



WHAT TO EXPECT

Your Kidney Transplant Journey

UPMC | HARRISBURG

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My kidney transplant coordinator is:

(Kidney Transplant Coordinator)

My Pre-transplant Educational Session took place on:

(Date)

Location: UPMC Harrisburg
717-231-8700
Telephone: **877-778-6110** Toll-Free
717-231-8753 Fax Number

Address: UPMC Harrisburg
205 South Front St.
Brady Building, 8th floor
Harrisburg, PA 17104

Website: **UPMCPinnacle.com/Transplant**

Office Hours: 7:30 a.m. to 4 p.m. / Monday through Friday

Holidays, evenings, and weekends:

For urgent issues, call **717-231-8700** or toll-free **877-778-6110**. The Medical Bureau of Harrisburg (an answering service) will answer your call. Ask to speak to the transplant coordinator on call.

IF YOU ARE HAVING A MEDICAL EMERGENCY, PLEASE CALL 911 FIRST!

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WELCOME

Welcome to UPMC Transplant Services in central Pa. Our team is here to help make your transplant experience a rewarding one. We will provide you with specific information about our transplant program, and answer any questions that you may have about transplantation.

Deciding to receive a transplant is a lifelong commitment. If you decide that transplant is the right treatment for you, we will provide you with the best care possible.

The transplant process will not be easy. It is normal to experience some stress and anxiety during this difficult time. You may be concerned and have many questions about your own health and the impact that this process will have on your loved ones.

UPMC will provide you with the emotional and practical support to get through the transplant process successfully. Because of our academic and research expertise, our program offers the latest breakthroughs in transplant science. Those resources, along with your firm commitment to take care of yourself and your transplanted organ, will offer you an excellent chance of returning to a normal lifestyle after transplant.

This manual is designed to be a resource for you. It will answer many questions that you may have about kidney transplant, such as wait time, expectations, and care after transplant.

If you have any questions during any point in the process, contact your transplant coordinator.

Thank you for choosing UPMC. We sincerely hope that your experience here is a rewarding one.

YOUR PROVIDERS

Transplant Providers

Harold C. Yang, MD, PhD
Surgical Director/Attending Surgeon

Danielle Ladie, MD, MPH
Attending Surgeon

Vijay Gopal Menon, MD
Attending Surgeon

Manpreet Singh, MD
*Medical Director
Nephrologist*

William Hoffman, MD
*Director, Living Donor Program
Nephrologist*

Mary Waybill, MD
Research/ Transplant Nephrology

Rhonda Saylor, MSN, CRNP, CCTC
Nurse Practitioner

Stephanie Midile, MSN, CRNP, CCTC
Nurse Practitioner

Transplant Director

Unit Director

Pre-Transplant Coordinators

Living Donor Transplant Coordinators

Post-Transplant Coordinators

Research Coordinator

Transplant Social Workers

Transplant Financial Coordinators

Transplant Pharmacist

SURGEONS

Harold Yang, MD, PhD

Dr. Yang received his medical degree at the University of Chicago, where he also completed his surgical residency. His fellowship was completed at Massachusetts General Hospital. His specialty is kidney transplantation.



Danielle Ladie, MD, MPH

Dr. Ladie earned her bachelor of science degree from Penn State University and received her medical training at St. George's University. She is fellowship trained in transplant surgery from the University of Virginia and completed her residency at UPMC where she served as chief resident.



Vijay Gopal Menon, MD

Dr. Menon earned his medical degree from University of College London Medical School and completed his surgical residency at University of California San Diego Medical Center. Dr. Menon is fellowship trained in Abdominal Organ Transplantation from Massachusetts General Hospital.

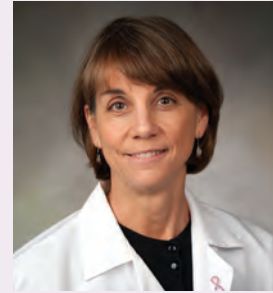


NEPHROLOGIST

Mary Waybill, MD

Dr. Waybill received her medical degree at Temple University School of Medicine in Philadelphia. She completed her residency at the Medical College of Virginia. Dr. Waybill also completed her fellowship in nephrology at the Medical College of Virginia.

Dr. Waybill oversees the transplant research protocols and participates in the care of our transplant patients and living kidney donors. Dr. Waybill is certified by the American Board of Internal Medicine in nephrology.



Manpreet Singh, MD

Dr. Singh completed his nephrology fellowship at Boston University and a transplant nephrology fellowship at University of California, San Francisco. A graduate of Government Medical College in Patiala, India, he completed his residency at SUNY Stony Brook Medical Center in New York.

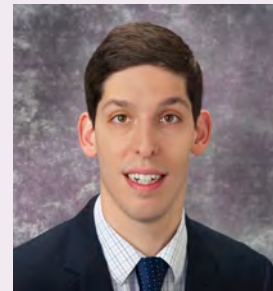
Dr. Singh is fluent in English, Punjabi, and Hindi.



William Hoffman, MD

Dr. Hoffman completed his nephrology fellowship at the University of Pittsburgh, where he was the chief fellow. Additionally he completed a fellowship in transplant nephrology and a research fellowship in transplant immunology through the University of Pittsburgh.

Dr. Hoffman completed his residency at University of Rochester, Strong Memorial Hospital.



NURSE PRACTITIONERS

Nurse practitioners work closely with doctors, nurses, and staff to extend the care of the doctors. Nurse Practitioners participate in the care of transplant candidates, recipients of kidney transplants, and living kidney donors.

