

Kidney Transplant Donor Guide



Welcome

Thank you for your interest in kidney donation. There are many steps to the kidney donation evaluation. This is to have the best results for you and the person getting your kidney.

Your participation is voluntary. You have the right to delay or stop the donation process at any time.

Please complete and return forms as advised in postage-paid envelopes. You may need to schedule a physical exam with your doctor if you have not had one in the past year. This will be at your expense. Talk to your donor coordinator about the costs you may need to pay.

Why Should I Read This Booklet?

This booklet will answer some of the questions you may have.

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What Is Kidney Donation?

The purpose of kidney donation is to give a healthy kidney to a person (recipient) who has chronic kidney disease (CKD) or end-stage renal disease (ESRD). Kidneys are organs that filter blood to remove wastes and fluids. A healthy kidney may allow someone to avoid dialysis. The recipient may have a more healthy life after transplant.

Giving a kidney is a very meaningful thing to do. This is called living donation. The decision to donate a kidney is very personal. This is a very important decision. Please read all the information you are given. Be sure to ask a lot of questions. There are strict guidelines to be followed. The teaching you receive will help you understand:

- Your rights and responsibilities
 - This includes your right to education in your preferred language and in the way you learn best.
- The donor evaluation process
- Your hospitalization
- Required follow-up care
- Possible risks

Benefits of Living Donor Transplants

- There may be a better match with a living donor
- The kidney is out of a body for less time
- Lower doses of anti-rejection medicine may be needed
- Less time waiting for a kidney transplant
- More time to prepare:
 - Surgery can be planned well ahead of time and this can decrease stress
- More likely to avoid or limit time on dialysis for the recipient. This may improve their quality of life.
- A recipient who was on a waiting list no longer needs to be. This makes a transplant possible for someone else.

What Are the Other Treatment Options for Kidney Failure?

Kidney donation is considered a life-enhancing gift. There are other treatments if living donor kidney transplant is not possible. These include:

- Dialysis
 - Filters blood
 - Removes wastes and extra fluid
- Getting a kidney from someone who has died (deceased kidney donor)
 - During evaluation, sometimes a deceased donor's kidney becomes available.

Who Can Be a Kidney Donor?

Most people are born with 2 kidneys. A person can donate 1 kidney and still have a healthy life. To be able to donate you must:

- Be over the age of 18
- Have excellent health
- Be mentally stable and free of substance abuse problems
- Agree to testing of your physical and mental health
- Volunteer to donate and not be pressured
- Understand no money or goods can be given for donating a kidney
 - Buying and selling of human organs is against the law
- Be willing to donate and accept possible risks

Living relatives who donate a kidney may be the best match. Living related donors can be:

- Parents
- Siblings
- Children of recipient
- Aunts or Uncles
- Cousins

Living unrelated kidney donors are not related by blood but have a compatible blood type. These people could be:

- Spouses
- Close friends
- Co-workers
- Church members

Sometimes, donors do not know the recipient. They may have heard about a need and wish to donate to that person. This is known as a **directed donation**.

Non-directed donors may also be called anonymous donors. A kidney is donated but the match is made with someone on the national transplant list at the local center. A system is in place to make sure the kidneys are matched and given fairly.

The donor and recipient may or may not meet. A meeting would not occur prior to the actual donation. A special plan and consent form is used to exchange information if both parties agree.

Who Cannot Be a Kidney Donor?

Rules can vary between transplant programs. In general, you may not be accepted as a living kidney donor if you have:

- Diabetes
- Kidney disease
- Heart disease
- Active mental health or substance abuse issues
- Infectious disease
 - HIV may be considered by some centers
- Uncontrolled high blood pressure
- Very overweight
- A history of cancer (this can be evaluated on a case-by-case basis)

Kidney Paired Donation (KPD) or Paired Exchange

This is a transplant option that helps living donor and recipient pairs exchange kidneys to find a match. By exchanging kidneys two or more transplants are made possible. All medically eligible donor recipient pairs could consider this program. Participation is voluntary. More than one transplant center may be involved in KPD.

