



Health Facts for You



Your kidney and pancreas
transplant evaluation

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

After Your Evaluation Testing

When your evaluation testing is done, the transplant team will meet to review 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 additional testing or information to make the decision.

You will be notified of the decision and next steps.

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)

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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.

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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.

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 still 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 require dialysis for a short time after their transplant. Up to 30% of deceased-donor kidneys and 5% of living donor kidneys may have some degree of DGF.

How do I know I have DGF?

With DGF, your new kidney may make little or no urine. Kidney labs (creatinine) remain high in your blood tests. During this time, if you were on dialysis before the transplant, you will continue to need dialysis. Usually 3 times per week. If you were not on dialysis before your transplant, your old kidneys will still make urine. The transplanted kidney will not be able to clear the wastes from your blood. You may have to be placed on dialysis for a short time. This is to clear the

wastes from the blood until the new kidney starts to work properly.

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 will have to follow salt, potassium, phosphorous, and water restrictions. It is like the plan you were following before the transplant. 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. Also, changes in your diet, fluid intake, and diuretics may be needed.

Will my kidney recover from DGF?

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

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 have to limit your fluid intake just like when you were on dialysis before your transplant. You should also limit salt, phosphorous and potassium in your diet. This is called a renal 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. Most often, it will be cared for by nurses in the Transplant Clinic.

Delayed Graft Function (DGF) Clinic

The DGF Clinic is set up so that we can follow you closely. You do not have to stay in the hospital until your DGF improves. If you live close to UW Health (less than about 50 miles) you can be discharged from the hospital and go home. If you live far away from UW Health (greater than about 50 miles), you will likely stay in a hotel close to the hospital. 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. If you stay in a hotel the cost will be covered by UW Health.

You will return to the Delayed Graft Function (DGF) Clinic three times a week for labs, dialysis and clinic appointments with transplant nephrology. This is to closely follow your kidney function and fluid status.

Sometimes you may have to return for an extra visit. You will have labs drawn here in the outpatient lab before each clinic visit. After your clinic visit, it will be decided if you need dialysis on that day. If you need dialysis, this can be done in our dialysis unit at the hospital. We will also decide if your anti-rejection, blood pressure, and anemia medicines need to be changed. You will also have a clinic visit with your transplant surgeon about 2 weeks after discharge. 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.

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 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.
- 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 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 on the waiting list or waiting for living kidney donor. Patients come to the UW Health for this re-evaluation visit. The doctor 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.

Caring for Yourself While Waiting

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.

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 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 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 becomes available. You will be asked:

- To stop eating and drinking.
- About your current health status.

- To come to UW Health **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 be brought to the hospital when you get the call. 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.

What to Bring to the Hospital

You need to 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, 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.

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 directed.
- Follow the diet and exercise plan advised by your doctor.
- Go to your clinic visits.
- Get your 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. 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. This might include 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 transplant issues. 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, 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. 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.

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, your nurse, or social worker can help you cope with these emotions. The transplant team can help to find a mental health provider close to home to help you during this stressful time. 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.
- Discussing your wishes about advance directives.
- Attending transplant support groups.
- Visiting a counselor.
- Being paired up with a mentor.

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 status. Make sure the transplant team has that person’s contact information.

Financial Planning

Understanding Your Insurance Plan

You will need to learn more about your insurance plan. A person who gets a transplant needs life-long follow-up care and medicines. Learn about your co-pays and deductibles for clinic visits and tests. This will help you budget for this expense.

Many plans have a yearly maximum for co-pays or deductibles. When you have reached the limit, your insurance may pay 100%. Refer to your insurance booklet and keep track of your healthcare expenses.

Contact your insurance company. Ask about your lifetime and transplant maximums. You may need secondary coverage or other ways to pay for expenses. Once you reach the limit, insurance will not cover more. Transplant patients often reach their limit.

Know the referral guidelines of your health plan. UW Health is a hospital-based clinic. You will get bills from the hospital and the doctors. If guidelines aren't followed, you may need to pay for the bill.

You may need to stay in Madison for some time after your transplant. Most insurance plans require prescriptions to be filled at certain pharmacies. Know your preferred pharmacy in your hometown and in Madison.

Common Financial Questions

Below are some common questions which other transplant patients have found helpful.

- My lifetime insurance maximum is: \$ _____
- What would be my monthly total co-pay be if prescribed 15 medicines? 15 x \$ _____ (the co-pay amount per prescription) = \$ _____
- What are the co-pays and deductibles for clinic visits and procedures? What do I need to pay out-of-pocket? Monthly clinic and procedure co-pays: \$ _____
- How would this expense fit into my budget?
- How will I get coverage if I reach my lifetime maximum?
- What would I do if my insurance was changed? (Notify your coordinator right away!)
- My health plan referral guidelines:

Other Coverage Options

Your social worker will talk with you about eligibility for government programs. Always notify your transplant team of any current or future insurance changes or updates.

“Find health and drug plans”) or call your plan.

Part D covers some medicines. If you did not have Medicare at the time of transplant, it may pay for your anti-rejection medicines. Premiums vary by plan. You can explore options at www.medicare.gov.

