Waiting for Transplant
For a kidney/pancreas transplant

After you have completed your evaluation, you are ready to be added to the wait list. This chapter explains details about the wait list and things you can do until you get called in for your transplant.

What is the wait list?
The wait list for organ transplants is a national list managed by the United Network for Organ Sharing (UNOS). UNOS is a nonprofit, federally funded organization that maintains the transplant list for the entire country.

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

This list contains patient data on everyone in the United States who is waiting for a kidney, pancreas, or other organ.

How do I get on the list?
We will enter your specific 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 particular donor. The computer makes a list of patients who best match that kidney or pancreas. It also factors in wait time and sensitization (see definition at the bottom of this page).

Who will get the transplant depends on:

• Your blood and tissue type (HLA).
• How long you have been on the list.
• Your age – patients 18 years or older have priority.
• Whether or not you are sensitized. Being sensitized means you have antibodies in your blood that could fight against many potential organ donors. If you are sensitized, you could have a harder time finding a kidney or pancreas that your body will accept. Because of this, you will be given a slight advantage on the wait list over those who are not sensitized.
Where am I on the wait list?

This is not an easy question to answer because there is not a ranking order on the list, such as being first, second, or third. Receiving a transplant depends on the type of donor available. Organs and transplant recipients are matched based on both medical compatibility and how long you have been on the list.

This means you may have waited longer than someone else on the list but will not get the next available kidney or pancreas because it matches best with someone else. It also means you could get transplanted 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 written notice.

How long will I wait?

Your transplant team can give you an “average” wait-list time based on your blood type. This estimate does not predict for certain how long your wait will be. Your waiting time may be affected by a number of factors that are explained in “Tissue Matching,” Chapter 5.

Can I be on more than 1 wait list?

Even though you are now on UWMC’s wait list, you may also choose to be listed at other transplant centers. Getting on a wait list at another center in the Seattle or Spokane area will not change your wait time, since all programs in these areas use the same list.

But, being listed with transplant programs in other areas of the U.S. may change your wait time. Check the United Network for Organ Sharing (UNOS) website at www.unos.org to see the wait times for different areas of the country. Listing with other programs may require that you go to these programs to be evaluated for transplant.

Things to Do While Waiting

- Call your transplant nurse coordinator at least once a year (perhaps on your birthday) or whenever there has been a major change in your health status or lifestyle. Also call if your insurance coverage changes.

- Keep your transplant coordinator updated on your contact phone numbers, address, health status (recent hospital stays or infections), financial status (including insurance changes) and when you plan to be out of town.

- Make your own planning checklist as a guide for what to monitor while you are on the waiting list.
• Have yearly medical checkups. These may include a cardiac stress test, heart evaluation, pap smear, mammogram, PSA screening test, and other tests that the transplant team has asked you to have.

**Tests I need at least yearly are:**

_____________________________________________________
_____________________________________________________
_____________________________________________________
_____________________________________________________
_____________________________________________________

• Keep monthly blood samples for deceased donor crossmatching current. 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. It is very important to do this. If the HLA lab does not have your current blood samples, you may miss a chance to have a transplant.

• Stick to the medical regimen you developed with your referring doctor. For example, attend dialysis, have regular doctor visits, and take your medications as prescribed. Also watch fluid gains and phosphorus levels. This will maintain your active status on the list.

**My regimen includes:**

_____________________________________________________
_____________________________________________________
_____________________________________________________
_____________________________________________________
_____________________________________________________
_____________________________________________________
_____________________________________________________

• Maintain a healthy lifestyle:
  - Eat healthy foods.
  - Get your 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.

**My goals to maintain or improve my health are:**

- Learn more about kidney or kidney/pancreas transplantation. Ask questions. Read the handouts you receive. See “Resources,” Chapter 17.
- 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.

**My prescription insurance plan:**

- I will get my prescriptions filled at:

- Assess your insurance coverage and personal finances. Learn about all the costs of having a transplant. Find out the details about what your plan covers, including how your plan works when you are outside of 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.

**My plan for travel to Seattle:**

**My plan for housing in Seattle:**
• **You will need a support system in Seattle.** If you are from out of town, make plans for family and friends to *stay with you* or *live near you*. Ask our staff for help, if needed. Of course, if you are from Seattle, you will still need a plan for support if and when you have your transplant.

• Be ready when you are called in for transplant. Be prepared if it happens quickly, and be prepared to cope with the wait if it takes longer. Ask for help if you need help coping while you wait.

**Getting Called for Transplant**

You will be called when an organ is available for 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 at ALL times. Even if you are out of town, at a party, or at a conference, **we must be able to reach you**.

If there is someone who will always know where you are, give us that contact number as well. We have lots of stories about patients who could not be reached. 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 have been called in as a primary or back-up recipient. We will tell you of the plan as soon as the cross-match results are final.

Once you are called to come in:

• Do **NOT** eat or drink anything, unless instructed otherwise. Your stomach needs to be as empty as possible when you have surgery.

• If you have diabetes and take insulin, and you are told not to eat, take only ½ of the insulin you would usually take. Also, ask the coordinator who has called you if you should take a different amount instead. The amount of insulin you should take will depend on the expected time of your surgery.

• Get to the hospital quickly and safely. You may feel excited and afraid at the same time.
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 *Guide to Your Kidney/Pancreas Transplant*
- Your UWMC clinic card
- Information about your insurance plan
- Photo identification
- A list of emergency contact phone numbers
- All your medicines
- An extra exchange (if you are on peritoneal dialysis)
- Reading glasses, if needed

We also recommend you bring these items with you to the hospital, to make sure they are working properly:

- A blood pressure cuff
- A thermometer
- A blood glucose meter, if you use one

Do **not** bring:

- Jewelry
- Valuables

If you think you will need money, bring credit cards and photo identification. You can ask the Admitting Office or the admitting nurse to put these items in the hospital safe.