



Health Facts for You



Your kidney and pancreas
transplant evaluation

UWHealth

Welcome to the UW Health Pancreas and Pancreas and Kidney 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 adult patients needing a pancreas or a pancreas and kidney transplant.

The Pancreas and Kidney

It is good to have basic knowledge of how the kidneys and pancreas work.

What does my pancreas do?

- Makes enzymes that your body uses to break down food.
- Makes glucagon and insulin to manage blood sugars.

Options If Your Pancreas Stops Working

- Transplant
- Management using insulin.

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.

Options If Your Kidneys Stop Working

- Dialysis (peritoneal or hemodialysis)
- Transplant (living donor or deceased donor)
- Medical management

After Your Evaluation Testing

When your evaluation testing is done, the transplant team reviews and discusses your results. There are three possible decisions:

1. You are approved to be added to the list. Or,
2. The team feels transplant is NOT the best option for you. Or,
3. The team needs more testing or information to make the decision.

You will be notified of the decision and next steps, which may include an insurance review.

Where My New Pancreas and 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.

Deceased Donor Donation	
What?	Who?
Patients 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 and pancreas or pancreas 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.
Types of Deceased Donor Organs	
<p>Donation After Brain Death (Deceased Donor)</p> <p>The most common type of organ donor is a person who has suffered a head injury causing brain death. “Brain death” occurs when the brain doesn’t get enough oxygen and the brain stops working. This is often due to trauma or a stroke. Tests are done to tell when someone is brain dead. People who are brain dead are on a breathing machine. The breathing tube and medicines keep the heart beating and supply the organs with blood and oxygen until a transplant team arrives. Once the kidney and pancreas or pancreas is removed, it should be transplanted within 24 hours. Organs from these types of donors are called “standard donor” organs.</p> <p>Donation After Circulatory Death (DCD)</p> <p>Sometimes 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. 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 or pancreas may have some damage due to lack of blood flow. 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 and pancreas from a DCD donor are the same as with a brain death donor.</p>	

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. It can last longer than a month. 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 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 chance of getting a transplant sooner increases if you agree to receive a kidney with KDPI more than 85%. This could most benefit those who have many health concerns and those having trouble with dialysis. Your waiting time may be shorter 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 work similar to 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 can all be treated with medicines. We believe that the risks of getting an

infection from 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 and cure this virus, so we can often use organs 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 an organ 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 stay active on the waiting list for a future kidney offer.

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 possible 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 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.

Delayed Graft Function

What is delayed graft function (DGF)?

Your transplanted kidney is called a graft. Delayed graft function (DGF) can occur right after surgery. It means your new kidney is not working as it should and you may need dialysis. You may hear your transplant team say that the kidney is "sleepy". This means you have delayed graft function. It takes some time for the kidney to heal from the transplant surgery. Some people may need dialysis for a while after their transplant. Up to 30% of deceased-donor kidneys and 5% of living donor kidneys may have some degree of DGF.

How is DGF treated?

The function of your new kidney is checked by creatinine levels. Your urine output is also checked. You may need dialysis or diuretics (water pills) and close watch of your kidney function. Your doctor may biopsy the kidney to check for rejection. You may have to follow salt, potassium, phosphorous, and water restrictions. The transplant team will decide when this diet plan is no longer needed. Your blood pressure, anti-rejection, and other medicines will be changed as needed.

Will my kidney recover from DGF?

Most transplanted kidneys with DGF do recover. Only 1 to 2% of all kidney transplants fail to work. At UW Health, 95% of kidney transplants are working one year after transplant. After the kidney starts working, it will work like any other transplanted kidney.

How long will DGF last?

There is no exact timeline for how long DGF will last. It will vary from patient to patient. DGF recovery is most often seen in about 7-10 days but can take up to 3-4 weeks for full DGF recovery.

What will happen after I am discharged?