PHARMACISTS

Transplant pharmacists help you and your loved ones understand the importance of your medicines and answer any questions you may have about your medicines before and after transplant.

Managing the complex medicines taken after transplant is an important part of your care. Both before and after transplant, the pharmacist will review your medicines for potential drug interactions, help prevent and monitor for potential reactions, work with the doctors to adjust medicine doses, and help make sure your medicine plan meets your individual needs.

TRANSPLANT COORDINATORS

The transplant coordinators will be your main source of contact with the transplant team. The coordinator is a Registered Nurse with specialized education who will be a key part of your transplant process both before and after transplant.

Before transplant, your pre-transplant coordinator will guide you through the education and work-up process. Your pre-transplant coordinator will be your contact person for any questions or concerns while you are waiting for your transplant.

After transplant, the post-transplant coordinator will educate you about how to care for yourself. The post-transplant coordinator will also keep track of your lab work and care after transplant, as well as answer any questions you may have.

LIVING DONOR COORDINATORS

Living donor coordinators guide living donors through all phases of the donation process. They are your resource for all questions and concerns about living donation.

RESEARCH TRANSPLANT COORDINATORS

Research coordinators are transplant nurses who coordinate and oversee patients who participate in research protocols.

TRANSPLANT SOCIAL WORKERS

The transplant social workers will help you review your social, financial, and support systems to make sure that your transplant can be a successful experience. They will also be available after transplant to help you get the medicines you need as well as address other social concerns you may have.

TRANSPLANT FINANCIAL COORDINATORS

The transplant financial coordinators will look at your insurance coverage for transplant and medicines after transplant. They may also be able to make recommendations for additional coverage to reduce your out-of-pocket expenses after transplant.

KIDNEYS: HOW DO THEY WORK?

Location:

Your kidneys are located deep in your abdominal cavity. They are located at waist level and toward your back. They are well protected from external injury by muscles, body fat, and your lower ribs. Each kidney is about the size of your fist.

Function:

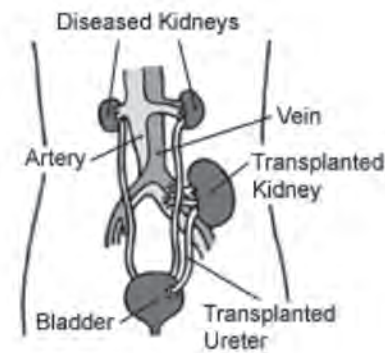
Your kidneys have several important jobs:

- *Filter your blood*—Your kidneys remove toxins and waste products, which are produced by normal body activities such as breathing, eating, and exercise.
- *Produce hormones*—These hormones help regulate your blood pressure and red blood cell production.
- *Fluid management*—Your kidneys help control (get rid of or keep) fluid in your body, as well as maintain salt and acid levels.

Kidneys with normal function are able to perform all of these activities without difficulty. Kidneys that are damaged or diseased are unable to perform some or all of these jobs. This can lead to build up of excess fluid, waste products, high blood pressure, and a low blood count. When this occurs, dialysis and medicines are needed to clear these waste products and prevent death.

Once dialysis is started, many patients tend to feel better. Some patients feel dialysis limits their ability to work and socialize. They feel tired and may have other complications such as sexual dysfunction, poor appetite, bone disease, and heart disease.

A kidney transplant eliminates the need for dialysis, provides a better quality of life, and for most people a longer, healthier life. A working kidney transplant is able to remove waste products from the body 24 hours per day, while dialysis can only do 10% of the work of a functioning kidney.



FORM OF TREATMENT

Transplantation is a form of treatment for kidney failure. However, it is not a cure. There are benefits and risks to both dialysis and transplant. You must look at all of these benefits and risks and decide whether or not transplant is right for you.

It is okay to decide that you do not want to receive a transplant.

The alternative treatment to transplant is dialysis therapy.

Once you have received a transplant, you are committed to take care of it for the rest of your life. This includes things like taking a lot of medicines every day for the rest of your life, frequent blood draws, frequent clinic appointments, and increased risk for infections. These requirements and risks are discussed later in this booklet in detail.



EVALUATION PROCESS

To determine if transplant is a safe form of treatment for you, several steps must be completed. It is possible that the testing process will show that the risks of transplantation are higher than any benefit you would receive, and you may not be a candidate for transplant.

- *Step 1: Transplant Education Class* - This is a 2-hour appointment where you will learn the basics of kidney transplant. You will learn about the evaluation process, the surgical procedure, and the care required after transplant.
- *Step 2: Evaluation at the Transplant Clinic* - This 3 to 4-hour appointment includes a medical history review, a physical exam, psycho-social evaluation, insurance review, and blood draw for specialized laboratory testing, including HLA type, viral screening, and blood type.
- *Step 3: Completion of required tests/procedures* - This step normally takes between 2 and 3 months to complete. You will be scheduled for several diagnostic tests to determine if transplant is a safe form of treatment for you. The test requirements will be determined by the transplant team after you have had your evaluation appointment. These tests will be scheduled at a UPMC facility. The results of these tests provide information necessary to minimize risk to your health at the time of transplant and to determine if the transplant procedure is the best option for you. These tests can also identify potential health concerns BEFORE they occur. This allows your transplant team to safely care for you before, during, and after your transplant.
- *Step 4: Review of Test Results* - Your test results will be reviewed by the transplant coordinator and doctor. If any tests are abnormal, you may need to have additional tests or meet with a specialist.
- *Step 5: Presentation at Transplant Selection Committee* - Your information will be presented at the Transplant Selection Committee. This committee is made up of all members of the pre-transplant team. If approved, you will then be placed on the National Transplant List. If denied, your transplant coordinator will provide you with an explanation via phone and in a letter. This letter will be sent to you, your nephrologist, and your dialysis unit.
- *Step 6: Listed for Transplant* - Once approved for listing, you will be required to review and sign a consent for transplant listing. You will be asked to come to the transplant office to do this. You will also receive a letter notifying you of the date you were placed on the transplant list.

