



A BRIEF SUMMARY

What You Should Know About Kidney and Pancreas Transplants



MICHIGAN MEDICINE
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TRANSPLANT CENTER



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For detailed information please refer to the Kidney and Pancreas Transplant Program Patient Education Guide.

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How do Kidney Transplants Work?

All kidneys available for transplant are a result of a gift (donation) from one person (donor) to another (recipient). Kidneys can come from either living or deceased donors. In order to receive a kidney transplant, you will need to complete an evaluation. You will need to be considered a good medical and surgical candidate with mental wellness.

- Your transplanted kidney will be placed in your pelvic area above the groin (the groin is where the thigh meets the stomach).
- Original kidneys normally stay in the body.
- The incision for kidney transplant is approximately four to 12 inches long. It is located on the lower left or right side of the stomach.
- The process is usually between two and four hours long.

After the transplanted kidney is connected to your blood supply, living donor kidneys usually begin to make urine. A deceased donor kidney can take some time before it makes urine. The transplanted ureter (the tube that carries urine from the kidney to the bladder) is attached to your bladder. As the new kidney begins to work on filtering waste products from your body, you will begin to feel better.

What is Living Kidney Donation?

A living kidney donation is a kidney from a living donor. Some advantages to receiving a living kidney transplant include:

- You do not have to wait as long for a transplant.
- Living donor transplants last longer than transplants from deceased donors.
- You have the chance to receive a transplant before debilitating complications of kidney disease.
- You receive transplant before becoming too ill to have a transplant.



Who are Living Donors?

Living donors may be related or unrelated to you. People who wish to be considered as a living kidney donor must contact the transplant center to show their interest. A donor coordinator will review the process with the interested donor before setting up an evaluation appointment.

How are the Kidney Donors Evaluated?

The donor team is very careful and thorough when deciding if a person can donate. The donor team will not allow donation if they feel that it is not medically safe for the living donor. If a living donor develops end stage renal disease (ESRD) and needs a kidney transplant sometime in the future, the living donor will be put close to the top of the waiting list.

What is Paired Donation?

Paired kidney donation is an opportunity to provide you with a transplant when you do not match your potential donor (either by blood type or positive cross match). This program identifies pairs: where the donor from one pair donates his/her kidney to the recipient of the second pair and vice versa.

How Do Pancreas Transplants Work?

Pancreas transplants are usually performed on people with Type 1 diabetes mellitus so that complications can be avoided, halted or delayed. However, some people with Type 2 diabetes can receive pancreas transplants. Pancreas transplant can be performed in one of three different ways depending on your needs. These include:

- **Simultaneous Pancreas Kidney Transplant (SPK)**

This includes kidney and pancreas transplants occurring during one operation. This option is selected when you have Type 1 diabetes mellitus and are at or near end stage renal (kidney) failure.

- **Pancreas After Kidney (PAK)**

This transplant is done after you have already had a successful kidney transplant. You must be stable and at least three months after your kidney transplant.

- **Pancreas Transplant Alone (PTA)**

Patients who receive PTA do not have kidney disease. This is done when you have Type one diabetes mellitus with life threatening high or low blood sugar that does not respond to maximum medical management and insulin therapy.

What Happens During the Pre-transplant Evaluation Appointment?

The pre-transplant evaluation appointment will take a full day, around eight hours. The appointment has 3 parts: meetings with several doctors and other members of the transplant team, education and testing.



Meetings With Your Health Care Team

During this first evaluation appointment, you will see a transplant coordinator, a physician assistant or nurse practitioner, a transplant nephrologist (kidney doctor), a transplant surgeon, a social worker, a registered nurse and a dietitian.

Education

On the day of the evaluation, you and your family will attend a patient education class with other potential kidney or pancreas recipients. We urge you to bring a support person to be with you throughout the evaluation day to take notes and ask questions.

Testing

Testing is done in order to determine if you are an appropriate candidate for transplant. Many times, all of the initial testing can be completed on the day of the evaluation. Further testing might be needed depending on your medical history. Testing includes:

- A complete history and physical.
- Complete blood work, blood chemistry, counts, type and immune system functions.
- A chest X-ray to determine the health of your lungs and respiratory track.
- An electrocardiogram (EKG) to check the electrical activity of your heart, with some further testing of the heart to follow.

Evaluation Decision

After all the test results are completed, the transplant team will meet to discuss whether transplant is an appropriate treatment option for you. It is important to remember that you are not listed for transplant at the end of your evaluation appointment. You will be notified the following week about the decision and if any additional testing is required for listing.

How Can I Remain a Good Candidate for Transplant?

Medication and Dialysis

It is important to be organized about your medications and understand why you are taking them. Transplant medicines must be taken on a strict time schedule, so you must get on a regular schedule with your current medicines.

