LIVING DONATION

What You Need to Know





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ABOUT LIVING DONATION

Introduction

Donating a kidney is a generous act that can help improve another person's life. It allows someone whose own kidneys have failed to live without needing dialysis. If you are thinking of donating a kidney, you should learn as much as you can from many different sources. This brochure will help you get started. It will give you some basic information about living donation.

What is living donation?

Living donation takes place when a living person donates an organ (or part of an organ) to another person. The person who donates an organ is called a "living donor."

The living donor can be a family member, friend, or spouse. In some cases, it could even be someone you've never met.

The kidney is the most common organ that is donated by a living person. However, it's also possible to donate part of your liver, pancreas, lung, bone marrow, or intestine. This brochure will focus on living kidney donation.

Who can be a living kidney donor?

To donate a kidney, you must be in good physical and mental health. As a general rule, you should be 18 years or older. You must also have normal kidney function. There are some medical conditions that could prevent you from being a living donor. These include having uncontrolled high blood pressure, diabetes, cancer, HIV, hepatitis, or acute infections. Having a serious mental health condition that requires treatment may also prevent you from being a donor.

Are there different types of living donation?

There are two main types of living donation:

Directed donation

This is when the donor names a specific person who will receive the kidney. It is the most common type of living donation. Directed donations are often between blood relatives, like parents, siblings, or children. They can also occur between people with close personal relationships, such as a spouse, friend, or coworker.

Nondirected donation

This is when a person does not name a specific person who will get the kidney. In this case, the donor is matched with someone in need.

How long does a transplanted kidney last?

On average, a kidney from a living donor lasts about 15 to 20 years. Some will last longer; others might last less.





THE EVALUATION PROCESS

How do I donate a kidney?

If you want to donate to someone you know, your first step is to talk to him or her and the transplant center where the person is listed. Transplant centers are hospitals that perform kidney transplant operations.

If you are interested in donating to someone in need as a nondirected donor, contact a transplant center of your choice. Let them know you are interested in donating a kidney to someone in need.

Becoming a living donor has many benefits, but it also has risks. Your decision to donate will affect the lives of your family members as well, so it should not be taken lightly. Learn all you can about the process, evaluation, surgery, and recovery. Make sure you consider how donation will affect your life, including your family relationships, your finances, your health, and your employment. Talk with family members,

friends, and others you trust. Be sure to include people you trust in your decision-making process. You may also be interested in speaking with other living kidney donors to learn more about their experiences.

What will happen after I contact a transplant center?

After you contact the transplant center staff, they will begin a basic medical screening. They will ask you questions about your medical history to find out if you have any conditions that would prevent you from donating. You may be sent a health questionnaire to fill out. This initial screening is followed by a blood test to find out whether you are compatible with the recipient.

You will also be assigned an Independent Living Donor Advocate (ILDA), who will assist you during the donation process. This person's sole job is to look after your best interest. They will answer your questions and help you get information. They will also make sure you understand the possible risks and benefits of donation, and any impact it may have on your emotional life, finances, family, future employment, and health. Everything that is discussed between you and the ILDA is kept private and confidential.

If you are interested in donating a kidney, you will start a full evaluation process. This serves two purposes—to protect you and to help ensure the success of the transplant.

What does a "full evaluation" involve?

You must complete a financial consultation, a psychological evaluation, and extensive medical tests. The results will be kept completely confidential. They will not be shared with the recipient.

Financial consultation

Staff at your transplant center will ask about your finances and insurance coverage. In general, if you are donating to a family member or friend, the recipient's insurance will pay your expenses for testing and surgery. However, you may be responsible for travel expenses, lost wages, and some follow-up care. If any health problems that require treatment are discovered during your medical tests, you or your health insurance will be responsible for them.

Psychological evaluation

The transplant team makes sure that each donor is in good mental health and understands the donation process. They will educate you about all aspects of living donation and make sure you are able to make an informed decision.



