



Health Facts for You



**Your child's
kidney transplant
evaluation**

Welcome to the UW Health Kidney Transplant Program. The team takes pride in building a care plan tailored to your child's needs. We are committed to their success. UW Health is a national and international leader in the field of transplantation. Our program provides care for both adults and children. We offer both deceased and living donor transplantation.

The Kidney

Knowing how the kidneys work will help you understand the transplant process.

What do the kidneys do?

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

What are the options if my child's kidneys stop working?

- Dialysis (peritoneal or hemodialysis)
- Transplant (living donor or deceased donor)
- Manage with medicines

After Your Child's Evaluation Testing

When your child's evaluation testing is done, the transplant team will meet to review results. There are three possible decisions:

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

You will be notified of the decision and next steps.

Where My Child's New Kidney Will Come From

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 liver 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. These patients may or may not be able to donate.

Transplant teams are on site when the life support is turned off. When the heart stops beating, the person is declared dead by the doctor. The transplant teams can then 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.

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

Your child 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. Your child will also be tested for HIV, Hepatitis B and Hepatitis C before 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 child’s transplant they 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 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 your child receives a kidney from a donor who has had hepatitis C, we will do tests to check for signs of this virus.

Organs from donors with an active hepatitis C infection can be safely used. This is because we now have medicines to treat this virus. 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, your child will not lose their place on the waiting list.

What will we be told about my child’s donor?

Privacy laws limit how much we can tell you about your child’s 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) tells the UW Transplant team 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. The donor's evaluation and screening results may impact your child's 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 of 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 your child.

Waiting for Your Child's Transplant

The Waitlist

The United Network for Organ Sharing (UNOS) manages the waiting list. They match donor organs to recipients, 24 hours a day, 365 days a year. The factors that impact your child's place on the list include:

- 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.

Multiple Listings and Transferring of Waiting Time

Multiple listing is when your child is listed for transplant at two (2) or more transplant centers. Multiple listing can increase your child's chances of getting an organ offer. It does not assure a shorter wait time.

UW Health allows multiple listing. Your child needs an evaluation at each transplant center. Each transplant center then decides whether to accept your child on their waiting list. You should check with your insurance to see if they cover more than one evaluation. Keep your child's health information and contact information updated at each transplant center where you are listed.

Many things affect wait times 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 child's transplant care will be done at the center where the transplant happens. To learn more about multiple listing or transferring waiting times, contact the transplant center where your child is 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 child's transplant may take many months or years or may happen very quickly. Your child may go through many health changes during this time. It is vital to keep the transplant team informed of any changes in your child's health status.

Examples of things that you should call about include:

- Taking antibiotics or having an active infection.
- Getting a blood transfusion.
- Being hospitalized.
- Having a change in insurance coverage.
- Changes in contact information (such as phone number or address).
- Changes in your child's support person or plan.
- Planning to travel away from home.

The transplant team needs to be up to date on this information. This will help to ensure that your child is in the best condition for transplant. Some medicine changes or hospitalizations could change your child's status on the waitlist. It is vital that you contact the team with any health changes.

Re-evaluation While Waiting for Transplant

To stay active on the UNOS waiting list, some of your child's medical tests will need to be updated on a regular basis. Most of these tests will be done at American Family Children's Hospital, but if they can be done locally, we will help arrange this. Your coordinator will give you the proper orders. We expect that the tests will be done quickly. We want your child to be ready if an organ becomes available. If these tests are not done, your child may be made inactive on the waitlist until they are done.

We require that all patients go through a formal re-evaluation every 1-2 years while

on the waiting list. Patients come to American Family Children's Hospital for this re-evaluation visit. The transplant doctor does a physical exam, reviews records, and discusses any new issues that might affect your child's ability to have the transplant.

Our goal is that when an organ becomes available, your child will be ready. Knowing about changes in your child's health ahead of time helps to assure us that it is safe for your child to have surgery when the time comes.

Waiting on the transplant list can be stressful. Be sure that you talk with your support people about your child's appointments, health status, and plans.

Getting the Call

When your child is on the deceased donor waiting 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 with an organ offer and you are not available to return the call within one hour, 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 American Family Children's Hospital?
- Who will come with you and your child?
- Who will take care of things at home while you are in the hospital, such as your other 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 becomes available. You will be asked:

- To have your child stop eating and drinking.
- About your child's current health status.
- To come to American Family Children's Hospital **OR** keep a phone 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 they know that you need to be reachable at all times. They should also know the plan for you to bring your child to the hospital when you get the call. You will need to make plans for the care of your pets, other children, work duties, and other responsibilities ahead of time. Being prepared will help to lower your stress.

What to Bring to the Hospital

You need to be prepared when you get the call. This call can come anytime, day or night.