You will be followed in the DGF Clinic at the UW Transplant Clinic. You will be told if you need to continue to follow a fluid restriction or special diet. You must check your weight daily and blood pressure twice each day. You will be given a urine collection device. You will measure and record how much urine you are making each day. Bring the record with you to each clinic visit. This is an important sign of your kidney starting to work. If you are being discharged with a new dialysis line, your nurse will tell you how to take care of that line.

The DGF Clinic is set up so that we can follow you closely. We will arrange a hotel room for you close to the hospital. If you stay in a hotel the cost will be covered by UW Health. If you live close to UW Health, you may be able to go home and drive back and forth to Transplant Clinic. **You will need to have a support person staying with you** (either at home or in the hotel). You will need to have someone transport you to and from the clinic for your visits.

You will return to the Delayed Graft Function (DGF) Clinic up to three times a

week for labs, clinic appointments, and dialysis, if needed based on your labs. If you need dialysis this will be done in the dialysis unit at the hospital.

We will also decide if your anti-rejection, blood pressure, and anemia medicines need to be changed. When you no longer need dialysis, you will be discharged from the DGF Clinic. You will return to the UW Transplant Clinic for routine follow-up visits.

The Transplant Waitlist

Completing a transplant evaluation does not guarantee being put on the waitlist. After evaluation if you are approved for transplant, you will then be put on 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 based 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 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. Everyone's wait time will be different.

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. 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 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 having an active infection.
- starting a new medicine
- Getting a blood transfusion.
- Being hospitalized or going to the emergency room
- 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 local doctor information
- Changes in your support person or plan.
- Planning to travel away from home.
- If you receive a transplant at another center

The transplant team needs to be up to date on this information. 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 will 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 waiting for a transplant. Patients come to UW Health for this re-evaluation visit. The provider does an 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.

Staying Healthy Before Transplant

Taking care of your health is very important while waiting. It is expected that you will take all medicines as directed by your doctor and attend all appointments. You must also follow your plan for diet and exercise.

Nutrition

Nutrition plays a key role in the transplant process. Eating well and exercising before transplant may help you recover faster after surgery. After surgery, your body needs enough nutrition to promote healing, fight and prevent infection, and gain back weight you may have lost. In the long-term, good nutrition plays a key role in keeping you healthy.

Frailty

You may be frail if you have lost weight without trying, feel weak or tire easily, walk more slowly, or need help for daily activities. This could include bathing, dressing, eating, getting out of bed and moving around on your own.

Causes of frailty include aging, being less active, chronic diseases, not eating well and malnutrition. People who get a transplant when they are frail stay longer in the hospital and get more infections. They are less likely to go home from the hospital and more likely to need rehabilitation.

Improve Your Strength with Exercises

You can improve your strength if you add 30 minutes of exercises daily. This could be walking, weightlifting, or sitting chair exercises. If you cannot exercise on your own, you may need physical therapy (PT). Let your nurse or doctor know if you think you need PT.

It is important to exercise even if you have physical limitations. You can do these exercises at home. You can do these sitting down with either resistance bands or light weights. You can use common household items that have some weight to them. Examples could be filled water bottles, canned goods, or rocks. To gain strength, do these exercises daily. For each exercise, complete 3 sets of 10-15 repetitions. Do not rush. Go slowly.

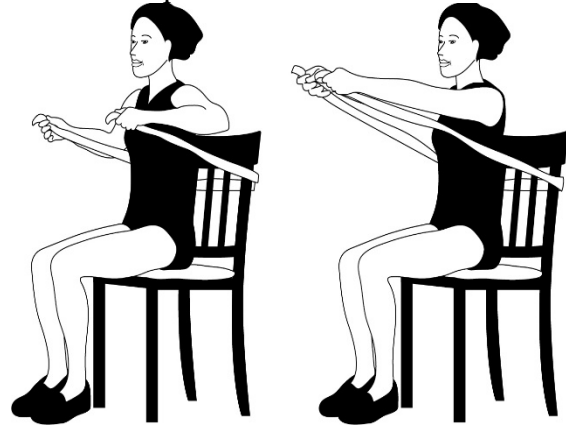
Overhead Press

Sit on edge of a chair with your feet planted flatly on floor. Grab light dumbbells or a resistance band. Take a deep breath and tighten your core. Push the weights or band evenly over your head. Keep your neck and back in a neutral position. Bring the weights or band back down to the level of your ears and repeat. You can also do this activity standing with your feet evenly spaced apart. Keep your feet firmly on the ground.