TESTING

The following is a list of routine tests used to see if you are eligible for transplant listing. ***Your exact list of tests may vary depending on your medical history and physical findings.*** These tests will be determined by the transplant team.

History and Physical: This provides information about your current physical condition and past illnesses.

Chest x-ray: This is a picture of your lungs and lower respiratory tract, which will show any abnormalities.

EKG (electrocardiogram): This is an electrical picture of your heart rhythm.

Blood Draw: This will be required at least 2 times to determine your blood type and complete screening for viruses and special transplant tests.

Cardiac Stress Test: This test will show us how your heart functions under stress (similar to how it will need to work during and immediately after your transplant surgery). There are several types of stress tests. The one that is best for you based on your health and history will be ordered.

Echocardiogram: This is a non-invasive ultrasound procedure used to look at the heart's function and structures.

Cardiac Catheterization: This test looks for cardiac disease that may not be detected by other tests like stress tests or echocardiograms.

Colonoscopy: This is required if over age 50 for cancer screening.

Age and gender-appropriate screenings: This includes gynecology exams and mammograms for women and prostate exams for men.

Transplant Cardiology Consult: Some patients will be required to meet with a cardiologist (heart doctor) who has expertise in the care of transplant patients.

STANDARD SELECTION CRITERIA

The following conditions must be met for a patient to be listed for transplant at this center.

- Body Mass Index (BMI) less than or equal to 40
- Clearance from a transplant cardiologist if requested
- Ejection Fraction (heart function) greater than 35%
- Adequate blood flow to support the transplanted organ
- Normal results of tests such as EKG, chest x-ray, and routine screenings
- Appropriate psychosocial support system
- Adequate financial coverage
- Documentation of compliance with current prescribed treatments

The following conditions may prevent someone from being a candidate for transplant at this center:

- Uncorrectable heart or vascular disease
- Liver cirrhosis
- HIV (AIDS) that is unresponsive to therapy
- Disseminated malignancy (cancer)
- Chronic infections that are not responsive to treatment
- Inadequate social support system
- Active substance abuse
- Uncontrolled psychosis
- Non-compliance with prescribed medical treatments
- Current incarceration
- Resident of long-term care facility
- On-going tobacco use in candidates who have known COPD, atherosclerotic disease, or tobacco-related malignancy in the past
- Pulmonary hypertension



WAITING

The average wait time for a deceased donor transplant is 4 to 6 years. Please keep in mind that this is an average. Some people do not wait as long, some wait longer. We are unable to determine how long you will need to wait for a transplant. The wait time for deceased donor transplant is so long because of the number of people that are on the wait list for a transplant. Currently there are more than 90,000 people in the United States waiting for a kidney transplant.

This waiting time can be very frustrating. You can find support and encouragement during this time at several places. Speak to your dialysis support group, become or stay involved in a church or speak to your transplant coordinator and social worker.

The following things are very important for you to do during this time:

- 1. Stay Healthy:** The healthier you are before transplant surgery, the better and quicker you will recover and return to a more normal lifestyle. The following are some quick tips to consider:
 - See your primary care doctor on a regular basis
 - Exercise if your doctor says that it is okay
 - Follow your renal (kidney) diet to prevent additional health complications
 - Keep your routine health screens up to date (such as gynecology exams, prostate exams, mammograms, and dental exams)
 - Complete any additional testing that we may request during this time
 - Most patients are required to have a yearly cardiac (heart) stress test and all candidates must return to our clinic yearly while waiting for transplant. If these requirements are not completed, your transplant may be delayed or postponed.
- 2. Keep Us Informed:** Please call when any of the following things occur:
 - Changes of name, address, or phone numbers
 - Change of insurance carrier
 - Change of doctor or dialysis unit
 - Change of type of dialysis
 - Any hospital admissions or Emergency Department visits
 - Any infections that are treated with antibiotics
 - Any surgical procedures
- 3. Be Available:** It is extremely important that we are able to contact you when a kidney becomes available. We have a very limited amount of time to be able to contact you (1 hour). Please make sure we have phone numbers where you can be reached.

4. **Send Blood:** While you are on the transplant waiting list, you must send us a sample of your blood the 1st week of each month (1 tube). This blood is used to do your antibody screen (PRA) as well as start crossmatch testing with potential donors. Without current blood, your transplant may be postponed or delayed.
5. **Blood Transfusions:** If you should require a blood transfusion, please remind the person giving you the transfusion that you should only receive leukopoor filtered blood, because you are awaiting transplant. This filter is used to help prevent you from developing antibodies to the proteins in the donor blood. A high antibody level could make it **very** difficult to find a compatible kidney and usually means a longer wait time for transplant. You must also notify your transplant coordinator as soon as possible, as you will need to have additional blood draws to monitor your antibody levels.

TYPES OF TRANSPLANTS

Living Donor Transplant:

This type of transplant occurs when a living person volunteers to donate one of their kidneys to another person in need.

There are several benefits to receiving a kidney from a living donor. **Kidneys from living donors last longer and work better than kidneys from deceased donors.**

Kidneys from living donors are better quality and begin to work right away. Also, with a living kidney donor your surgery can be scheduled and planned for ahead of time.