Types of Kidney Paired Donation

Incompatible pairs will most often take part in this program. Reasons are:

- Incompatible blood type
- Incompatible tissue type

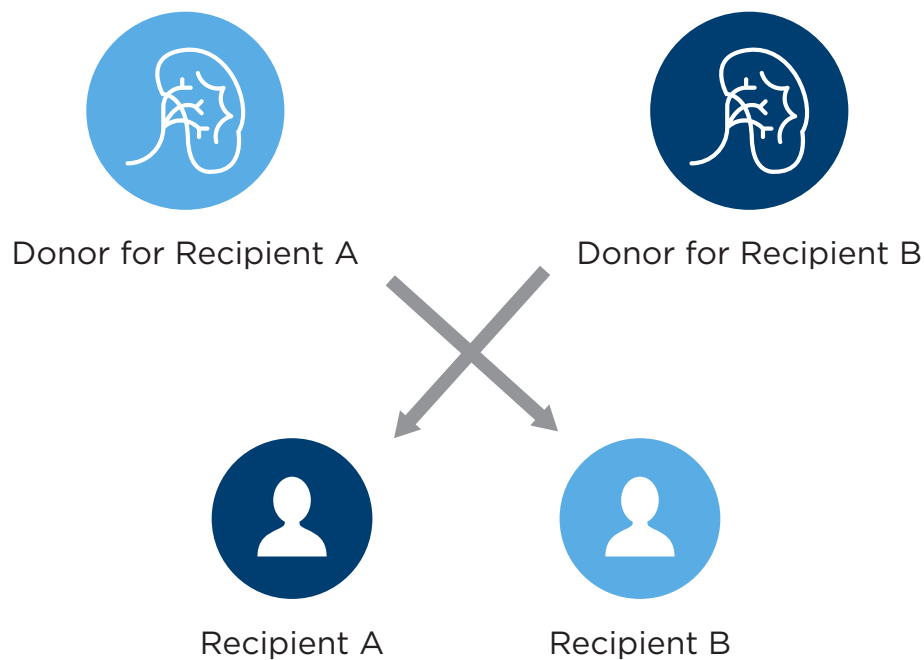
Compatible pairs may also take part in this program. Reasons are:

- To find a younger donor
- To find a better matched donor
- To help the incompatible pairs on the KPD waiting list

Non-directed donors in KPD usually do not have a recipient in mind. These non-directed donors are matched with recipients on the KPD waiting list.

If you are interested in participating in a KPD program more education will be provided by your donor team.

You may see more information at: <https://www.unos.org/donation/kidney-paired-donation/>



How Will You Be Evaluated to Donate a Kidney?

All potential donors must make the first contact with the transplant program.

- You will be asked to sign a release of information to obtain records from health care providers you have seen in the past.
- You will be screened for:
 - Infectious disease
 - Illness that may affect your kidney function
 - Increased risks for surgery

All donors must have a recent health screening with a primary care doctor. The health screenings are to be as recommended for age and gender. You will be responsible for the cost of the health maintenance screenings. These may include:

- Pap smear
- Mammogram
- Colonoscopy
- Prostate specific antigen (PSA)

There are no costs to you for the kidney donation evaluation. Common tests include:

- Blood tests:
 - To match you and the recipient
 - To check your overall health
 - To make sure you do not have any diseases
 - Positive tests for HIV (the AIDS virus) or certain sexually transmitted diseases must be reported to public health authorities
- Urine tests
- Chest x-ray
- Heart rhythm test (Electrocardiogram or ECG)
- X-rays of your kidneys
- Based on your history and findings, more tests may be needed

There are risks to testing. This could include allergic reaction to contrast dye. You may find out you have a serious medical or genetic problem you were not aware of. These findings may require more tests. You will have to pay for these extra tests and related treatment.

Early testing does not have to be done at Sanford. You will need to travel to the transplant center to complete the donor evaluation. We will find the time that works best for you.

