Donating a Kidney for Transplantation

Living Kidney Donation Patient Education
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Indiana University Health has a long history in the field of transplantation, and consistently ranks as one of the largest transplant programs in the nation by volume. IU Health Transplant performed Indiana's first kidney transplant in 1965. Since then, more than 5,900 kidney transplants have been performed at IU Health, and over 1,800 of these have been living donor kidney transplants.

The purpose of kidney transplantation is to give a healthy kidney to a person who has kidney disease. A successful kidney transplant may prevent the need for dialysis and the complications associated with kidney failure. The kidney that is transplanted can come from a person who has died (a “deceased donor”), or it can come from a person who wishes to donate while alive (a “living donor”). There are not enough deceased donor kidneys for the number of people who need a kidney transplant.

You are considering having major surgery to give one of your kidneys to another person. We ask that you read the following information and ask any questions you may have before agreeing to undergo this procedure. The IU Health Transplant team is available to assist you throughout the entire donation process, from evaluation through follow-up care. The living donor coordinators are available Monday – Friday, 8am – 4 pm, and can be reached at 800.382.4602 or 317.944.4370.
Evaluation Process

You will be evaluated with consultations, lab tests and various procedures to determine the medical appropriateness of kidney donation. You will interact with many members of the transplant team who may include:

- **A Financial Coordinator** is a nurse case manager who will work with your recipient’s insurance so transplantation will be at no cost to you the donor.

- **The Transplant Coordinator** is a registered nurse who specializes in the transplant and donation process. Your coordinator will provide you with education regarding the donation and transplant process. You are encouraged to ask questions and to become fully informed about the kidney donation and transplant process. He or she will also discuss any possible costs associated with donation so that you understand the costs that may not be covered by insurance.

- **A Nephrologist** is a physician who specializes in kidney disease. The nephrologist will assess the function of your kidneys and the safety of your donation.

- **Your Surgeon** will meet with you and discuss the appropriateness of donating one of your kidneys. The surgeon will also discuss the significance of donating one of your kidneys, the risks of the surgery and the possible complications after your donation.

- **An Anesthesiologist** will meet with you the day of surgery, review your medical history, and discuss your risk from anesthesia.

- **A Psychiatrist/Psychologist** will conduct an in-depth evaluation and assessment of your psychosocial history, the relationship between you and the intended recipient and your ability to cope with the donation process.

- **Social Workers** are available to provide support and identify resources that may be beneficial when needed.

- **A Registered Dietitian** is available to perform a nutritional assessment and provide nutrition education.

- Some potential donors may be referred to another service for consultation. For example, some patients need to be seen by a pulmonologist (lung doctor) or a cardiologist (heart doctor) to assess for other medical conditions.
Many different tests are done to determine if you are a suitable donor. Some of the following tests may be included in your evaluation process. Remember, other tests may need to be done based on the results of these tests.

- Blood tests are done to determine your blood type and identify any possible reason that you might not be able to donate one of your kidneys. These tests will screen for your immunity to or the presence of specific viruses, including HIV. Additional blood tests may be used to determine how well other organs are functioning.

- A chest X-ray helps your physician identify any problems with your lungs.

- A urine test is used to screen for the presence of urinary tract infections and kidney diseases.

- An EKG, echocardiogram and/or stress test will show how well your heart is functioning. This will help your physicians decide if your heart is strong enough for surgery.

- A CT scan will be done to identify anatomy, blood flow to and from your kidneys, and the presence of tumors or kidney stones.

- Testing will be done to make sure that you have adequate kidney function.

- Pulmonary function tests may be required, especially if you have a history of smoking or a history of lung disease. This is a breathing test to analyze your lung capacity and function.
**Surgical Procedure**
The surgery will be conducted under general anesthesia. The surgeon will place three small holes in your abdomen for a camera and surgical instruments, and one incision will be made to remove your kidney. Your abdomen will then be closed.

You will have a small IV tube and a urinary tube (catheter) in place for 1 – 2 days after surgery. Most donors remain in the hospital for 2 – 3 days. You will probably feel more tired than usual for one to three months after the surgery. Depending on your job’s physical requirements, you should be able to return to work in 2 – 6 weeks.

**Alternative Treatments**
Alternative treatments or therapies may be available for the recipient’s medical condition such as dialysis or deceased donor kidney transplant. Please feel free to discuss kidney disease and/or any possible alternative therapies with the healthcare team.

**Potential Surgical and Medical Risks**
A donor undertakes risk and receives no medical benefit from the operative procedure of donation. There are inherent risks in all surgeries, especially surgeries conducted under general anesthesia. Many complications are minor and get better on their own. In some cases, the complications are serious enough to require another surgery or medical procedure, and although rare, there is the risk of death.