There are several types of living donor transplants:

1. **Living related** – kidney is donated from someone who is genetically related to the recipient.
2. **Living unrelated** – kidney is donated from someone who is known to the recipient (friend, co-worker, spouse, etc.) but there is no genetic relationship.
3. **Non-directed or Good Samaritan** – kidney is donated from someone who feels emotionally/socially drawn to help another in need and is a stranger to the recipient.
4. **Paired exchange** – A paired exchange transplant occurs when incompatible living donor and recipient pairs exchange (or swap) donor kidneys with another incompatible pair. This allows both patients to receive a living donor transplant and the benefits that go along with a living donor transplant.

Deceased Donor Transplant:

This is a transplant that occurs from someone who has been determined brain dead (no brain activity) or from someone who has experienced an irreversible brain injury and the family has decided to withdraw life support (donation after cardiac death). There are several challenges in deceased donor transplant, including a longer wait to find a match and delayed organ function.

DECEASED DONOR ORGAN ALLOCATION

Unfortunately, the demand for kidneys is far greater than the supply of deceased donor organs. Kidneys are placed based on a system that considers distance from the donor hospital, sensitization, medical urgency, and other determining factors. Recipients receive points based on these factors to determine how the kidney is assigned.

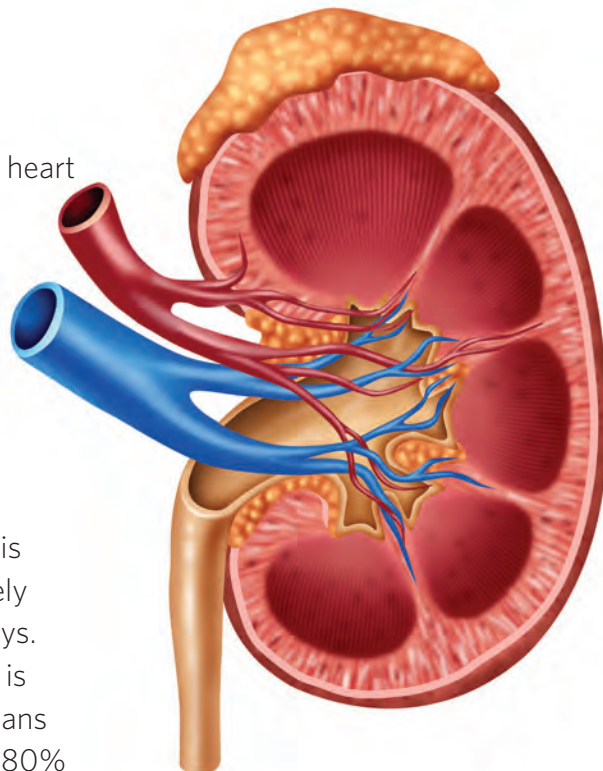
The United Network for Organ Sharing (UNOS) is a non-profit, charitable organization that manages the nation's transplant system—known as the Organ Procurement and Transplantation Network (OPTN)—under contract with the federal government. As the OPTN, UNOS helps create and define organ sharing policies that make the best use of donated organs.

This matching system helps more people have longer function with their transplanted kidney and may help shorten the waiting time for some groups of people who are hard to match with most kidneys.

Every kidney that is offered for transplant receives a Kidney Donor Profile Index (KDPI) score. This score is based on facts about the donor that affect how long the kidney is likely to function. These factors include:

- Age
- Height
- Weight
- Ethnicity
- Whether the donor died due to loss of heart function or loss of brain function
- Serum creatinine value (a measure of kidney function)
- Stroke as cause of death
- History of high blood pressure
- History of diabetes
- Exposure to the hepatitis C virus

The KDPI score ranges from 0 to 100 and is associated with how long the kidney is likely to function when compared to other kidneys. The lower the score, the longer the kidney is expected to last. A KDPI score of 20% means the kidney is likely to function longer than 80% of other available kidneys.



Each kidney candidate (someone on the kidney waiting list) has an individual Estimated Post Transplant Survival Score (EPTS). The EPTS is calculated based on facts about the candidate that affect how long they likely will need a kidney.

These factors include:

- Age
- Length of time on dialysis
- Having received a previous transplant of any organ
- Current diagnosis of diabetes

The lower the EPTS score, the longer the recipient is likely to need the transplanted organ. These 2 numbers (the KDPI and the EPTS) are important in the allocation system. The 20% of kidneys that are expected to last the longest (those with a KDPI of 20% or less) will first be offered to patients likely to need a transplant the longest (those with an EPTS score of 20% or less).

Kidneys with high KDPI scores are expected to function for a shorter amount of time than others and may be best used to help candidates who are less able to stay on dialysis for a long time. The 15% of donated kidneys likely to function the shortest time (those with a KDPI of 85% or greater) will be offered to a wider area of the country than other kidneys. The goal is to encourage use of these kidneys by finding a suitable patient as quickly as possible.

Candidates qualify for waiting time based on the start date of chronic dialysis.

Candidates who are very difficult to match because they have developed immune system antibodies also get additional points on the list, as it is much more difficult to find a matching kidney for them.

The allocation system is very complex; it was designed with input from transplant professionals and people who have personal experience with donation and transplantation to make sure we are efficiently using a very precious resource—a kidney, the gift of life.

Candidates who are not on dialysis begin their wait time when they are put on the list and their glomerular filtration rate (GFR) is 20 ml/min or less. The GFR is a measure of kidney function.

LIVING DONOR TRANSPLANTATION

Often patients are concerned about asking someone else to donate a kidney to them for transplant. It is important to understand that living donation is a very safe procedure for the donors. Living donors can live a long and healthy life with one kidney. Donors are screened and tested very thoroughly before donation to make sure that removing a kidney will not affect their health in any adverse way. Our practice with our potential kidney donors is that we DO NOT put them at any risk either now or in the future.