Seated Press

Wrap your band around the back of your chair and make sure it is secure. Sit with your weight evenly distributed. Take a deep breath. With a flat back and even posture, push your arms straight out in front of you. Make sure you are using your chest to push out your arms. Try not to move the position of your back. Bring your hands back to your chest and repeat.



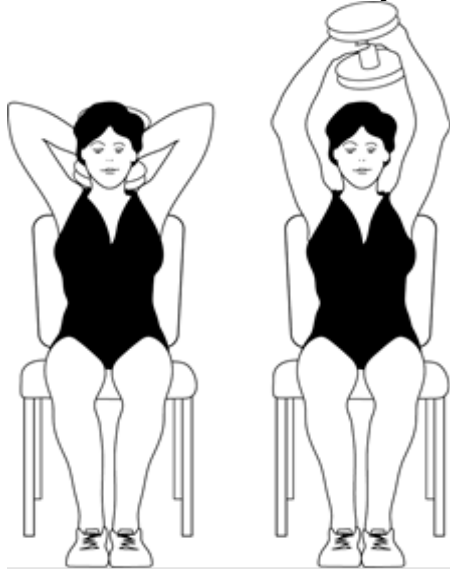
Horizontal Row

Sit on the floor with your back straight. Place your band around your feet at the halfway point on the band, so the sides are even. Pull the band towards your chest. Squeeze your shoulder blades together. Slowly release the band back to the start. Repeat.



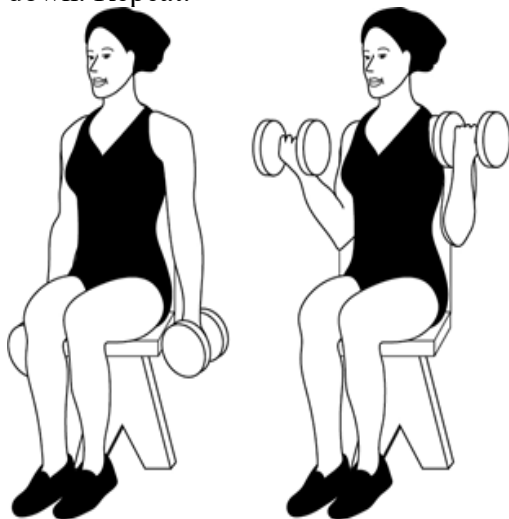
Triceps Extension

This movement can be done with a band or light weights. Squeeze your arms up so they line up with your ears and bring them back down to the start. If you are using a band, make sure it is secure before you begin.



Biceps Curl

Take a deep breath and exhale. Without changing your posture, curl the weights or band up to your shoulders and push back down. Repeat.



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 are not available to return the call up to 30 minutes from the first phone call attempt, the team will move on to 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.?
- Where will your support stay while they are in Madison?

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. You will be directed when you should come to the hospital. It is important to arrive when instructed. Your safety when traveling is important, so be careful on your way here. The transplant is often done within 1-2 days of the call.

The Organ Allocation Specialist will call you if an organ becomes available. You may be asked:

- To stop eating and drinking.
- To stop taking one or more of your medicines
- About your current health status.
- About your recent immunizations, illnesses, infections and medicines
- To come to UW Health **or** to keep a phone available, but to wait at home until you are called again.

It is very important that family and friends are involved in the planning process. Be sure they know that you need to be reachable at

all times. They should also know the plan for you to get to the hospital when you get the call. You will also need a plan to get home from the hospital since you will not be able to drive. 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 to lower your stress.

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

You need to be prepared when you get the call. This call can come anytime, day or night. Be sure your cell phone is on and ready to call in case of delay or questions (608-263-6400 or 1-800-323-8942).