One reason this is done is to make sure there is no pressure from friends or family, no promise of financial incentive, and that your expectations are realistic. This is also an opportunity for you to express yourself more fully than you might be able to with family or the recipient present.

Medical tests

The following is a general description of the medical tests. The process may vary from center to center.

- Medical history. You will be asked to give a complete and thorough history of any illnesses, surgeries, and treatments you've had in the past. You will also be asked about your family's medical history. If any problems or abnormalities are found, they will be investigated further.
- Physical exam. You will be given a physical examination to make sure you are healthy enough to donate a kidney.
- Chest X-ray and electrocardiogram (EKG). These tests are done to check for heart or lung disease.
- Radiological testing. These tests allow physicians to look at your kidney, including its blood vessel supply.
- Urine testing. A 24-hour urine sample is collected to make sure you have good kidney function. If it is found that your kidney function is low, they will most likely advise against donation.
- Gynecological examination. Female donors may need to have a gynecological exam and mammography.
- Cancer screening. You may also be given some cancer screening tests, which may include a colonoscopy, prostate exam, and skin cancer screening.



- Compatibility tests. A blood sample will be taken to check for compatibility between you and the recipient. This includes:
 - Blood typing. Your blood type will be checked to see if it is compatible with the recipient.
 - Tissue typing. This blood test checks the tissue match between your white blood cells and the recipient's white blood cells.
 - Crossmatching. In this test, blood cells from the donor and recipient are mixed. If the recipient's cells attack and destroy the donor cells, the crossmatch is positive. A "positive" crossmatch means that your organ will not match the recipient's. A "negative" crossmatch means that your organ is compatible with the recipient's.

 Other blood tests. Additional blood tests are done to check for any viral activity or transmissible diseases (like HIV/AIDS, hepatitis, cancer, or others), glucose intolerance, electrolyte balance, and to assess your kidney function.

What if my kidney is not compatible with my intended recipient?

You may consider a "paired exchange." A paired exchange involves two pairs of living donors and their recipients. The two recipients "swap" donors so that each receives a kidney from a compatible donor. If this is an option for you, your transplant team will coordinate the entire process, including finding the matching pair.

How long does the evaluation process take?

The length of time it takes to complete the evaluation process is different for each person. It will depend on your availability for testing, the results of your tests, and the individual policies and procedures of the transplant center involved. If the recipient's transplant center is far away, you may be able to complete some tests at a hospital or lab near your home.

What happens after the evaluation is complete?

Your test results will be sent to the transplant team, who will review them carefully. They will make a decision about your physical health and suitability as a donor. If you are a suitable candidate for living donation, and you decide to go ahead with it, an operation will be scheduled. The final decision to proceed will be a group decision among you, your recipient, and the transplant team.

SURGERY AND RECOVERY

What does the operation involve?

In general, you will be given a general anesthetic in the operating room. You will be asleep and will not feel any pain during the surgery. In most cases, you and your recipient will be in adjacent operating rooms. One of your kidneys will be carefully removed and transplanted in the recipient. Typically, the surgery takes 3–5 hours with time in the recovery room afterward for observation. Removing your kidney may be done by laparoscopy or open surgery. The surgery to remove a kidney is called a "nephrectomy."

• Laparoscopy is the preferred method for kidney donor transplants. It involves the use of a laparoscope (wand-like camera) that is passed through a series of small incisions or "ports" in the abdominal wall (stomach). It is used to view the abdominal cavity and remove the kidney through a small incision. The advantages of laparoscopic surgery include shorter recovery time, shorter hospital stay, smaller incisions, and fewer post-operative complications. Laparoscopic surgery takes special skills to perform and is not available at all hospitals. Also, whether you can have laparoscopic surgery depends on your medical condition and overall health.



 Open nephrectomy is also done under general anesthesia and is a more invasive procedure. The surgeon makes a cut (incision) in the abdomen or in the side of the abdomen. A rib may need to be removed to perform this procedure. After the kidney is removed, the incision is closed with stitches.