There are several benefits to receiving a kidney from a living donor:

1. There is no need to wait for a deceased donor kidney to become available (most living transplants take place 4 to 6 months after the evaluation process begins).
2. The kidney usually begins to work immediately, even in the operating room. There is a very low occurrence of delayed transplant function in living transplants.
3. There are fewer episodes of rejection. As a result, living donated kidneys tend to last longer and work better than deceased donor transplants.
4. Living donor transplants can be scheduled. This allows both you and the donor to plan for absences from work, childcare, and other social concerns.



ELIGIBLE DONORS

Living kidney donors must be over the age of 18. They may not have a history of cancer, diabetes, or autoimmune diseases such as Lupus. A donor must be a compatible blood type to donate directly to you (see below). If potential donors do not know their blood type, the living donor coordinator can arrange for this to be tested. If potential donors are not blood type compatible, participation in a paired exchange program is a great option.

Potential donors must call the transplant office to start the donor evaluation process. We are unable to call potential donors. They must start this process on their own. The donor coordinator can answer questions that anyone may have about the donation process.

Confidentiality of Patient Information

Due to patient privacy and to make sure that accurate information is received from both the potential recipient and potential donors, all information is treated as private. This means that no information about the donor will be shared with the potential recipient and no information about the recipient will be shared with the donor.

Blood Type Compatibilities:

Recipient Blood Type *Can RECEIVE a kidney from donors with blood type*

A A, O

B B, O

AB A, B, AB, O

O O

Donor Blood Type *Can DONATE a kidney to patients with blood type*

A A, AB

B B, AB

AB AB

O A, B, AB, O

Rh factors (+, -) Do NOT need to match

KIDNEY REMOVAL

Laparoscopic donor nephrectomy (kidney removal) uses small scopes and instruments (3 to 4 very small cuts on the belly) to free the kidney, which is then removed through a small incision a few inches below the donor's belly button. A kidney removal done this way results in very little pain or discomfort for the donor, a very short hospital stay (1 to 2 days), and very fast return to normal activity. Most donors are ready to return to work and normal activity within 2 to 3 weeks of surgery.



RISKS AND BENEFITS OF TRANSPLANTATION

Transplant is a form of treatment for kidney disease. Transplant is not a cure for your disease. Like any other treatment, there are risks and benefits which must be reviewed to determine if transplant is a treatment option that is right for you. Like other forms of treatment the potential benefits of transplant are not a guarantee.

Benefits include, but are not limited to the following:

- Patients may avoid the need for dialysis.
- Patients may have an improved quality of life.
- Patients may live longer than those who stay on dialysis.
- Patients may have improved blood counts and energy level.

Potential risks may include, but are not limited to the following;

1. Medical Risks:

- Patients may get a wound infection after surgery.
- Patients may be at risk for pneumonia or other infections.
- Patients may develop a blood clot in the legs.
- Patients may have transplanted organ rejection, failure, or the need for another transplant.
- Patients will have to take immunosuppressant medicines for as long as they have a functioning transplant – which may be the rest of their life.
- Patients may have complications that require another operation.
- Patients may be at a higher risk for certain cancers after transplant.
- Patients may have irregular heart rhythms or cardiac complications.
- Patients may have multi-organ failure or even death.

2. Psychosocial Risks:

- Patients may experience some depression after transplant.
- Patients may be at risk for post traumatic stress disorder (PTSD).
- Patients may have generalized anxiety.
- Patients may have difficulty dealing with the need to depend on others for help.
- Patients may experience feelings of guilt.

RECEIVING THE CALL, AND GETTING A TRANSPLANT

Be prepared! You never know when you will get a call that an organ is available for you. Organ offers often happen in the middle of the night. Be sure you have worked out details like:

- Transportation: Who will drive you to the hospital?
- Child care: Who will watch or care for your children?
- Pet care: Who will care for your pets?

When the transplant coordinator calls you with an available organ offer, they will do several things:

- Brief medical/physical review: This is done to make sure that it is safe to proceed with transplant at that time.
- Instructions: The coordinator will give you specific instructions about coming to the hospital.

**** You will need to bring a list of your current medicines, your ID, and your insurance cards with you to the hospital****

You will be notified if you are the first patient for the available organ or a back-up patient. To avoid wasting available organs, there are always several patients in line for each organ. This is done to make sure that every available organ is transplanted.

ARRIVING AT THE HOSPITAL

When you arrive at UPMC Harrisburg, you will report to Patient Registration (follow the purple "A" signs for Hospital Main Entrance). After you are in your hospital room, there will be a lot of activity. You will have blood drawn, a complete physical, EKG, chest x-rays, and an IV placed in your arm. Some of the blood that is drawn is used to perform a final crossmatch. This is a test to make sure that you and the available organ are compatible. This test takes between 4 to 6 hours until results are available.

It may be many hours from the time you arrive at the hospital until a determination is made if you will get the transplant. This time can be long and difficult for patients. The transplant coordinator will communicate information to you as it becomes available. A final determination to transplant an organ can not be made until the donor surgery takes place and our transplant team has the information they need. In addition, the final crossmatch must be completed. This process can take a very long time (many times more than 12 hours).

