



Indiana University Health

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# **Donating a Kidney for Transplantation**

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Living Kidney Donation Patient Education

## **Donating a Kidney for Transplantation**

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 7,000 kidney transplants have been performed at IU Health, and over 2,000 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, 8 am - 4 pm, and can be reached at 800.382.4602 or 317.944.4370.

### **Who Can Donate?**

In general you must be healthy, in good physical and mental health, and at least 18 years old to be a living donor. You will complete a thorough medical and psychosocial evaluation and you will be fully informed of the known risks involved with donation. Your decision to donate should be completely voluntary and free of pressure or guilt.

### **Types of Living Donation**

- Related – Blood relatives of transplant candidates, including parents, children (over 18 years old), brothers, sisters, half brothers and sisters, aunts, uncles, cousins, nieces and nephews.
- Non-Related – Donors emotionally close to transplant candidates, but not related by blood, including spouses, in-law relatives, close friends, coworkers, neighbors or other acquaintances.
- Non-Directed – Donors not related to or known by the recipient, but who make a decision to donate purely out of unselfish motives. This type of donor is commonly referred to as an anonymous or altruistic donor.
- Paired Donation – An option for kidney recipients and their donors who are not compatible or are poorly matched to be matched with other recipients and donors. The recipients “trade” donors to allow the transplants to occur.

### **Evaluation Process**

Living donors must be chosen carefully in order to avoid outcomes that are medically and psychologically undesirable. You will be evaluated with consultations, lab tests and various procedures to determine the medical appropriateness of kidney donation. IU Health takes all reasonable precautions to provide confidentiality for both the donor and the recipient.

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 the donation process 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.
- A **Living Donor Advocate (LDA)** is independent of the recipient transplant team and acts solely on your behalf to ensure that your rights are protected and that your decision to donate is informed and voluntary. The LDA is available to you throughout the donation process.
- 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(s) from anesthesia.
- A **Psychiatrist** or **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.
- A **Social Worker** is available to provide support and identify resources that may be beneficial when needed. You will meet with a Social Worker during your evaluation.
- A **Registered Dietitian** is available to perform a nutritional assessment and provide nutrition education and support.
- 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 human immunodeficiency virus (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 disease.
- An EKG, echocardiogram and/or stress test will show how well your heart is functioning. This will help your physician 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.

### **Potential Risks of the Living Donor Evaluation Process**

Health information obtained during the evaluation could reveal conditions that must be reported to local, state, or federal public health authorities. During the evaluation process, risks that a donor may encounter include:

- Allergic reactions to contrast (dye used in some testing)
- Discovery of reportable infections
- Discovery of serious medical conditions
- Discovery of adverse genetic findings that may be unknown to you

Routine donor evaluation tests are paid for by IU Health Transplant. **PLEASE NOTE:** If you seek evaluation testing outside of the IU Health system, we cannot guarantee that the outside hospital will accept or follow the billing process required for IU Health Transplant to pay the claims. If this occurs, you may be financially responsible for those bills. In addition, if medical issues are identified during the evaluation process that are unrelated to donation, you will be referred to your primary physician for further follow-up. Financial responsibility for any testing or care you receive that is not related to the kidney donation will be yours and/or your insurance provider.

The IU Health Transplant team may determine that you are not a candidate for living donation at this center. If this occurs, you may choose to pursue evaluation by another transplant hospital that might evaluate you using different selection criteria.

### **Information Regarding Transplant Candidates/Recipients**

- Each transplant hospital determines candidacy for transplantation based on existing hospital specific guidelines or practices and clinical judgment
- It is possible that a deceased donor kidney could become available for a recipient who is listed on the United Network for Organ Sharing (UNOS) waiting list before the living donor evaluation is completed or the living donation/transplant occurs
- 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
- Any transplant candidate may have an increased likelihood of adverse outcomes (including but not limited to graft failure, complications, and mortality) that:
  - Exceed local or national averages
  - Do not necessarily prohibit transplantation
  - Are not disclosed to the living donor

- IU Health Transplant can disclose to the living donor certain information about transplant candidates only with the permission of the candidate, including:
  - The reasons for a candidate's increased likelihood of adverse outcomes
  - Personal health information collected during the candidate's evaluation, which is confidential and protected under privacy law
- 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.

## **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 1 - 3 months after the surgery. Depending on your job's physical requirements, you should be able to return to work in 2 - 6 weeks.

## **Potential Surgical and Medical Risks**

A living 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. Potential complications and risks will be discussed with you further during the evaluation process. To reduce some of these risks, it is required that IU Health living donors discontinue use of all nicotine, including nicotine replacement products.