Your transplant center can give you the most current medical information about the surgical process. They will help you determine what is best for you.

What are the risks of surgery?

Surgery for kidney donation involves the same level of risk for the donor as any other major surgery. These risks should be discussed with your transplant team.

- Pain. You will receive medication for pain after the surgery.
- Infection. An infection can delay the healing process or cause scarring or other problems. If the wound from the surgical incision becomes infected, it will be treated with antibiotics. Antibiotics are powerful medicines that fight bacterial infections
- Pneumonia. Surgery increases the risk for pneumonia (an inflammation of the lungs caused by bacteria or a virus).
 You will be asked to cough and breathe deeply during your recovery period. Taking a deep breath and coughing forces air to the bottom of your lungs, which helps to expand them and lessens your risk for pneumonia.

- Damage to the kidney. There is a possibility that the kidney could become damaged during the surgical procedure. Every attempt will be made to minimize this risk.
- **Blood clotting.** You will be asked to move around as soon as you can after surgery. This will stimulate blood circulation to help prevent blood clots.
- Collapsed lung. The kidney is close to the lung, and the pleura (the space around the lung) may be inadvertently opened during surgery. If this happens, the lung may collapse. The doctors would then insert a tube into the chest to expand the lung.
- **Urinary tract infection.** This is an infection of the bladder or kidneys. It can be treated with antibiotics.
- Allergic reaction to anesthesia. Anesthetics are drugs
 that prevent pain. During the evaluation process, the
 transplant team will try to identify any allergies you might
 have. If you have an allergic reaction to anesthesia, the
 doctor will take immediate action to correct the problem.
- Death. There is always a risk of death with any major operation. However, the risk of death from surgery for living kidney donors is very low. Living donors undergo careful pre-operative testing and evaluation to make sure they are healthy enough for surgery. In one study of over 80,000 living kidney donors, death from surgery was 3.1 per 10,000 donors. This rate has not changed for the last 15 years.



What should I do if I have concerns about surgery?

It is quite normal for you and your family to have some fears about the operation and possible complications. You should speak openly with your transplant team about any fears or concerns you have. All conversations between you and the transplant team will be kept confidential. The results of your medical tests will also be kept confidential.

How long will I need to recover?

This depends on which type of surgery you have, but most people are in the hospital three to seven days after surgery. However, everyone is different and the rate of recovery will vary greatly among individuals. Ask your transplant center for their best estimate of your recovery time.

After leaving the hospital, most people will feel tenderness, itching, and some pain as the incision heals. Most kidney donors can return to normal activities after four to six weeks, depending on the physical demands of their daily living and work tasks. Heavy lifting should be avoided for about six weeks following surgery. You may not be able to drive for up to two weeks.

Make sure to see your primary care practitioner regularly for follow-up care, and have your urine, blood pressure, and kidney function (GFR) checked yearly.



AFTER DONATION

What are the long-term risks of donation?

The amount of research into the long-term risks of kidney donation is limited. However, most studies suggest that you can live a normal, healthy life with one kidney. In fact, when one kidney is removed, the single normal kidney will increase in capacity to compensate. This is called "compensatory growth." Studies show that your total kidney function returns to roughly 70% within 10 to 11 days, and about 70 to 80% at long term follow-up.

One possible long-term risk may be high blood pressure. Research shows that many people who donate a kidney have slightly higher blood pressure after several years.

African-Americans and Hispanics are known to have an increased risk for high blood pressure, kidney disease, and diabetes. Kidney donation may increase this risk for some donors.

There have been occasional reports of patients who developed kidney failure after donation, possibly due to heredity factors (family background). If kidney failure occurs, you will be given a higher priority for a kidney transplant on the waitlist for a deceased donor. The typical wait for a kidney donor in 2015 was 145 days versus 1607 days for other people. You may have some period of time on dialysis while waiting for a transplant.

There is also some risk with pregnancy. Women who donate a kidney and become pregnant have a higher risk for gestational diabetes, gestational hypertension, preeclampsia, and fetal loss. If you are planning on having children, make sure you discuss childbearing with your transplant team before donating a kidney.