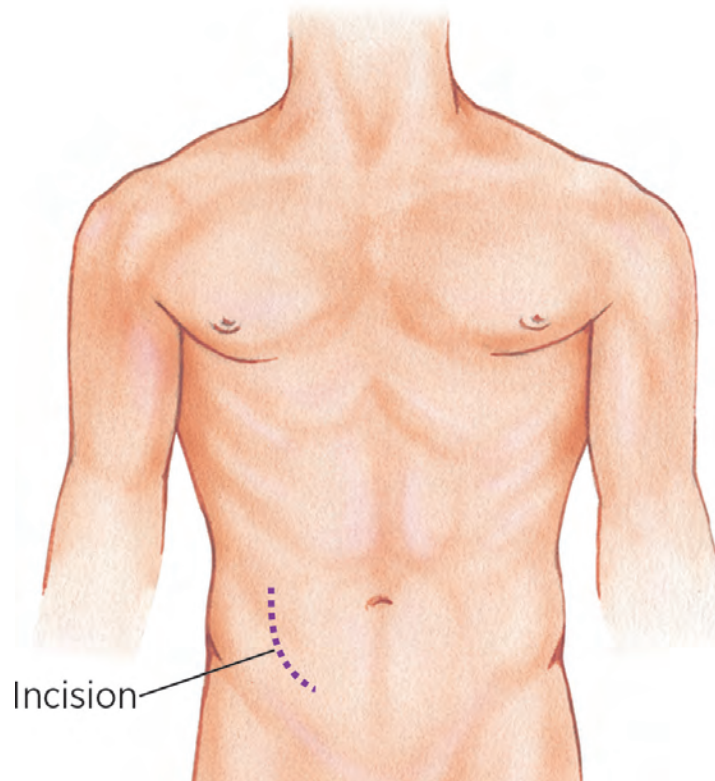
Patients are often called into the hospital for potential transplant several times until they actually are able to get a transplant.

When the organ is accepted by our team for transplant, you will be prepared to go to the operating room.



TO THE OPERATING ROOM

- Your transplant operation will take between 2 and 4 hours.
- Your transplanted kidney will be placed in your abdomen (lower front side of belly). This will allow us easy access to your newly transplanted kidney for ultrasound or biopsy if necessary.
- Your incision will be between 6 to 8 inches long.
- Your transplanted kidney is hooked up to the main artery and vein that supplies blood flow to your leg. It is also connected to your bladder.
- In most cases, your natural (native) kidneys do not need to be removed. If a native nephrectomy (kidney removal) is required, your transplant coordinator and surgeon will discuss this with you.
- It is unusual for patients to require blood transfusion during or after transplant. In rare occurrences blood transfusions are required for a patient's benefit and safety after transplant.





RIGHT AFTER SURGERY

You will wake up in the surgical intensive care unit (ICU), where you will stay overnight. During this time, your heart rate, blood pressure, and urinary output will be monitored closely.

You will have a special IV, called a central line, inserted near your collar bone (placed while you are asleep in the operating room). This catheter allows us to monitor your fluid levels, as well as give you fluids and medicines as needed.

You will have a catheter in your bladder. This will allow us to check your urine output closely. You will be asked to get out of bed the day after your surgery and start walking. This is done to prevent complications after surgery such as blood clots and pneumonia.

Everyone's hospital stay is different based on an individual's needs. Most patients are in the hospital 4 to 5 days after transplant. During this time, you will learn how to care for yourself and your newly transplanted organ.

WHAT YOU NEED TO DO AFTER TRANSPLANT

There are several expectations that patients must be prepared to meet to have success after transplant. Understanding these expectations before deciding to have a transplant is very important.

1. *Return to Clinic* – patients are expected to return to clinic for care and management after transplant on a routine basis and as requested for urgent issues. Routine post-op visits include weekly visits for the 1st month after transplant, and 3, 6, and 9 months after transplant. In addition, visits at 1 year, 18 months, and then every year for as long as the kidney is functioning. We can not provide transplant patients safe care without seeing them in clinic on a regular basis.
2. *Get Blood Drawn* – For the first few months, you will need to have blood drawn twice a week. After that the amount of times will decrease.
3. *Take Medicines* – Patients are required to take medicines at least 2 times a day and may need to take medicines up to 4 times a day after transplant.
4. *Take Vital Signs* – Patients are required to take their weight once a day and their blood pressure and temperature twice a day after transplant and write that information down.



MEDICINES

Immunosuppression Medicines: These are medicines that you will need to take for the rest of your life. These medicines will suppress your immune system. Your immune system is responsible for fighting off infections and destroying invading foreign substances. Your immune system will look at your transplanted organ as something foreign that does not belong. As a result, it will try to attack and destroy your newly transplanted organ. This is known as rejection. To prevent this from happening, you will need to take medicines to decrease the function of your immune system (immunosuppression) for the rest of your life. After your transplant, you must take these medicines **forever**.

It is important that you continue taking these medicines. Stopping these medicines may cause you to lose your transplant and become very sick.

Side Effects: These medicines have potential side effects. Not all transplant patients experience the same side effects. These can be anything from a few side effects for a short period of time, to many side effects for the life of your transplant.

The following is a list of some of the immunosuppressive medicines that you will need to take after transplant, as well as their potential side effects.

1. *Steroids* (prednisone, Deltasone®, Solu-Medrol IV®)
 - Stomach ulcers, indigestion
 - Salt and water retention, as well as increased fatty deposits, especially in face area (round, full, “moon” face)
 - Increased appetite, weight gain
 - Sun sensitivity
 - Cataracts/glaucoma
 - Difficulty sleeping
 - Mood swings
 - Delayed wound healing
 - Increased circulating blood sugar, diabetes

2. *Cellcept*[®] (mycophenolate mofetil, MMF)
 - Decreased white blood cell count
 - Diarrhea and vomiting
 - Will cause birth defects in unborn child (Pregnancies must be planned after transplant. Your transplant coordinator needs to be informed so we can change your medicines.)