You will see many doctors and other specialists. You will meet with members of the donor team. These may include:

- Donor Coordinator
- Nephrologist (a doctor who specializes in the kidney)
- Transplant and Donor Surgeon
- Donor Advocate
- Social Worker
- Transplant Pharmacist
- Registered Dietitian (nutrition)
- Psychologist (mental health)
- Pulmonologist (lung doctor)
- Cardiologist (heart doctor)

After completing all the steps, your results will be presented to a selection committee. This group will:

- Review your test results to be sure you are healthy enough to be a donor
- Make recommendations if more tests are needed
- Decide if you are able, or not able, to donate

If you do not agree with the decision, you have the right to be evaluated at another transplant program.

How Is the Surgery Done?

During the kidney removal (nephrectomy) you will be completely asleep. This is called general anesthesia. Kidney donation surgery can be done with a special scope. This type of surgery is called laparoscopy (lapa ros kop e). The incision is about 4 inches long. There will also be 2 or 3 smaller cuts from surgery tools. The surgery may take 3 to 4 hours. You will be in the hospital for 2 to 4 days after surgery. An open surgery may be done if a laparoscopy is not possible. This type of open surgery may require a longer recovery.

A surgery guide will be given to help you get ready.

What Are the Risks If You Donate?

Before deciding to donate, it is important to be aware of the risks. There are risks with all surgeries and general anesthesia. This includes the risk of death. Every effort is made to avoid short term or long term risks. The donor assumes all the risks and receives no medical benefit from the operation of donor nephrectomy (kidney removal).

If problems or complications occur, they are usually minor and get better. In the event of a major complication during your surgery, the kidney would not be removed. In very rare cases, another surgery or procedure could be needed.

Kidney donation does not change the length of your life (life expectancy).

Possible Complications of Surgery

Surgical risks may be for a short time or could be permanent. Risks could include:

- Decreased kidney function
- Acute kidney failure
 - This could mean dialysis or kidney transplant

Bleeding can occur during or after surgery. This may require blood transfusions or blood products that could contain bacteria and viruses that can cause infection. Although rare, these infections include, but are not limited to:

- Human Immunodeficiency Virus (HIV)
- Hepatitis B Virus (HBV)
- Hepatitis C Virus (HCV)

Blood Clots may develop. They can break free and move to the heart or the lungs. This can cause serious problems with breathing. It can lead to death. If blood clots occur, you will be treated with drugs that may need to be taken for a period of time.

Infections can occur at the incision sites or where any tubes were placed in your body. Infection can occur at a specific site such as at your incision, in your lungs (pneumonia), urinary tract, or in your bloodstream.

Damage to nerves may occur during surgery. Nerve damage can cause numbness, weakness, paralysis, or pain. In rare cases, damage can last for long periods of time or become permanent.

Other Possible Complications Include:

- Injury to organs in the abdomen
- Sore throat from the breathing tube
- Allergic reactions to medicines
- Pressure sores on the skin
- Burns caused by the use of electrical equipment during surgery
- Damage to the arteries and veins
- Heart attack
- Stroke
- Permanent scarring at the site of the incision
- Genital pain or swelling
- Hernia at the site of scars which could need a later surgery to repair
- Stomach or bowel problems such as:
 - Nausea
 - Bloating
 - Constipation
 - Bowel obstruction
- Pain
- Feeling tired

Risks After Donation

Most often, living donors will have a 25-35 percent permanent loss of their kidney function after they donate.

ESRD may develop faster in people with one kidney. Dialysis or a kidney transplant would be needed for end stage renal disease.

Your chances of developing CKD or ESRD are higher if your remaining kidney is damaged.

Chronic kidney disease (CKD) most often develops in mid-life (40-50 years of age).

End Stage Renal Disease (ESRD) most often develops after age 60.

Your risk of having ESRD is not greater because of donating a kidney when compared to others like you in terms of age, race, and medical history. Your risk does increase if you are overweight, have high blood pressure, or other health problems.