Plan to bring these items:

<input type="checkbox"/> Copy of Advanced Directives/Health care power of attorney if it has changed
<input type="checkbox"/> All medicine bottles and list of medicines
<input type="checkbox"/> Form of payment for medicines at discharge
<input type="checkbox"/> Name of local pharmacy
<input type="checkbox"/> Loose clothing (sweatpants or something with elastic or drawstring waist bands), T-shirts, socks and supportive shoes for walking and therapy.
<input type="checkbox"/> If you use them, bring your glasses, hearing aids, dentures, CPAP machines/mask, blood pressure cuff, diabetes supplies
<input type="checkbox"/> Personal comfort items (electronic devices, phone, chargers, and blanket or pillow)

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

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, including biopsies and hospital stays.
- 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 directed.
- Follow the diet and exercise plan advised by your doctor.
- Go to your clinic visits.
- Get your labs drawn.
- Continue to live a healthy lifestyle by avoiding alcohol, smoking, and non-prescription drugs.
- Follow up primary care doctor for routine health maintenance.

Appointments

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, tissue samples are taken from the kidney. 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.



Primary Care Visits

You must have a primary care provider to address routine health issues. This might include diabetes, minor infections and illnesses, and regular health maintenance. Plan to see them shortly after your transplant.

We want you to live a healthy life after transplant. We will work closely with your primary care provider to give you the best care. We work together to advise you about your diet, exercise, and other health needs. The Transplant Team will manage your transplant medicines and address any transplant issues.

Types of Medicine After Transplant

You will need to know what medicines you are taking, why you are taking them, and the dose prescribed for you. Some of your medicines may need to be taken at the same time every day. Not taking your medicines correctly can lead to rejection and other health problems.



Immunosuppressive Medicines (Anti-rejection)

Medicines that suppress the immune system are called immunosuppressants. They are also called anti-rejection medicines because they are used to prevent rejection of new organs. All transplant patients will take anti-rejection medicines for the **rest of their lives**. There are many different kinds. Each works in its own way. Often, you will be on more than one kind of anti-rejection medicine. Your doctor will decide which ones you will need. You will need to take these many times a day.

These may include:

- Prednisone (corticosteroids)
- Tacrolimus (Prograf[®], Astagraf XL[®], Envarsus XR[®])

- Cyclosporine (Neoral[®], Gengraf[®], or other generic brand)
- Mycophenolate (Myfortic[®] or Cellcept[®])

Anti-infection Medicines

Anti-infection medicines are used to prevent common infections that can occur after transplant. You may need other medicines too based on the type of donor. You may need medicines to prevent:

- Bacterial infections of the bladder and lung.
- Viral infections such as Cytomegalovirus (CMV) or herpes (cold sores).
- Fungal infections

Most patients take other medicines to prevent stomach ulcers, control blood pressure and cholesterol, and supplements to support your bones and general health. You may also develop diabetes from the transplant medicines and need insulin or other medicines to manage blood sugar levels.

Some of these medicines are temporary but many are life-long. You may need opioid pain medicines right after surgery. You will not be able to take NSAID medicine after transplant.

Vaccines

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

The list below includes general guidelines. Your situation may be different. Other vaccines may be required. Your providers will discuss these with you on an individual

basis. **Always talk with your coordinator before getting any vaccines.**

Vaccines Recommended Before and After Transplant

- Inactivated influenza, injected
- COVID-19 boosters
- Hepatitis B
- Hepatitis A
- Diphtheria/Tetanus/ Pertussis (Tdap, DTaP, Td or DT)
- Polio, Inactivated
- Pneumococcal polysaccharide or conjugate
- Human papillomavirus (HPV) (for ages 9-26)
- Varicella zoster (Shingrix®)

Vaccines NOT Recommended After Transplant

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

Other Vaccines to Discuss With Your Provider

- Quadrivalent meningococcal conjugate or polysaccharide
- Haemophilus influenzae type b
- Travel vaccines

Health Concerns After Surgery

After transplant, people can live a healthy life. The main issues are the **increased risks of infection and rejection**. You are also at higher risk for cancer, especially skin cancer, after transplant.