3. *Prograf*[®] (Tacrolimus[®], FK 506[®])
 - Hand tremors
 - Numbness, tingling in hands and feet
 - High blood pressure
 - Nausea and diarrhea
 - Nightmares
 - Headaches
 - Slightly higher risk of drug-induced diabetes

4. *Simulect*[®] or *Thymoglobulin*[®]: These are IV medicines which are given while you are in the hospital to prevent organ rejection. They are powerful immunosuppressant medicines.

5. Anti-infectives—Because your immune system is affected by the anti-rejection medicines, you will need to take antibiotics, anti-viral, and anti-fungal medicines for several months after transplant. This will help prevent infections.

Other medicines you will be taking after transplant

You will be given other medicines to help with the side effects of the immunosuppressive agents as well as for other side effects related to surgery. They include:

- Anti-ulcer drugs, to decrease stomach acid production
- High blood pressure medicine
- Diuretic (water pills)
- Pain-relief medicines
- Vitamin supplements, such as multivitamins with folic acid
- Stool softener
- Baby aspirin

EQUIPMENT YOU WILL NEED AFTER TRANSPLANT:

1. Large 4-doses-a-day pill box
2. Scale to check your weight
3. Blood pressure cuff
4. Thermometer
5. Telephone answering machine or active voicemail box



POSSIBLE COMPLICATIONS

1. **Rejection:** This is your body's attempt to get rid of something it believes does not belong there (your transplanted organ). There are several kinds of rejection:
 - *Hyperacute* – This severe form of rejection happens within minutes or hours after transplant surgery. The new kidney must then be taken out. This form of rejection is very rare.
 - *Acute* – This is the most common type of rejection. While it can happen anytime, it more frequently occurs during the first 6 months after transplant. This type of rejection can be treated with medicine. It is usually reversible.
 - *Chronic* – This type of rejection can happen at any time, including years after the transplant. A common cause of (chronic) late rejection is not taking your medicine, skipping days, or taking the wrong dosage.

The medicines that you take will help lessen the number or severity of the rejection episodes, but may not completely prevent them. Most rejections that happen shortly after surgery can be treated medically.

2. **Infections:** After transplant you will need to take immunosuppression medicines to prevent rejection for the rest of your life. Because of this, you will always be at some risk for infections. This risk is highest the first few months after transplant. Most infections can be treated at home with medicines. Occasionally, patients will need to be admitted to the hospital for a few days for IV medicines to help treat infections. It is important to wash your hands often to prevent infections after transplant.
3. **Delayed Graft Function:** The functioning of your kidney transplant may be delayed, causing a need for dialysis or longer hospital stay until the kidney "wakes up." Delayed graft function may last from several days to several weeks.
4. **Diabetes:** Some of the immunosuppression medicines you take may cause diabetes. Diabetes is an increased level of glucose (sugar) in your blood. Your blood glucose levels will be monitored for the 1st year to help detect any problems early. If you develop diabetes, you will be taught how to deal with this problem. In some cases, it can be controlled by diet, weight loss, and exercise. Some people need oral medicines or insulin to help control their diabetes.

5. **Technical Problems:** As with any major surgery, technical problems can occur during or after the transplant surgery. There may be bleeding, collection of lymph fluid (called lymphocele), obstruction of the ureter, or kinking or tightening of the blood vessels. These are rare, but if they occur, may require medical or surgical treatment and a longer hospital stay.
6. **Recurrence of Kidney Disease:** There is a possibility, with some disease processes, that the disease can reoccur in the transplant organ. Some of these diseases are MPGN (membranoproliferative glomerulosclerosis), FSGS (focal segmental glomerulosclerosis), IGA nephropathy, diabetes mellitus, and others. We can discuss any concerns about this with you.

OTHER THINGS YOU NEED TO KNOW

- NO driving for 2 weeks after transplant.
- NO vigorous activity or lifting anything greater than 20 pounds for 4 to 6 weeks after transplant.
- NO contact with birds or turtles due to the risk of infections from these animals.
- NO smoking or use of any tobacco products.
- Gardening/Soil-When gardening or working with soil, you will need to wear gloves.
- Swimming-You may swim after transplant when your incision is completely healed. You may swim in the ocean or in a pool (no lakes, ponds, creeks, due to risk of infections).
- Fluids-You will be encouraged to drink a lot of water and fluids after transplant. Your newly transplanted kidney will need this to work properly. We recommend our patients drink at least 8 (8 oz) glasses of fluid a day after transplant.
- Diet-Your diet will not be as limited as before transplant. You will be able to eat many foods that you are currently not allowed to have while you are on dialysis. For example: bananas, potatoes, orange juice, and cheese.
- Return to normal activity-One of the major goals after transplant is to get you back to a normal lifestyle and activities as soon as possible. This will be done slowly, but you will be able to return to work, exercise, and perform many other activities shortly after receiving your transplant.

We recognize that deciding to get a transplant is an important decision for you. The transplant team at UPMC is here to help you through this difficult process. Being comfortable with your transplant team and the care that is provided to you is very important. We want to thank you for considering transplant at our center. Please keep this manual for future reference as you go through the transplant process. If you have any questions throughout this process please contact your transplant coordinator.



HARRISBURG REGIONAL LODGING

BAILEY HOUSE

The Bailey House is a comfortable home-like setting for loved ones of seriously-ill patients of UPMC Harrisburg. It is a lodging facility 1 block from the hospital sponsored by the UPMC Pinnacle Auxiliary.