Follow your dialysis treatment schedule as prescribed to maintain your best health. Attending all treatments and staying for your whole treatment is very important to stay as healthy as you can until you have the opportunity for transplant.

Social Support and Caregivers

As part of being a candidate for transplant, you need to have family or friends to look after you during your recovery. You will work with your transplant social worker to complete a Care and Support Plan. This plan includes individuals identified as:

- On-call driver – 24/7
- Support person during hospital stay
- In-home support person after surgery
- Driver to weekly clinic appointments

Drugs and Alcohol

People who are candidates for transplant are recommended to stop smoking and using smokeless tobacco products before transplant and to continue to refrain from tobacco products after transplant. Alcohol and illegal street drugs can cause serious health problems for transplant recipients. People who have significant substance abuse issues will need to work with the transplant social worker to create an appropriate treatment plan. Insurance companies may deny coverage for your transplant if there is evidence of untreated alcohol or substance abuse (past or present).

Mental Health and Transplant

Kidney transplant recipients are prescribed medicine that may cause mood changes for a short time. If you are a person who is dealing with depression, anxiety or other mental health issues, the transplant team will discuss a plan for managing your symptoms. This plan may include counseling or seeing a psychiatrist.

Staying emotionally healthy is very important. Our transplant social workers are trained to help patients and their loved ones cope with the challenges of long-lasting (chronic) illness and the specific challenges of kidney transplant patients. Remember to:

- Share your feelings with your family, friends and your dialysis or transplant team.
- Ask to be connected to a transplant peer mentor to learn about life after transplant.
- Stay involved in the activities you enjoy. Keep your life as normal as possible to help maintain stability during the waiting period.
- Find activities that help you relax and promote your spiritual well-being.

How Do I Remain Active on the Waiting List?

To remain active on the waiting list, you must keep up with the listing requirements which include:

- Yearly follow up visits with the transplant team (twice a year for patients over 70)
- Sending in your monthly blood sample
- If you have diabetes, yearly heart evaluation is required.
- If you are a female and over the age of 18, we strongly recommend yearly gynecologic clearance done by your local doctor.
- Active insurance coverage and prescription coverage



What Happens if I Do Not Keep Up With the Listing Requirements?

If you do not meet the above requirements, you will be placed “on hold.” People on hold cannot receive donated organs, but will stay on the transplant list. It is in your best interest to keep your testing current when listed. It is your responsibility to make sure testing is completed and results are sent to our office. You should contact your transplant coordinator to review your results.

How Do I Stay Healthy While Waiting for my Transplant?

While waiting for your transplant, we encourage you to stay as healthy as possible, physically and emotionally.

- Follow your recommended diet.
 - A transplant dietitian is available to help you if you have questions regarding what you should be eating or if you have been asked to lose weight.

- Stay active (At least 150 minutes of movement weekly).
- Quit smoking if you are a smoker.
- Women should avoid pregnancy.
- Talk to your transplant coordinator if you have any questions about maintaining a healthy lifestyle.

Who Do I Call if My Health Changes Before Transplant?

When your health changes occur while waiting for a transplant, it is very important to remain in contact with your transplant coordinator.

Pre-Transplant Kidney and Pancreas Coordinators (800) 333-9013 Monday-Friday, 8 a.m. - 5 p.m.

Call your coordinator if:

- You are hospitalized outside of Michigan Medicine
- Your medical condition changes
- Your telephone number changes
- Your medical insurance changes
- You need to travel out of town
- You or your family have questions or concerns
- Your support people are no longer available
- Your dialysis center changes
- You have changes with your insurance coverage

What Happens When an Organ Becomes Available for You?

The call about an available organ can come at any time. The first notification comes to the transplant coordinator, who then has one hour to accept or decline the organ offer. When a kidney or pancreas becomes available, they need to be able to find you and review current information with the surgeon. To ensure the organ can be considered for you, take the following steps:

- Keep the transplant team informed about how to reach you (24 hours a day).

- Answer a page or call even if you don't recognize the number.
- If you plan to leave home for business or vacation, provide the transplant office with your destination so that we can contact you if an organ is available.
- It's important to realize that even after you arrive at the hospital, the transplant team may determine that the donor organ is not suitable.

You will have adequate time to travel to the hospital. Your travel time has been considered in the arrangements for the operation. Drive safely and wear a seat belt.

What Happens After My Transplant?

Contact Information:

If you have questions after discharge, please call our clinic during business hours at **800-333-9013**. After business hours, holidays and weekends, please call Hospital Paging at **(734) 936-6267** and ask for the transplant on-call physician.

Support Team

Having a support team with you at the time of your surgery is recommended in learning new medicines, adjusting to lifestyle changes and helping with transportation. After surgery, you will be required to have many blood draws for the first several months. We will also see you in clinic every week in the beginning until you are stable. Have a plan ready so that you are prepared to accomplish these things.