There are also some financial risks to consider. Some donors have reported difficulty in getting, affording, or keeping disability or life insurance. You may also experience lost wages during your surgery and recovery time.



What can I expect after donation?

Living donors generally rate their experience as positive. Studies indicate that between 80–90% of donors say that, in retrospect, they would still make the decision to donate.

Some donors have reported feeling anxious or depressed after donation. Concerns about the recipient's outcome (as well as the donor's recovery) can contribute to feelings of anxiety, and many donors report a feeling of "let down" afterwards. Feelings of depression among living donors are not uncommon, even when both donor and recipient are doing well. The process of getting through the evaluation and surgery can be so time-consuming that donors do not always have time to process everything they are feeling. Having strong emotions come to the forefront after the donation and transplant takes place is understandable.

Let your transplant team know how you are feeling both physically and emotionally during your follow-up visits. Because your emotional health is important, too. If you find that you are struggling with mixed emotions at any time after you donate, you should:

- Talk to the transplant hospital's social worker for support and guidance.
- Seek professional counseling or other outside help to manage difficult emotions.
- Talk with other living donors who can be particularly supportive if they have experienced the same feelings.



MAKING AN INFORMED DECISION

How do I make an informed decision?

Donating a kidney can help improve another person's life. It is a generous act. But you will need to face some emotional, physical, and possible financial challenges. You should think about all of these things carefully. Talk to your loved ones, including your family and close friends. Talking to other donors about their experience can also be helpful. Be sure to gather information from many different resources, including those listed at the back of this brochure.

If you choose to begin the evaluation process, your transplant center will assign you an Independent Living Donor Advocate (ILDA), whose purpose is to help protect your rights. This person will help you understand all aspects of kidney donation, including the risks and benefits. They will also explain alternative procedures or types of treatments that are available to the transplant recipient, including dialysis or transplant from a deceased donor.

What if I decide not to donate?

Your decision to donate an organ must be completely voluntary and free from pressure. You have the right to decide that donating a kidney is not for you. You can delay or end the donation process at any time. The reasons for your decision will be kept private and confidential by the transplant team.

If necessary, you can ask the transplant team for support in declining donation. For example, if you fear that saying "no" to the recipient would cause someone to be upset or angry with you, you may want to ask the transplant team for support. They can help you develop an appropriate response, which could allow you to decline gracefully.

A person with kidney failure also has some important rights. They may decide they do not want a transplant. Or they may not choose to consider a living donor. Both your decision and the recipient's decision about transplantation must be respected.



MORE INFORMATION

Where can I find more information?

The National Kidney Foundation (NKF)

Toll-free: 1.855.NKF.Cares (855.653.2273)

Email: nkfcares@kidney.org www.kidney.org/livingdonation

The NKF offers a toll-free patient help line for people affected by kidney disease, organ donation, or kidney transplant. Patients, families, and caregivers can speak with a trained professional who will help answer questions and listen to concerns. You can also find free publications and other resources on organ donation, kidney transplantation, kidney disease, and kidney failure by calling, emailing, or visiting the website.



United Network for Organ Sharing (UNOS)

1.888.894.6361 www.transplantliving.org www.unos.org

UNOS offers free publications and other educational resources to help living donors, transplant candidates, recipients, family members, and others understand donation. You can search their website for the latest statistics on donation and transplantation in the United States.

National Living Donor Assistance Center 1.703.414.1600 www.livingdonorassistance.org

Provides financial assistance to those who want to donate an organ. Priority is given to individuals not otherwise able to afford the travel and subsistence expenses associated with living organ donation.

U.S. Department of Health and Human Services www.organdonor.gov

This government agency provides information on organ and tissue donation and transplantation.

The **National Kidney Foundation** is the leading organization in the U.S. dedicated to the awareness, prevention, and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of Americans at risk.

Help fight kidney disease. Learn more at www.kidney.org



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