- **Bleeding** during or after surgery may require blood transfusions or blood products that can contain bacteria and viruses that can cause infection. Although very rare, these infections include, but are not limited to, the Human Immunodeficiency Virus (HIV), the hepatitis B virus (HBV) and the hepatitis C virus (HCV).

- Despite efforts to prevent them, blood clots may occasionally develop in the legs and can break free and occasionally move through the heart to the lungs. In the lungs, they can cause serious interference with breathing, which can lead to death.

- The abdominal incision is a potential site for infection. Infections at the sites where tubes are placed in your body (tubes to help you breathe, tubes in your veins to provide fluids, nutrition and to monitor important body functions) can cause pneumonia, blood infections and local infections.

- Damage to nerves may occur. This can happen from direct contact within the abdomen or from pressure or positioning of the arms, legs or back during the surgery. Nerve damage can cause numbness, weakness, paralysis and/or pain. In most cases these symptoms are temporary, but in rare cases they can last for extended periods or even become permanent.

- Other possible complications include: injury to structures in the abdomen, burns caused by the use of electrical equipment during surgery, damage to arteries and veins, pneumonia, heart attack, stroke, permanent scarring at the site of the abdominal incision, pain, fatigue, abdominal or bowel symptoms (such as bloating and nausea).
Potential Psychosocial and Financial Risks
Choosing to donate a kidney can give you the opportunity to enrich the life of someone in need. There are, however, possible personal-risks which include but may not be limited to:

- Problems with body image
- Possibility of rejection of the transplanted organ and the need for recipient re-transplantation, recurrence of kidney disease in the recipient or recipient death
- Impact of donation on lifestyle or ability to obtain future employment
- Personal expenses of travel, housing, food, child care and lost wages related to live donation (some assistance may be available for qualifying individuals)
- Future health problems related to the donation may not be covered by your insurance
- After you donate one of your kidneys, health insurance companies may consider you to have a pre-existing condition and refuse payment for certain medical care, treatments or procedures
- After the surgery, your health insurance and life insurance premiums may increase and remain higher
- In the future, ability to obtain health, disability and life insurance could be affected; this risk of insurance coverage issues can be minimized by avoiding any gaps in your insurance coverage or maintaining continuous coverage

National and Transplant Center-Specific Outcomes
We are required to provide information about all organ transplantation to the United Network for Organ Sharing (UNOS). This includes information about the living donor, including name, birth date, sex, social security number, blood type, the donor's relationship to the recipient and some blood test results. UNOS then assigns a case number to the transplant recipient and the donor. The identifying information is not accessible to the public or to other researchers. This information is collected in order to determine how many live donor kidney transplants are done, how many are successful and what the complications are. We will provide you with the current national and IU Health Transplant survival statistics from the Scientific Registry of Transplant Recipients (SRTR). These can also be found at srtr.org.

Donor Commitment to Medical Follow-up
We are required to obtain and report information on all living donors at the time of donation, and at six months, one year and two years after the donation. We will send you a kit to have blood and urine samples collected and returned to IU Health for processing, as well as a brief health questionnaire. IU Health Transplant will cover the costs related to these tests.

We strongly recommend regular follow-up with your primary care physician at least yearly. The financial responsibility of this follow-up is yours, the donor.
Notification of Medicare Outcome Requirements Not Being Met by Center
Specific outcome requirements need to be met by transplant centers, and we are required to notify you if we do not meet those requirements. IU Health Transplant currently meets all requirements for transplant centers.

Right to Withdraw
You have the right to withdraw your participation as a donor at any time during the process. Information about your medical evaluation, diagnostic test results, etc., will not be discussed with the potential kidney transplant recipient. It is up to you what information you discuss with the potential recipient.

Transplantation by a Transplant Center Not Approved by Medicare
If you donate your kidney to a recipient having a transplant at a facility that is not approved by Medicare for kidney transplantation, the recipient’s ability to have immunosuppressive drugs paid for under Medicare Part B could be affected. IU Health Transplant is a Medicare approved transplant center.

Waiting Time Transfer and Multiple Listing
If listed for a deceased donor transplant, the recipient has the option of being listed for transplant at multiple transplant centers and has the ability to transfer waiting time to a different transplant center without loss of the accrued waiting time.

Sale or Purchase of Human Organs
To comply with the United Network for Organ Sharing (UNOS) Bylaws Appendix B, Attachment I Section XIII (C) (2), we are required to inform you that the sale or purchase of human organs is a federal crime and that it is unlawful for any person to knowingly acquire, receive or otherwise transfer any human organ for valuable consideration for use in human transplantation.

Additional Information
You might want to visit the websites listed below for additional information regarding living kidney donation and kidney transplantation.

IU Health Transplant: iuhealth.org/transplant
Donate Life America: donatelife.net/understandingdonation/livingdonation.php
National Kidney Foundation: kidney.org
Transplant Experience – Astellas: transplantexperience.com/kidney
United Network for Organ Sharing (UNOS): transplantliving.org
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

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