- Donor-specific pre-existing conditions including, but not limited to, age, obesity or hypertension may impact the morbidity and mortality of the donor.
- 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, human immunodeficiency virus (HIV), hepatitis B virus (HBV), and 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 and 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 of time 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 abdominal incision, pain, fatigue, scrotal swelling, hernia, bowel obstruction, and abdominal or bowel symptoms (such as bloating and nausea).
- Surgical risks may be temporary or permanent and include but are not limited to:
  - Decreased kidney function
  - Acute kidney failure and the need for dialysis or kidney transplant for the living donor in the immediate post-operative period.
- After kidney donation:
  - On average, living donors will have a 25 - 35% permanent loss of kidney function.
  - The baseline risk of end-stage renal disease (ESRD) for living kidney donors does not exceed that of the general population with the same *demographic* profile.
  - Living kidney donors may have a higher risk of developing ESRD than healthy non-donors with similar *medical* characteristics
  - Living donor risks must be interpreted in light of the known epidemiology of both chronic kidney disease (CKD) and ESRD. When CKD or ESRD occurs, CKD generally develops in mid-life (40 - 50 years old) and ESRD generally develops after age 60. The medical evaluation of a young living donor cannot predict the lifetime risk of CKD or ESRD.
  - Living donors may be at higher risk for CKD if they sustain damage to the remaining kidney. The development of CKD and subsequent progression to ESRD may be faster with only one kidney.
  - Dialysis is required if the living donor develops ESRD.
  - The current practice is to prioritize prior living kidney donors who become kidney transplant candidates.
  - Female living donors have increased risks of preeclampsia or gestational hypertension in pregnancies after donation
- Donation-related complications that occur, even after discharge:
  - May require the donor to return to IU Health to receive treatment

**PLEASE NOTE:** If you seek medical treatment related to the donation surgery that is outside of the IU Health system, we cannot guarantee that the outside hospital will accept or follow the billing process required for IU Health Transplant to bill the claims to your recipient's Medicare. If this occurs, you may be financially responsible for those bills.

## **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 to you as a result of donation which include but may not be limited to:

- Problems with body image
- Post-surgery depression or anxiety
- Feelings of emotional distress or grief if the recipient rejects the transplanted organ, has recurrence of disease or dies.
- Changes to your lifestyle
- 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 of a living donor following donation may not be covered by the recipient's insurance or your insurance
- Loss of employment or income
- Negative impact on your ability to obtain future employment
- 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, your ability to obtain, maintain or afford health, disability and life insurance could be negatively affected; this risk can be minimized by avoiding any gaps in your insurance coverage or maintaining continuous coverage

## **Reporting Requirements and Donor Commitment to Medical Follow-Up**

We are required to provide information about all organ transplantation to 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 if there are any complications.

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 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 for you to complete. IU Health Transplant will cover the costs related to these tests.

It is important for you to be aware that any infectious disease or malignancy discovered during the first two years of follow-up that is relevant to the care of the recipient of your kidney will be shared

with you, the recipient's transplant hospital, and through the Organ Procurement and Transplantation Network (OPTN) Improving Patient Safety Portal. Additionally, some infections may need to be reported to local, state, or federal public health authorities.

You will need life-long follow-up after kidney donation. We strongly recommend regular follow-up with your primary care physician at least yearly. The financial responsibility of the follow-up is yours, the donor.

### **National and Transplant Center-Specific Outcomes**

We will provide you with the current national and IU Health Kidney Transplant survival statistics from the Scientific Registry of Transplant Recipients (SRTR). These can also be found at [srtr.org](http://srtr.org). Specific survival outcome requirements must be met to be an approved transplant center by the Centers for Medicare and Medicaid Service. IU Health Transplant meets these requirements and is a Medicare-approved transplant center.

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.

### **Right to Withdraw**

You have the right to withdraw your participation as a donor at any time during the process, and we will assist you in doing so in a manner that is protected and confidential. 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.

### **Sale or Purchase of Human Organs**

The sale or purchase of human organs is a federal crime and it is unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration (i.e. anything of value such as cash, property, vacations) for use in human transplantation.

### **Additional Information**

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

- IU Health Living Kidney Donation: [iuhealth.org/living-kidney-donation](http://iuhealth.org/living-kidney-donation)
- IU Health Transplant: [iuhealth.org/transplant](http://iuhealth.org/transplant)
- Donate Life America: [donatelife.net/living-donation/](http://donatelife.net/living-donation/)
- United Network for Organ Sharing (UNOS): [transplantliving.org](http://transplantliving.org)
- National Kidney Foundation: [kidney.org](http://kidney.org)
- Transplant Experience – Astellas: [transplantexperience.com/Kidney](http://transplantexperience.com/Kidney)