Kidney Transplant Education
For the Pretransplant Patient

Indiana University Health
Welcome

Welcome to Indiana University Health Transplant. We have partnered with Indiana University School of Medicine to provide you with outstanding, comprehensive transplant care.

The information in this booklet has been prepared by transplant team members to tell you about our Kidney Transplant Program. We hope this information will answer many of your questions and ease some of the fears that you may have regarding transplantation. However, its purpose is to serve only as an introduction and basis for further discussions with your doctor about the option of transplantation. The information presented deals in general terms and addresses those questions common to most potential kidney transplant candidates. It is not meant to cover all specific medical and social issues that each patient may have, since this must be done on an individual basis.

We suggest as you read through this material, you discuss it with your family and write down any questions that come to mind. Then, please discuss your questions with any member of our transplant team. Our pretransplant coordinators are available Monday through Friday, 8 am to 4 pm, and can be reached at 800.382.4602 or 317.944.4370.

Kidney Transplant Team

Our team is a group of multidisciplinary specialists who provide the patient with comprehensive care. This team includes transplant surgeons, nephrologists, nurse coordinators, anesthesiologists, surgical team members, pharmacists, interventional radiologists, pathologists, urologists, dietitians, social workers, psychologists, nursing staff, chaplains, administrative staff, financial counselors and coordinators.

Transplant coordinators work closely with each patient, helping him or her throughout the entire transplantation process, from evaluation through follow-up care. Our dedicated transplant nursing staff provides excellent care in a specialized hospital unit created just for transplant patients.

About the Kidneys and Kidney Transplants

Most people are born with two, bean-shaped kidneys about the size of a fist. They are located in the middle of the back and their major function is to filter waste products and extra water from the body in the form of urine. In addition to producing urine, your kidneys also regulate your body’s salt, potassium and acid content and produce a variety of hormones that affect the way your other organs function. One hormone produced by the kidneys stimulates the production of red blood cells. Others help regulate your blood pressure and help your body process calcium.

There are two categories of kidney disease—acute and chronic. Acute kidney disease is a temporary condition that usually does not cause permanent damage to the kidneys. Chronic kidney disease (CKD) is the term for kidney damage and decreased kidney function that is permanent. There are many causes of CKD, but diabetes and high blood pressure are the most common. Some CKD conditions are inherited (run in the family), while others are congenital (born with an abnormality).

When patients have lost most of the function of their kidneys and have irreversible damage, this is called end-stage renal disease (ESRD). When the kidney function falls to 10 to 15 percent of normal capacity, dialysis or transplant is needed to survive. There are two different types of dialysis, continuous abdominal peritoneal dialysis (CAPD) and hemodialysis, but they do not work as well as a normally functioning kidney.

Advantages of kidney transplantation include the following:

- An improved feeling of well-being
- Freedom from the schedule of dialysis
- Reduced or eliminated dietary restrictions
- Increased lifespan in most cases

Pediatric Kidney Transplants

We performed the first pediatric kidney transplant in Indiana in 1969. The transplant team understands the special needs of these patients and their families during this difficult time. They are experienced with every aspect of caring for ill children and do so in the very child- and family-friendly environment at Riley Hospital for Children at IU Health.

Transplant Costs

Before moving forward with your evaluation and surgery, our financial counselors and coordinators review your insurance carefully and advise you if they find anything of concern. Many insurance companies have special rules when it comes to transplant benefits. Our finance team will help you understand the rules.

Much of the cost of kidney transplantation is covered by Medicare and private insurance plans. Indiana Medicaid also covers kidney transplantation. If you aren’t already on Medicare, our transplant social worker will discuss this option with you and help you apply for it after your surgery, if needed.
One of the main concerns is the cost of the medications that are needed after transplant. If problems are anticipated, our finance team can help you find programs that may be able to help.

If your insurance changes in any way (changes in coverage, open enrollment with an employer, loss of coverage, etc.), you must tell the financial team immediately. Any insurance changes could mean a big change in your transplant benefits, and our team can advise you on your best options.

