

## Waiting for Transplant

### *For a kidney/pancreas transplant*

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

### What is the wait list?

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



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

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

### How do I get on the list?

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

### How does the list work?

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

### Who gets the transplant?

Who gets the transplant depends on:

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

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

## **Where am I on the wait list?**

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

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

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

## How long will I wait?

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

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

## Can I be on more than 1 wait list?

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

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

## What to Do While Waiting

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

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

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

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

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

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

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

### **For Caregivers Who Wait**

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

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

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

### **Getting Called for Transplant**

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

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

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

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

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

When the coordinator calls you in for transplant:

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

After you receive this call:

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

## Have Your Bag Packed

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

Please also bring:

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

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

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

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

Do **not** bring:

- Jewelry
- Valuables

### Questions?

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

Transplant Services:  
206.598.3882