The 24-hour a day facility provides housing, refreshments and other home-like conveniences. Space is limited. Call **717-232-2721** for more information.

AREA HOTELS

If you or your loved ones need to stay overnight in Harrisburg, the following area hotels and motels offer preferred room rates for UPMC patients and their loved ones. When calling for reservations, be sure to mention that you will be receiving care at UPMC to receive the discount.



Quality Inn

525 Front St., Harrisburg, PA 17104
717-233-1611 ▪ qualityinn.com

Crowne Plaza

23 South Second St., Harrisburg, PA 17101
717-234-5021 ▪ basshotels.com

Days Inn, Harrisburg North

3919 North Front St., Harrisburg, PA 17110
717-233-3100 ▪ daysinnharrisburg.com

Best Western Premiere

800 East Park Drive, Harrisburg, PA 17111
717-561-2800 ▪ fourpoints.com

Hampton Inn, Harrisburg West

4950 Ritter Road, Mechanicsburg, PA 17050
717-691-1300 ▪ harrisburghampton.com

Hampton Inn, Harrisburg East

4230 Union Deposit Road, Harrisburg, PA 17111
717-545-9595 ▪ hampton-inn.com

Hilton Harrisburg & Towers

One North Second St., Harrisburg, PA 17111
717-233-6000 ▪ hilton.com

Radisson Hotel Harrisburg

1150 Camp Hill Bypass, Camp Hill, PA 17011
717-763-7117 ▪ radisson.com

GLOSSARY

Acute tubular necrosis (ATN) – Reversible kidney swelling resulting in delayed kidney function

Antibody – A substance made by the immune system to develop resistance against foreign proteins (antigens) or infections

Antigen – Proteins found on the surface of blood cells. Six antigens play an important role in kidney transplantation

Compatibility – Test performed by putting a donor's blood and a potential recipient's blood together to look for any signs of reaction, which could cause an acute (immediate and severe) rejection after transplant.

Deceased donor – An individual who has recently died of causes that do not affect the function of the organ to be transplanted. Their family has graciously offered their organs/tissues for transplant.

Graft – Word used to refer to a transplanted organ.

Immunosuppression – Decreased function of the immune system

- Decreases the body's ability to fight off infections
- Needed after transplant to prevent rejection

Living Donor – Someone who is related or unrelated who has a kidney removed for transplant.

Non-Compliance – Failure to follow any or all instructions given to you by your health care providers.

Rejection – Attempt by the immune system to attack and destroy a transplanted organ. If not treated, it will result in loss of the transplanted organ.

ONLINE RESOURCES

To learn about kidney disease and treatment options:

<i>American Assn. of Kidney Patients</i> aakp.org	Provides advocacy, education, and interaction for kidney patients
<i>Explore Transplant</i> ExploreTransplant.org	Supports patients and kidney care providers with educational programs and training seminars
<i>Kidney School</i> kidneyschool.org	Features educational models for patients and providers about kidney disease and its treatments
<i>Living Donors Online</i> ivingdonorsonline.org	Provides information for patients, medical professionals, and the public
<i>National Kidney Foundation</i> kidney.org	Provides information for patients, medical professionals, and the public
<i>Organ Procurement and Transplantation Network (OPTN)</i> optn.transplant.hrsa.gov/	Official U.S. Government web site managed by the Health Resources and Services Administration, U.S. Department of Health & Human Services
<i>PKD Foundation</i> pkdcure.org	Offers comprehensive information about polycystic kidney disease
<i>Renal Support Network</i> rsnhope.org	Provides non-medical services to those affected by chronic kidney disease, including education about transplantation
<i>Renewal</i> life-renewal.org	Provides education, referrals, and logistical support to Jewish patients seeking and receiving living donor transplantation or living donors
<i>Transplant Recipients International Organization (TRIO)</i> trioweb.org	Provides education about transplantation in general, as well as financial issues around transplantation
<i>Transplant Living</i> transplantliving.org	Offers information about living donation and supporting patients throughout the process
<i>United Network for Organ Sharing</i> unos.org	Provides information and data about transplants, the waiting list, and transplant centers
<i>U.S. Dept. of Health & Human Services</i> organdonor.gov	Provides comprehensive information about organ donation and transplantation

For financial assistance with transplant:

<i>American Kidney Fund</i> kidneyfund.org	Educates patients about financial support for treatment, medicine and surgery costs
<i>American Transplant Foundation</i> americantransplantfoundation.org	Financially assists with lost wages post-surgery and lack of access to essential medicines
<i>National Foundation for Transplants</i> transplants.org	Assists transplant candidates and recipients in raising money for costs not covered by insurance
<i>National Living Donor Assistance Center</i> livingdonorassistance.org	Provides financial assistance with travel costs and expenses associated with living organ donation

For education about alternative kidney transplant options:

<i>Alliance for Paired Donation</i> paireddonation.org	Links transplant candidates with matching potential living donors and provides education about paired donation
<i>Living Donation California</i> LivingDonationCalifornia.org	Provides education designed for potential living donors who have not identified a specific recipient
<i>National Kidney Registry</i> kidneyregistry.org	Links transplant candidates with matching potential living donors and provides education about paired donation
<i>United Network for Organ Sharing</i> unos.org	Provides information about kidney paired donation and about the Kidney Paired Donation Pilot Program

To learn about Medicare coverage and dialysis:

<i>Centers for Medicare & Medicaid Services (CMS)</i> cms.gov/center/esrd.asp	Provides resources to compare dialysis facilities and learn about Medicare coverage for end-stage renal disease (ESRD)
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