**Recipient Evaluation Process**
To be considered for a kidney transplant, the medical team must determine if there are any conditions that may affect normal recovery. Selection criteria for kidney transplant recipients include the following:
- Existing or impending end-stage renal disease
- Free of malignancies (history is evaluated individually)
- Free of active infection
- Intact or correctable urological system
- No active abuse of alcohol or drugs
- Heart and lung status consistent with being able to tolerate the surgery and consistent with a predicted good, long-term outcome
- Ability to follow transplant protocols and medication regimens
- An acceptable body weight

*Every potential candidate is considered on an individual basis.

The first step in your transplant evaluation process is a work-up and medical/surgical consultation. A variety of tests are done that provide the transplant team with information about all of your major organ systems.

**The basic evaluation includes the following tests:**
- Pelvic exam and Pap smear (females only)
- Heart testing (ECG)

Possible causes of kidney failure include:
- Chest X-ray
- Hepatitis, syphilis and AIDS blood tests
- Mammogram (females over age 40)
- Tuberculosis test
- Prostate blood test (males over age 50)
- Blood and HLA tissue typing
- Colon screening (age 50 and over)
- Psycho/social evaluation
- Dental exam and treatment if necessary
- Other tests/consults as needed if test results are abnormal, or if a medical or psycho/social condition suggests more evaluation should be done (determined by the transplant team)

Once you have completed all necessary testing and all the results have been reviewed and approved by the transplant team, your information must be sent to your insurance company for medical review and approval. Most insurance plans take an average of two to four weeks to approve you for a transplant.

**Please note—you are not a transplant candidate until you have completed the evaluation, any necessary corrective procedures and received prior approval from your insurance plan.**

Your transplant coordinator will tell you when the approval process is finished. Kidneys come from two kinds of donors—living donors and deceased donors. If you do not have a potential living donor, you will be added to the United Network for Organ Sharing (UNOS) wait list to wait for a deceased donor kidney transplant. This process is commonly referred to as being “activated” or “listed” and will be discussed in detail later.

**Kidney Transplant—Living Donors**
Because of the increasing shortage of available deceased donor organs and the resulting long wait times, many kidney transplant candidates choose living donor transplantation as an option.

Most people are born with two kidneys. After donating a kidney, a person can live a long and healthy life with just one, because the remaining kidney quickly takes over the work both kidneys were doing previously. Additionally, long-term studies have not shown any decreased kidney function in living donors. However, donors should have close medical follow-up and see their primary care doctor at least once a year for a blood pressure check and kidney function tests.

Living donors may be the following:
- Living-related—siblings, parents, aunts, uncles, children over age 18, cousins or grandparents
- Emotionally related—spouses, in-laws, friends or co-workers
- Altruistic donors—anonymous donors who have chosen to donate a kidney to help someone unknown to them

Of these donors, living-related donors are the most likely to be the best option for donation based on similar inheritance factors.

**Blood and Tissue Types**
Blood types are either A, B, AB or O. Type O is the most common (50 percent of the U.S. population has this type), followed by A (40 percent in the U.S.). Types B and AB are more rare. A table of compatible blood types is listed below. Living donors who are not a compatible blood type may still be able to donate by doing a “donor swap” with another pair that is incompatible or by doing treatments on the recipient before the transplant that would allow his or her body to accept the incompatible blood type.

In addition to blood type, tissue typing (white blood cell/lymphocyte or HLA type) is tested and examined for compatibility. HLA type is inherited, and this is why related living donors may be more likely to be compatible. Although, just like with blood types, the “donor swap” or recipient treatment option may be a possibility if the HLA type is incompatible with a living donor.

**Benefits of Living Donor Kidney Transplantation:**
- Better success rates
- Shorter waiting time
- Ability to schedule—Living donation allows patients to schedule a surgery time that is convenient for the patient and donor
- Avoidance of dialysis—Early referral may allow for transplant prior to initiation of dialysis therapy

**Critera for Donors:**
- Healthy adults at least 18 years old
- Normal renal function with two kidneys
- Free of active infections
- Free of malignancies (history is evaluated individually)

**Blood Type**  **Can receive from:**  **Can donate to:**

<table>
<thead>
<tr>
<th>Blood Type</th>
<th>Can receive from</th>
<th>Can donate to</th>
</tr>
</thead>
<tbody>
<tr>
<td>O</td>
<td>O</td>
<td>O, A, B, AB</td>
</tr>
<tr>
<td>A</td>
<td>A, O</td>
<td>A, AB</td>
</tr>
<tr>
<td>B</td>
<td>B, O</td>
<td>B, AB</td>
</tr>
<tr>
<td>AB</td>
<td>O, A, B, AB</td>
<td>AB</td>
</tr>
</tbody>
</table>

Living-related donors should first contact a living donor kidney transplant coordinator for medical screening. A person should only consider donation if he or she is in excellent health and genuinely wishes to donate without any outside pressure. The donor will then have blood testing to find out his or her blood type and HLA type (tissue typing) to determine compatibility with the recipient. These results are confidential and are given only to the potential donor.

