your transplant or about any new medicines or tests you have.
- Take all prescription medicines as prescribed.
- Follow the diet and exercise plan advised by your doctor.
- Go to your appointments, clinic visits, lab draws, and biopsies.
- Do not abuse your body by smoking, drinking alcohol, or using non-prescribed medicines and herbals.

Appointments and Medicines

The follow-up schedule is intense for the first few months. Labs and biopsies are done to check for rejection. This can happen when your body's immune system attacks your new organ. During a biopsy, pieces of tissue are taken from the inside of your organ and studied under a microscope. If a biopsy is done because your organ is not showing normal function, it may be somewhat urgent. You may need to make plans to come to UW Health without much warning.

After your transplant, you will be on many medicines. You will be on some of them for the rest of your life. This includes medicines which:

- Prevent rejection
- Prevent infections

- Control blood pressure
- Control cholesterol
- Prevent bone loss
- Provide you with extra vitamins and minerals
- Control blood sugars

You will need to know what medicines you are taking, why you are taking them, and the dose prescribed for you. Not taking your medicines correctly can lead to rejection and other health problems.

You must have a local doctor to follow your care. Plan to see your local doctor shortly after your transplant. We rely on the local doctor to address routine health issues such as diabetes, minor infections and illnesses, and regular health maintenance. We will work closely with your doctor to give you the best care. The Transplant Team will manage your transplant medicines and address any issues about your transplant. You will need to follow the advice of your local doctor and the transplant team for diet, exercise, and other health needs. We want you to live a healthy life after transplant.

Health Concerns After Surgery

After transplant, people can live a healthy life. The main issues are the **increased risks of infection and rejection**. To prevent infections, you will need to take extra care, wash your hands often, and wear a mask at times. Sometimes, it is best to avoid crowded places, areas with poor ventilation, or people who may be contagious.

The risk of rejection is greatest the first 6 – 12 months after transplant. It is common to have a rejection. This is the body's normal immune response to "foreign" tissue. When rejection occurs, we need to adjust your medicines to decrease your immune system further. These medicines have side effects that can cause new health concerns. High

blood pressure, high cholesterol, diabetes, and osteoporosis can occur. Most of these side effects can be treated. Diet, exercise, and how well you follow your treatment plan all affect how you will be able to manage the side effects.

Activity Levels

Over time, most patients can go back to their normal activity with minor adjustments. Please note that it will take some time to gain strength and endurance. Keeping up with an exercise routine once you have recovered from surgery is the best way to manage your weight and improve your well-being.

Going Back to Work

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

Things to Remember After Your Transplant

Take medicines as directed.

- Anti-rejection medicines include: Myfortic[®], prednisone, tacrolimus (Envarsus XR[®]), cyclosporine, Belatacept[®], sirolimus, and azathioprine.
- Your anti-rejection medicines and doses will be specific to you. The transplant doctors will order the medicines they feel will best fit your needs.
- It is important you do **NOT** miss doses of these medicines
- Do not change your medicine doses or stopping taking any medicine

without talking with the transplant team.

- Please call the transplant team before starting any new medicines including over-the-counter medicines or supplements

Labs

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

Anti-rejection Medicine Levels

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

Home Care

- Every day: Check your weight, blood pressure, pulse, and temperature as instructed by the transplant team. Please call your coordinator if you have:
 - Oral temperature higher than 100.5°F or 38.3°C
 - Blood pressure is higher than 180/90.
 - Weight gain of 3 pounds in one day or 5 pounds in one week.
- Activity: Do not lift, push, or pull more than 10 pounds for 8 weeks.
- It is good to walk and use stairs while healing.

Transplant Clinic Visits

- Complete labs as directed by staff with your appointments. **Please bring to all of your clinic visits:**
 - record book (including vital signs and blood sugars if checking) , and

- medication list.

- You will be told when to follow-up after discharge from the hospital.
- Please arrange a ride. You WILL have driving restrictions post-transplant until cleared by the doctor.
- Your coordinator will address other follow-up needs during discharge teaching.

Primary Care Visits

- See your primary care provider within 1 month of discharge. You will need to call to schedule this visit.
- This visit is to review your medicine list and new health concerns (ex: diabetes after transplant). Your primary care time will continue to be responsible for your general health care and health maintenance visits.
- The transplant team and your primary care doctor will work as a team in your care.

Contact Information

Your coordinator _____

Phone _____

General office number is: **(608) 263-1384**

After hours: For transplant questions that can't wait, call **(608) 263-6400** and ask for the Transplant nurse on call.

Emergencies, call **911**.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 2/2021. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#8142