Medication Schedule

Transplant patients start taking many new medicines after surgery. You will learn about your medicines and begin taking them in the hospital according to a personalized schedule. It is very important to never stop taking your transplant medicines. Skipping or decreasing doses of any medicine may cause harm to your new kidney or pancreas. If you have problems paying or getting your medicines, please call the Transplant Center at **(800) 333-9013** so we can help you. Plan ahead so that you always have your transplant medicines when you need to take them.

What Medication Will I be Taking?

There are three classes of medicine that you will be taking:

- **Anti-rejection** - also called immunosuppressive, these weaken your immune system without eliminating it. Immediately after transplant, you will start taking a combination of anti-rejection medicines. *Tacrolimus*, *mycophenolate* and *prednisone* are most commonly used.

Each medicine works differently in the body to prevent rejection of the kidney or pancreas.

- **Anti-infective** - usually only taken for the first one to six months after transplant because you will be at high risk for infection due to having a decreased immune system. Since you take anti-rejection medicines that lower the resistance to fight infections, some medicines are given to help prevent infections.
- You may need to continue some medicines to treat your other medical conditions that are not related to kidney failure or start new medicines to treat the side effects of the anti-rejection medicines.

The success of your transplant depends on the proper use of the anti-rejection medicines.

You and your caregiver will be expected to pass a quiz on the medicines before being released from the hospital. For your prescriptions, remember to call your transplant nurse a week before they run out to get a refill.

Note:

- You must contact the transplant team before you take any prescription or over-the-counter medicine.
- Pregnancy after transplant is considered high risk. It increases the risk of rejection to your transplanted organ and also causes complications with the pregnancy.

Returning to Local Nephrologist/Primary Care Physician

The University of Michigan Transplant Center requires that all patients have a local nephrologist. Six months after transplant you will return to your local nephrologist and continue to see them on a regular basis. Having a strong relationship with your nephrologist allows us and them to keep you and your kidney healthy. It is also important that you have a primary care doctor who you should see for non-transplant issues.

Transplant Specialty Pharmacy

The Transplant Specialty Pharmacy is dedicated to serving only transplant patients. The pharmacy staff have ongoing and timely access to their medicines. For questions about the pharmacy, call **(866) 946-7695**.

Diet and Food Safety After Transplant

After transplant, you will take immunosuppressant (anti-rejection) medicine. The suppression of the immune system makes it difficult to fight off infection. Your risk is highest one to six

months after transplant. Food can cause an infection if proper food safety guidelines are not followed. Your diet after kidney transplant will be different than before your transplant.

- Continue to limit salty foods.
- Drink two liters of water, eat six to eight ounces of protein, and eat four to five servings of fruits and vegetables daily.
- Avoid eating undercooked meat, fish and eggs.
- Avoid salad bars and buffets. The transplant dietitian is available to help you meet diet needs.

How Do I Plan for the Cost of My Transplant?

Transplant is an expensive treatment. Throughout the process, a transplant financial coordinator will work with you on coverage, insurance and financial issues. They may help you in many areas including:

- Determining your current coverage
- Identifying additional coverage you may need
- Making sure an authorization is in place for your transplant
- Providing the documentation necessary to allow you to apply for End Stage Renal Disease (ESRD) Medicare after your transplant (if you didn't have Medicare before transplantation)
- Providing resources such as the National Kidney Foundation, the American Kidney Fund and Help Hope Live

Planning for Your Financial Obligations

There are many phases of transplant, with each having a different level of coverage. There may be maximum allowable limits or exclusions for certain services. To help you through this process, your financial coordinator will contact your insurance company. Having a financial plan is the key to minimizing the financial strain and stress to you and your family as you go through the transplant process.

Once it has been determined what your insurance covers, you will have a better understanding of the out-of-pocket medical expenses you should expect. In addition, you may need to pay for other expenses often considered “non-medical.” If your insurance changes while you are on the transplant list, it is important to call the transplant financial coordinator to report the change. Many patients will also need to take an antiviral medicine called Valcyte® for three to six months following transplant. Your transplant coordinator will verify your co-pay before your transplant.

Medicare Coverage

Medicare health insurance is for:

- People age 65 and older
- People of any age with a disability: Inability to work for 24 months
- People of any age with End Stage Renal Disease (ESRD): Being on dialysis or kidney transplant



If you have Medicare only for End Stage Renal Disease (ESRD), coverage will end three years after a successful transplant. If you are uncertain about qualification, you should call **(800) 772-1213** or go to **www.medicare.gov** for more information.

Inpatient Hospital Stay- Medicare Part A

Medicare Part A covers your inpatient hospital stay and all costs associated with it.

- Medicare Part A is free but has a deductible.
- If you have primary coverage through an employer, Medicare Part A covers costs that your primary insurance doesn't during your hospital stay. Medicare then becomes your secondary coverage.