If the potential living donor wishes to continue with the process, he or she will have a detailed evaluation to enable the transplant team to decide if he or she is eligible to donate. The evaluation includes a complete medical/surgical history and physical exam; blood tests, X-rays and procedures to check for general overall health, cancers, heart and lung diseases, and infections; a special kidney X-ray and a psycho/social evaluation. If any problems are found with the routine evaluation, additional testing may be necessary. The transplant team may decide a potential donor is unacceptable to donate at any time during the evaluation. Information about the potential living donor’s medical evaluation will not be discussed with the potential recipient.

Although living kidney donation has been performed for many years and appears to be safe, complications may occur. Surgical and medical risks will be carefully discussed with the donor and their family during the evaluation. All the costs for the living donor evaluation are covered by the transplant center and all costs related to the donor surgery are charged to the recipient’s insurance. Costs that cannot be covered include time lost from work and transportation.
The donor’s hospital stay is normally two to three days. The ability to return to normal activities and work varies, but generally this is possible within two to eight weeks.

Many donors find living kidney donation to be extremely rewarding and meaningful. They are often thrilled to have helped restore health to someone despite the risks. Many family members say it has strengthened the bond with their loved one by donating. Those who choose to donate a kidney are seen by the recipient and the recipient’s loved ones as a true hero.

The transplant team is committed to making the living donation process as easy as possible for the donor and the recipient.

**Kidney Transplant—Deceased Donors**

If a recipient does not have a potential living kidney donor, or chooses not to have one, he or she can be placed on the deceased donor waiting list.

The National Organ Transplant Act of 1984 required the development of uniform national policies to define how all solid organs from deceased donors are distributed. UNOS was established and oversees organ allocation on a national basis. Balancing fairness with medical usefulness is the intention of this system. The distribution of kidneys is complicated, but currently deceased donor organs in Indiana are usually offered to recipients on Indiana waiting lists first, but kidneys can be exported to and imported from anywhere in the United States. Please keep in mind that national policies are constantly reviewed and subject to change. You will receive the most current information on kidney distribution once you are activated.

Once you are activated, you will need to be sure your transplant coordinator always has current information on how to reach you.

**On the Waiting List**

No one can predict how long it will take before a deceased donor kidney becomes available and we discover the recipient has a health problem that we were unaware of. You always want to be honest and inform your coordinator of any fever, a productive cough or any other health concerns. Doing a transplant when you are not in the best of health could cause multiple serious problems. The transplant team will decide if it is safe to proceed with the transplant.

While you wait for a deceased donor kidney transplant, you will have a monthly blood sample sent to us for panel-reactive antibody (PRA) testing. If you are on dialysis, they will draw this sample and send it to us. If you are not on dialysis, you will be sent orders and supplies to have this done monthly. This blood sample is tested to determine if you have, or have developed, anti-HLA antibody since your initial tissue typing tests were done. As you recall, the HLA type is another compatibility test that is looked at along with the ABO blood type. Recipients can develop antibodies against specific HLA markers that can make them incompatible with a deceased and/or living donor who has those specific markers. These antibodies can develop or change over time and need to be monitored carefully to predict the likelihood of there being incompatibility. Things that can possibly change a recipient’s PRA are blood transfusions, pregnancy and previous transplants. Testing called a final crossmatch is always done just prior to a deceased or living donor transplant to make sure that there are no compatibility issues. A negative crossmatch is the desired outcome.