Questions to Ask

Medicare is complex. Your transplant social worker and transplant financial counselors can help answer your questions. Here are some examples:

1. What is my co-pay for anti-rejection medicines? (covered under Part B, not under Part D)
2. Is my benefit affected by in-network vs out-of-network pharmacies? Can I use a local retail pharmacy? Am I restricted to a mail order pharmacy? Does this impact the cost?
3. How much is my deductible? How much are my co-pays and yearly out of pocket maximums? How much will I have to pay for medicines during the year?
4. When will my eligibility start?
5. What if I have an employer group health plan?
6. What if I have COBRA?
7. Can I be denied Medicare coverage?

After Signing Up for Medicare

After sending in your application, you should get a card from the Social Security Administration within 8 weeks. If you have not received a card by that time, contact the Social Security Administration.

When you get your card, call UW Health Registration **(608) 261-1600** to update your information. You should also call your Transplant social worker. **Always notify your transplant team of any current or future insurance changes or updates.**

Types of Medicine After Transplant

Immunosuppressive Medicines (Anti-rejection Drugs)

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[®])
- Sirolimus (Rapamune[®])
- Everolimus (Zortress[®])
- Belatacept (Nulojix[®])
- Azathioprine (Imuran[®])

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 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. These include:

- Omeprazole (Prilosec[®])
- Pantoprazole (Protonix[®])
- Ranitidine (Zantac[®])
- Famotidine (Pepcid[®])

Supplements

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

- Multivitamins
- Calcium
- Vitamin D

Aspirin

This prevents blood clots and decreases the risk of heart problems.

Docusate with Senna

This prevents constipation and helps your bowels move. You do not need this when your bowels are moving well.

Other Medicines

Many patients have high blood pressure after their transplant. You may require medicine to treat this. Sometimes transplant patients get diabetes after their transplant. You may need insulin or other medicines to manage blood sugar levels. You may need narcotic pain medicines right after the transplant. We will send you home with these. They should last until your first clinic visit.

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. **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 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. Transplant medicines can lower your appetite or change your sense of taste. 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, 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.

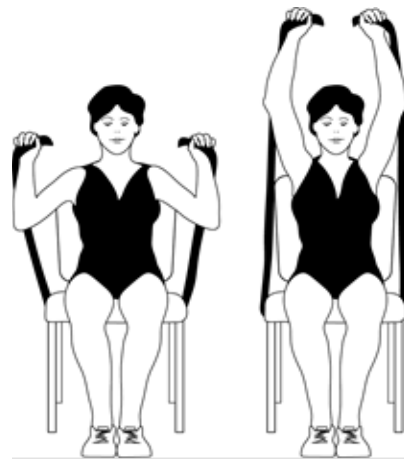
Improve Your Strength with Exercises

You can improve your strength if you add daily 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. They can help set it up.

There are exercises you can do at home even if you have physical limitations. 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.

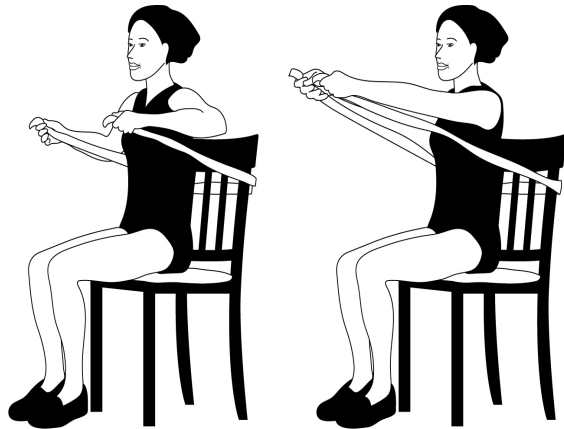
Overhead Press

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.



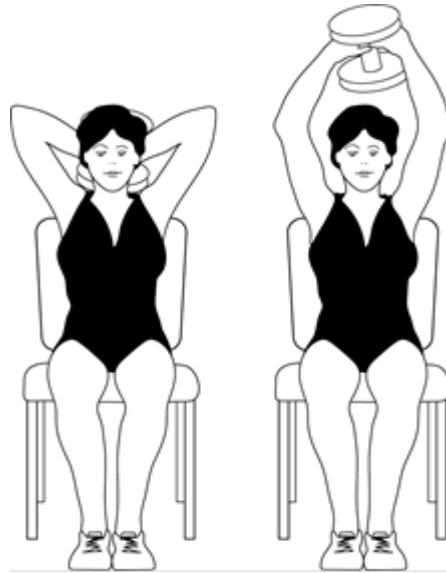
Seated Press

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.



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.



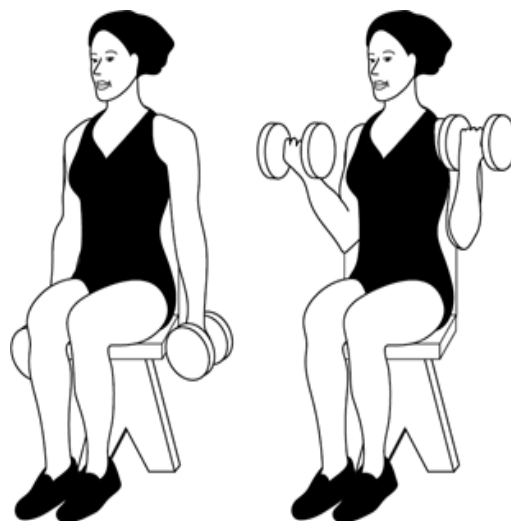
Horizontal Row

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.



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.



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 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.

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.

Organize personal affairs. 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.

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.

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>

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#8141.