You should plan to bring these items:

- Cell phone on and ready to call in case of delay or questions (**608-263-6400** or **1-800-323-8942**); bring phone charger
- **All** medicine bottles and list of medicines
- Insurance/Medicare/Medicaid cards
- Contact information for your child's pediatrician or primary care physician (family doctor)
- Local pharmacy phone number
- **Not** a lot of money/credit cards (just enough to pay for 1 month's supply of medicines after discharge)
- **Special toys, security/comfort items for your child**
- Loose fitting clothing for your child, socks, shoes or slippers that cover the feet
- Personal toiletries or comfort items (hygiene or entertainment related)
- Blood pressure cuff (if applicable)

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

Commitment to Follow-Up Care

Your child's care after a transplant is for their 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 child's transplant or about any new medicines or tests they have.
- Take all prescription medicines as directed.
- Follow the diet and exercise plan advised by your transplant doctor.
- Go to your child's clinic visits.
- Get your child's lab draws and biopsies.
- Talk with your child about not abusing their body by smoking, vaping, drinking alcohol, or using non-prescribed medicines (including those prescribed to someone else) 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 child's immune system attacks their new kidney. During a biopsy, pieces of tissue are taken from the inside of the kidney. If a biopsy is done because your child's kidney is not showing normal function, it may be somewhat urgent. You may need to make plans to come to American Family Children's Hospital without much warning.

After your child's transplant, they will be on many medicines. Your child will be on some of them for the rest of their life. This includes medicines which:

- Prevent rejection
- Prevent infections
- Control blood pressure
- Control cholesterol
- Prevent bone loss
- Provide extra vitamins and minerals

You will need to know what medicines your child is taking, why your child is taking them, and the dose prescribed. Not giving your child's medicines correctly can lead to rejection and other health problems.

Your child must have a local doctor to follow their care. Plan to see your child's local doctor shortly after transplant. We rely on the local doctor to address routine health issues. This might include well child visits, vaccinations, minor infections and illnesses, and regular health maintenance. We will work closely with your child's doctor to provide the best care. The Transplant Team will manage your child's transplant medicines and address any transplant issues. Follow the advice of your child's local doctor and the transplant team for diet, exercise, and other health needs. We want your child to live a healthy life after transplant.

Health Concerns After Surgery

After transplant, children can live a long, healthy, and productive life. The main issues are the **increased risks of infection and rejection**. To prevent infections, wash your hands and your child's 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. We will talk about when they can return to school.

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 child’s medicines to decrease their immune system further.

Activity Levels

Most children can go back to their normal activities relatively quickly. It will take some time to gain strength and endurance. Keeping up with an age-appropriate exercise routine after recovering from surgery is the best way to manage your child’s weight and improve your child’s well-being.

Going Back to School

We encourage children to return to school after having a transplant. Your child’s transplant team will talk with you about any activity restrictions and when to plan on return to school. The team will help you with return to school paperwork as needed and help to fill out any paperwork you may have.

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 child’s medicines. Talk with someone about how you or your child is feeling. The transplant team, your child’s nurse, child life staff, or social worker can help your child cope with these emotions. Sharing your feelings with your loved ones and others may also be helpful. Most areas have support groups for transplant recipients and loved ones.

Family Support

The transplant process can be very tough for family members. Many family members have anxiety during the process. Your social worker can help you find resources in your area. There are many things that can be done during this time to ease concerns. This includes:

- Talking about hopes and fears.
- Attending transplant support groups.
- Visiting a counselor.
- Being paired up with a mentor.
- Play therapy for your child.

Keeping Family Members Updated

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

Types of Medicine After Transplant

Immunosuppressive Medicines (Anti-rejection Drugs)

Immunosuppressants, also called “anti-rejection medicines,” block or suppress your immune system. They are used to prevent rejection of new organs. All transplant patients take these medicines for the **rest of their lives**. There are different kinds. Often, your child will be on more than one kind. Your child’s transplant doctor will decide which ones your child will need. Your child will need to take these multiple 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[®])
- Sirolimus (Rapamune[®])
- Everolimus (Zortress[®])
- Belatacept (Nulojix[®])
- Azathioprine (Imuran[®])

Anti-infection Medicines

Anti-infection medicines prevent common infections 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 CMV or herpes (cold sores).**
- **Fungal** infections.

Medicines to Reduce Stomach Acid

Most patients take medicines to reduce stomach acid. They also prevent stomach ulcers and reflux disease.

Supplements

These provide your child’s body with needed vitamins and minerals. Patients may take:

- Multivitamins
- Calcium
- Vitamin D

Other Medicines

Some children have high blood pressure after their transplant. They may need medicine to treat this.

Vaccines

Timing of when your child receives a vaccine can impact when they can receive a transplant. Your child must be screened for conditions or medicines that might make the vaccines unsafe because of their 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
- 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

Staying Healthy Before Transplant

Nutrition

Nutrition plays a key role in the transplant process. Eating well and being at a healthy weight may help your child recover faster after surgery. After surgery, your child's body needs enough nutrition to promote healing, fight and prevent infection, and gain back weight they may have lost. Transplant medicines can lower your child's appetite or change their sense of taste. In the long-term, good nutrition plays a key role in keeping your child healthy.

Staying Prepared

Make sure your child's transplant team knows how to reach you. Contact your child's 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 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.

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 transplant materials you are given including resources on the next page.
- Join a transplant support group in person or online.
- If you have questions, contact your transplant coordinator.

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

Guided Imagery

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

The use of relaxation and meditation to improve mood and physical well-being.

Know Your Rights

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

Information to end discrimination in organ transplant.

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 © 5/2022 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8246.

Mindfulness Meditation

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

Mindful meditation may reduce reactions to stress.

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>

Meet your transplant team, read patient stories, watch educational videos, and more. Information about mentor programs

UW Health Transplant Mentor Programs

<https://www.uwhealth.org/transplant/transplant-mentor-program/10615>