While you are waiting for a transplant, you will be expected to keep current with your general health care maintenance (dental visits, Pap smears and mammograms, etc.) and to keep us informed of any changes in your health status. Although your nephrologists and/or dialysis staff share information regarding your health with us, you need to be an active participant also. You may be placed “on hold” on the wait list if there is a problem until it is resolved. This temporary inactive status will not affect your place on the list. One of the most distressing events is when a deceased donor kidney becomes available and we discover the recipient has a health problem that we were unaware of. You always want to be honest and inform your coordinator of any fever, a productive cough or any other health concerns. Doing a transplant when you are not in the best of health could cause multiple serious problems. The transplant team will decide if it is safe to proceed with the transplant.

**General Health Tips While Waiting for Your Transplant**

Waiting for a donor organ can be a stressful experience, especially because the amount of time you’ll have to wait is unknown. Regardless, there are important steps transplant candidates can take to ensure they are ready for surgery when the important call comes.

- **Take care of your health.** Try to stay as healthy as possible, and take your medicines as they are prescribed. Notify your transplant coordinator if any additional medicines are prescribed or altered, or if you are hospitalized for any reason.
- **Keep scheduled appointments with your physician.** Until your transplant, you will need to continue to see your physician(s) to evaluate your overall health.
- **Follow dietary guidelines.** Weight management is very important while waiting for your transplant. A dietitian can work with you to plan and develop a diet program that will give you the greatest benefit before and after transplantation.
- **Occupy yourself by staying involved.** Spend time doing what you enjoy, and stay as active as your physical condition will permit. Keep up with your work, studies and/or leisure activities, or start a project or hobby that can help distract you.
- **Maintain contact with family and friends.** Good company will take your mind off of waiting and enrich your life.
- **Just relax.** Reading or listening to music or relaxation CDs can be helpful in taking your mind off your transplant and avoiding negative thoughts.

**Getting the Call**

Unlike a living donor transplant that is scheduled in advance, a deceased donor kidney transplant is last-minute notice. “The call” can come at any time, day or night, and it is your responsibility to make sure you are always available to receive this call. When you are activated, your transplant coordinator will ask you to provide multiple phone numbers for the best ways to reach you. Please be sure to update your coordinator with any changes in your contact information.

For deceased donor kidneys, the transplant coordinators have one hour to reach you for the potential kidney transplant. If the coordinator cannot find you in one hour, then you will be passed by, and the next patient on the list is called. Please be assured that the coordinator will do everything possible to find you, but ultimately, it is your responsibility to make sure the coordinator can locate you. Once the coordinator reaches you, he or she will give you specific information about the admission process.

**Tips for the Call**

- **Make sure you are available.** It is important for your transplant team to know how to get in touch with you at all times. Cell phones and/or pagers allow you to be away from home and still able to be reached. If you will be out of town and still want to be included, you can call your coordinator with other ways to reach you. If you are gone and know it would be difficult to get back for a transplant, you can be placed “on hold” temporarily, and your name will not come up during that time. This will not affect your ranking for future calls. You must remember to update us if any of your contact information changes.
- **Be prepared by having a list of things you need to bring with you.** This list should include insurance information, driver’s license and medications. Other things to bring if you have them are your pager, blood pressure cuff, glucometer, loose fitting clothing and any other necessities.
- **Be prepared with transportation.** When you are placed on the waiting list, your first responsibility is to plan how to get to the transplant center. Prepare yourself for this call by making the necessary arrangements for transportation well in advance.
There can be times that a patient is called in and does not receive a transplant. Examples include the following:

- More than one potential recipient is called even though only one kidney is available for transplant. This usually happens when the first patient has a high PRA and might have a positive final crossmatch. A positive crossmatch means that the new kidney would probably be rejected, so the transplant is not done. Since crossmatches take several hours to do, a “backup patient” is called in so the kidney can then be transplanted quicker than having to try to locate another recipient. The sooner a kidney is transplanted, the better chance of it working properly.
- Occasionally, after a recipient is called in, a problem is discovered with the donor or the donor’s kidney. Obviously, the transplant team only wants to use kidneys that are safe and will benefit you. In these cases, the transplant recipient would be sent home to wait for the next call.
- If a health problem for the recipient is found and the transplant team feels it would be unwise to proceed with the transplant at that time, the recipient will be sent home and placed on hold temporarily until the issue is resolved.

Your Transplant Surgery and Hospitalization

When you come to the hospital, you will have preoperative evaluation and testing done before either a living or deceased donor kidney transplant.