To prevent infections, 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 (problems with your bones) can occur. Many of these health concerns can be treated by your primary care provider. 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. 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. When you are ready to return to work depends on the type of work you do. Talk with your transplant team about returning to work. We will

complete medical leave paperwork for your job if needed.

Coping After Transplant

During the transplant process, it is common to feel anxious, depressed, or frustrated. Stress can cause these feelings and so can your medicines. Talk with someone about your feelings. The transplant team is here to support you. If you want to see a mental health provider you can contact your primary care provider or insurance company. Sharing your feelings with your loved ones and others may also be helpful. There may be support groups for transplant recipients available. You can ask your social worker for resources. The resources below may also be helpful.

Depression

<http://www.helpstartshere.org/mind-and-spirit/depression>

Anxiety

<http://www.helpstartshere.org/mind-and-spirit/anxiety/about-anxiety-disorders.html>

Coping Emotionally after an Organ Transplant

<http://www.webmd.com/a-to-z-guides/life-after-transplant-coping-emotionally>

Guided Imagery

<https://www.healthjourneys.com/>

Mindfulness Meditation

<https://www.mindfulnesscds.com/>

Mindful meditation may reduce reactions to stress.

Support People

The transplant process can be very tough for support people. Many support people have anxiety during the process. It is important for support people to take care of themselves during this time.

Keeping Support People Updated

It is a good idea to choose one person as the primary contact. This person can update other family members and friends about your status. Make sure the transplant team has that person's contact information.

Staying Prepared

Make sure your transplant team knows how to reach you. Contact your transplant coordinator if contact numbers change for you or your support persons.



Have your support persons in place. This is often a family member or close friend. Choose 2 people you feel close with who have the time, health and flexibility to be your caregiver. Your support person must be an adult.



Allow others to help you. Letting go of pride and your desire to be independent can be difficult. It is important though during the transplant process. 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 picking up a few things at the store, bringing a meal, or helping with outdoor or household chores. When you are back to full speed, you can do small favors in return if you choose.



Life preparations for surgery – This means completing advance directive forms. Transplant social workers can answer questions 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 in advance will make it easier for someone to take over for you at any time.

Arrange for your transportation needs to and from appointments and testing.



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.
- Review resources on the next page.
- 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. It can be 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.



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 ©4/2024. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#8141.

Helpful Resources

The resources below may be helpful for transplant patients and their families.

Kidney School

<https://www.kidneyschool.org/>

An online education program for people who want to learn how to manage and live with chronic kidney disease.

NKF Peers

<https://www.kidney.org/patients/peers>

Speak with a trained peer mentor who can share their experiences about dialysis, transplant or living kidney donation with you

National Kidney Foundation

<http://www.kidney.org/> and

<http://www.kidneywi.org/>

A nonprofit health organization dedicated to preventing kidney and urinary tract diseases, improving the health and well-being of individuals and families affected by kidney disease and increasing the availability of all organs for transplantation

Know Your Rights

<https://autisticadvocacy.org/policy/toolkits/organs/>

Information to end discrimination in organ transplant.

Scientific Registry of Transplant Recipients

<http://www.srtr.org>

Data on national, regional and center-specific success rates.

Transplant Living

<http://www.transplantliving.org>

A patient education site developed by UNOS. Information on support groups and the costs of transplant can be found here.

UNOS

<http://www.unos.org>

United Network for Organ Sharing (UNOS) is the private, non-profit organization that manages the nation's organ transplant system.

UW Health Transplant

<https://www.uwhealth.org/transplant/transplant/10355> or scan the QR code below. Meet your transplant team, read patient stories, watch educational videos, and more.

Information about mentor programs



Who and When to Call

Transplant Nurse Coordinator

Call:

- If you are hospitalized or receive a blood transfusion
- When you finish the required evaluation tests

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
- 608-263-1384

Social Worker

Call for:

- **Change in support person plan**

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
- 608-263-1384

Financial Counselor

Call for:

- Change in insurance

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
 - 608-263-8770
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