Doctor Bills and Outpatient Medical Expenses

- Medicare Part B will cover 80 percent of all inpatient and outpatient doctor bills and 80 percent of outpatient medical expenses (if Medicare is primary).
- Part B also covers 80 percent of your anti-rejection medicines as long as you have Medicare the month you receive your transplant.
- Medicare Part B can help you pay for prescription co-pay, annual deductibles and cost shares that you may otherwise need to pay.
- There is a monthly premium for Part B coverage.
- To avoid penalties or higher premiums, it's important to enroll in Part B at the same time as Part A.

Prescriptions

- Medicare Part D helps with coverage for your prescriptions.
- You can enroll in Medicare Part D three months before and after the effective date when you are first approved for Medicare coverage or during the open enrollment period.
- If you have group prescription coverage, you do not need to enroll in Part D.
- Monthly premiums can range from \$25 to \$60 plus co-pay amounts that you need to pay.
- Once you've totaled a certain amount of prescription costs, there is a period known as the "donut hole" where you will need to pay 100 percent of your prescriptions covered by Medicare. Once you reach the out-of-pocket maximum, you will then have catastrophic coverage where Plan D covers at 95 percent.
- Premiums, co-pays and out-of-pocket amounts change each year. You must be prepared to cover those out-of-pocket costs.

We recommend that you apply for the Extra Help benefits when applying for Medicare Part D. Learn more by calling **(800) 633-4227 (MEDICARE)**, contacting your local Social Security office or visiting **www.medicare.gov**. Extra Help benefits are based on your income and can greatly reduce your out-of-pocket cost.

If you are on Medicare Part A and B at the time of your transplant, Medicare Part B will pay for 80 percent of the anti-rejection (immunosuppressive). Part D only pays for non-immunosuppressive medicines.

If you are not on Medicare at the time of transplant, but get it later with Part D, then Part D would pay for both medicines. This is a very important point to understand about Medicare coverage for medicines. Please see the table below for additional explanation.

ON MEDICARE At the time of transplant	NOT ON MEDICARE At the time of transplant – Have Medicare coverage now
Anti-rejection drugs paid by: Medicare Part B and supplemental coverage	Anti-rejection drugs paid by: Medicare Part D or regular prescription coverage
Other medicines paid by: Medicare Part D or regular prescription coverage	Other medicines paid by: Medicare Part D or regular prescription coverage

Is Secondary Insurance Necessary?

Medicare coverage alone is not sufficient to cover the cost of transplant. If you have Medicare, you will need to apply for an additional policy to help cover the cost for the 20 percent Medicare will not pay. You must have Medicare Part A and B, because after 30 months Medicare becomes primary over the group health plan (if you had one). Your transplant financial coordinator is knowledgeable about Medicare coverage and is available to help you when making decisions about applying for Medicare.

Children Special Healthcare Services (CSHCS)

The CSHCS program is part of the Michigan Department of Public Health. It provides healthcare benefits to residents of Michigan under the age of 21 with qualifying chronic disease. Benefits may include transportation, lodging and payment of medical expenses, including transplant services. Contact your transplant social worker for more information and for help with the application process.

Are There Donation Costs for Living Kidney Donors?

Those who generously offer to be evaluated as kidney donors are not responsible for any medical bills for their donation work-up, surgery, prescriptions or follow-up care related to donation. Contact your transplant financial coordinator immediately if a donor mistakenly receives a bill.

Fundraising Opportunities

There are two main groups that we recommend our patients use to help in fundraising efforts.

- **Help Hope Live**
(800) 624-8399
www.helphopelive.org
- **National Foundation for Transplants (NFT)**
(800) 489-3863
www.transplants.org

United Network of Organ Sharing (UNOS)

The UNOS mission is to advance organ availability and transplantation by uniting and supporting its communities for the benefit of patients through education, technology and policy development.

UNOS Patient Service phone line, **(888)-894-6361**, can provide information about the Organ Procurement and Transplantation Network (OPTN) and UNOS allocation policy and other resources available to you. Additional information is available online at the following websites:

- **National Living Donor Assistance Center**
<https://www.livingdonorassistance.org/Home/default.aspx>
- **United Network for Organ Sharing (UNOS)**
<http://www.unos.org>
- **United Network for Organ Sharing Transplant Living**
<http://www.transplantliving.org>
- **U.S. Department of Health and Human Services Organ Procurement and Transplantation Network**
<http://optn.transplant.hrsa.gov>
- **Scientific Registry of Transplant Recipients (SRTR)**
<http://srtr.org>

Who Do I Contact if I Have Questions?

If you have any questions at any point during the kidney transplant process, please contact your transplant coordinator or the Transplant Call Center at **(800) 333-9013**.





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