Blood will be drawn for routine lab tests and final donor/recipient crossmatching, in addition to heart testing and a chest X-ray. If this final evaluation confirms that you don’t have new medical problems and that the crossmatch is acceptable, then the transplant surgery will proceed.

If you are on hemodialysis, you may have to dialyze prior to your surgery. Continuous Ambulatory Peritoneal Dialysis (CAPD) patients will usually do exchanges until the time of surgery. Most recipients who have not begun dialysis will not need to have dialysis prior to surgery, but there can be exceptions.

Surgery

The kidney is placed into the lower part of the abdomen, on either the right or left side just above the hipbone. It is put in this spot because it is close to the blood supply it needs and the bladder. The incision for the surgery is usually about eight to 10 inches long. The kidney blood vessels are attached to branches of the patient’s main artery and vein (aorta and vena cava). The ureter (the tube that carries urine from the kidney) is attached to the bladder. In most instances the recipient’s own kidneys are left in place.

The surgery usually takes two to four hours. Family members can expect a five- to six-hour wait from the time you are taken to surgery until the time you get to the recovery room.

Family members may wait in the surgery waiting area where they will be updated frequently by the operating room staff. The transplant surgeon will meet with the family to tell them about your condition after the surgery.

Risks and Complications of Transplant

As with any surgery, there can be complications. Generally the complication rate after a kidney transplant is very low. Some of these complications are the following:

- Technical complications—These happen less than three percent of the time but can include the following:
  - Clotting of the blood vessels to the kidney
  - Bleeding
  - Blockage of urinary drainage from the kidney to the bladder
  - Urine leak
- Other complications related to general anesthesia and abdominal surgery:
  - Heart attack
  - Stroke
  - Hernia
  - Reaction to anesthesia
  - Bowel problems
  - Pulmonary embolus (blood clot to the lungs)
  - Poor healing of the surgical incision
  - Death
- Rejection—Rejection occurs when the body recognizes the transplanted kidney as not belonging and tries to destroy it. There are different types of rejection, but most can be treated and reversed. It may be necessary to do a kidney biopsy to identify the presence and severity of rejection so the proper treatment can be started. The highest risk for rejection is within the first three months after the transplant, so close monitoring is critical. But, it is important to remember that rejection can happen at any time, even years later. Therefore, it is critical that you follow all medical guidelines that the transplant team gives you.
- Infection—The drugs taken to prevent rejection can decrease your body’s ability to fight infections. Infections in a transplant patient can be serious and even life threatening. Your medications will be closely monitored and adjusted as needed to keep the risk of infection as low as possible.
- Malignancy—Transplant patients have a slightly higher risk of cancer than the general population. Skin cancers are the most common, but the risk can be decreased by avoiding prolonged exposure to the sun and wearing sunscreen.
- Recurrent disease—Although uncommon, certain types of kidney diseases may come back in the transplanted kidney and can lead to progressive loss of kidney function. For some patients, no one knows what caused their kidneys to fail before the transplant, so it is impossible to say if the same thing will happen to the transplanted kidney.
- Donor risk factors—Both living and deceased donors are screened very carefully, however, there is still potential risk of contracting diseases that are not detected at the time of donation.

Transplantation is not a cure—it is a treatment option, as is dialysis. It is important that you consider your treatment options carefully and discuss your choice with your family and/or support person(s). The transplant team is available to answer any questions you may have.

You have the right to refuse transplant at any time up to the time of surgery.

After Surgery

You will go from the operating room to the recovery room where you will be closely monitored. After you have recovered from the anesthesia, you will usually then go to the specialized Organ Transplant Unit. Pediatric patients generally spend approximately one day in the Riley Hospital Pediatric Intensive Care Unit. After that time they are transferred to the Riley Transplant Unit.

Catheter—During surgery, you will have a catheter inserted in your bladder so your urine can drain and the output can be carefully measured and monitored. The catheter is usually taken out two to four days after surgery. At that point, you may feel the need to urinate frequently. This is because your bladder has gotten used to working very little before the transplant since your kidneys were probably not making much urine. The bladder will adjust and normal frequency will usually return within a few weeks.

Stent—Sometimes a stent (plastic tube) will be put in the ureter to keep it open to drain urine. The surgeon will decide whether to place a stent during the surgery. A urologist will remove the stent about six weeks after the transplant during an outpatient procedure called a cystoscopy.

Activity—In most cases, the staff will help get you up in a chair within 24 hours of surgery. You will also be encouraged to do deep breathing and coughing exercises to prevent lung complications.

Pain control—Your nurse will provide you with pain medication and will monitor its effectiveness.

Monitoring vital signs and fluids—You will have an IV (intravenous) line placed in surgery so IV fluids and medicines can be given to you. There will be frequent checks of your vital signs and measurements of your fluid intake and output.

Kidney Function Testing—You will have frequent blood and urine tests to check the function of your transplanted kidney.

Nutrition—You will be started on a liquid diet right after surgery. The diet will be advanced as tolerated to a healthy heart diet.
Dialysis—In most cases, the transplanted kidney starts to work right away. If that does not happen, you may need dialysis until the kidney recovers from the “shock” of being transplanted. If you were on Continuous Ambulatory Peritoneal Dialysis (CAPD) before surgery, you would need hemodialysis because of the increased risk of infection with CAPD. CAPD catheters are generally removed six to eight weeks after a successful kidney transplant.

The length of time recipients need to stay in the hospital varies; however, many recipients are able to leave the hospital in as few as three to five days.

Family members who have any type of infection should not enter your room. Children are welcome on the Organ Transplant Unit, but they should receive a health clearance at the information desk.

Cut flowers are not allowed in your room because of harmful bacteria that may grow in the water, but potted plants, Mylar balloons and cards are welcome.

Discharge and Follow-up

Following the transplant surgery, your transplant team’s goal is to assist you in rehabilitation and return to wellness, and to prepare you to care for yourself when you go home. You and your support person(s) are active members of this team. The nursing staff and clinical coordinators will teach you about proper care and important skills such as blood pressure monitoring, measuring intake and output, taking medications properly, etc. Written instructions and a teaching video (DVD) will be provided.

You will receive a transplant handbook that you should bring with you to all your follow-up visits. Add questions you may have, and consult the transplant coordinator.

Immunosuppressives and Other Medicines

You will take immunosuppressive (anti-rejection) medication for as long as you have your transplanted organ. You will probably be taking two or three immunosuppressive medicines that work in different ways to prevent rejection. All are equally important. To receive the maximum benefit, they should be taken exactly as directed. Your doctor will choose the best drug regimen for you.

All immunosuppressives, while preventing rejection, also lower your resistance to infection. For this reason, it is especially important to review the measures for preventing infection. If you experience any symptoms of illness, contact your transplant coordinator.

Please remember that your transplant will fail without immunosuppressive medicines. The most common reason that a transplanted kidney is rejected after one year is that the recipient fails to take his or her medicine properly. It is your responsibility to make certain that you have an adequate supply of medicine and that you take it every day as directed. We strongly suggest you keep a two-week supply of all your medicines on hand should weather or illness prevent you from traveling to obtain prescription refills.

Most patients take other medicines in addition to their immunosuppressive drugs. These may include medicines to prevent infection, anti-hypertensives (for high blood pressure), vitamins, diuretics (water pills), antacids, etc. Some of these medicines may only need to be taken for a short time, while others may be continued for other medical conditions you have. If another doctor prescribes medication for you, it is wise to let the transplant team know to make sure that they do not interfere with your immunosuppressive medicines.

After Kidney Transplant

Most kidney transplant patients have an excellent quality of life. They enjoy new dietary freedoms and a life free of dialysis. To make sure things stay that way, you’ll need to keep focused on the things that can impact long-term health after your transplant.

We at IU Health Transplant look forward to working with you to achieve this goal!

For more information, contact us at:
Indiana University Health Transplant
550 N. University Blvd., Room 4601
Indianapolis, IN 46202
T 800.382.4602
iuhealth.org/transplant
A private, nonprofit organization, Indiana University Health is Indiana’s largest comprehensive health system and is comprised of hospitals, physicians and allied services dedicated to providing preeminent care throughout Indiana and beyond. Our unique partnership with the Indiana University School of Medicine gives our highly skilled physicians access to innovative treatments using the latest research and technology.

Discover the strength at iuhealth.org