A medical evaluation of a young donor cannot predict future health problems.

Donors should avoid long-term use of non-steroidal anti-inflammatory drugs (NSAIDs) (ibuprofen containing products). Your healthcare provider should know of your kidney donation when prescribing future medicines.

Healthy people who donate a kidney recover and lead normal lives. Rarely, people have lost the function of their single remaining kidney. Causes of kidney failure could include:

- Kidney cancer
- Trauma
- Kidney stones with infection
- Kidney disease that was not found at the time of the donor evaluation

This would lead to the same situation your recipient is in now. Dialysis or a kidney transplant would be needed. If this occurs, you would receive priority on the kidney transplant waiting list. This guideline could change in the future.

Pregnancy After Donation

If you become pregnant after donation you may have a higher risk of:

- Pre-eclampsia (high blood pressure and protein in the urine)
- Gestational hypertension (high blood pressure)

Both these conditions have risks to the mother and the baby. If you plan on becoming pregnant sometime after donation, you may want to speak with your OB doctor about any concerns.

Possible Psychosocial Risks

Organ donation can be one of life's most rewarding experiences. Donation may increase stresses related to emotional, family, social, employment, or financial situations.

You may feel anxious or sad after donation. Most donors say they feel very positive about donation. Possible psychosocial risks include:

- Problems with body image (what you think of your body)
- Depression
- Anxiety
- Lifestyle changes related to your kidney donation
- Emotional distress or feelings of grief or loss if the recipient has health problems after the transplant. Problems can include needing dialysis, a second transplant, or death.
 - As the donor, you will not be told all the risks the recipient may have that could cause future complications for the recipient.

The information is not meant to frighten you. There are risks that could happen. The donor team is available to provide ongoing support before and after donation. It is important to share your concerns with the donor transplant team.

Possible Risks to the Recipient

The goal of donation is for the recipient to benefit from the transplant. Recipients are at risk for rejecting the organ. They may have other problems or even die due to the transplant surgery. Recipients may already have a health condition that may place them at greater risk when having surgery.

Success depends on many things. All transplant candidates are checked well before having surgery. Recipients must also take their transplant medicines for the rest of their lives or the organ will be rejected.

Financial Implications and Risks

The donor's costs are most often paid by the recipient's medical insurance. Finances must be discussed with the social worker during the donor evaluation.

Donating a kidney may not be possible for everyone. Some of the costs of kidney donation may not be paid back to you. The need to not donate due to money reasons will be respected. You may be able to get help with some costs. This will depend on your income and the recipient's income.

- Possible financial risks due to donation could include:
- Loss of income during the donor evaluation, hospitalization, and recovery
- Personal expenses from donation:
 - Travel
 - Lodging
 - Meals
 - Child-care
- Loss of your job or being able to get a job in the future
- Being able to pay for health insurance
- You could have life-long health problems that you need to pay for

Talk to the donor social worker about possible resources that may be available to help with donation related costs.

Health and Life Insurance

Your present or future ability to get health, disability, or life insurance could be affected by kidney donation. It may be difficult to get, keep, or pay for disability or life insurance. Assistance is available to appeal those decisions.

Your recipient's insurance will not cover health problems that you may have in the future. All donors are encouraged to have health insurance so that routine yearly physicals will be paid.

State Income Tax Deductions

Some states allow for an income tax deduction for living donation expenses related to traveling, lodging, and lost wages. Keep track of your expenses and talk to your tax preparer.

Donor Benefit

There is no health or physical benefit to you from donating a kidney. Most donors report an emotional benefit from donation with a similar or better quality of life than before.

It is illegal in the United States to financially benefit from donation. There may be financial resources available to offset possible costs that may be part of the donation process. The transplant center staff can help answer these questions.

Donor Follow-Up

You will be seen in the transplant clinic about 2 weeks after you are discharged. It is important to follow instructions to make sure you remain healthy.

It is your duty to let the transplant staff know of any problems related to the donation. Any problems related to the donor procedure are billed to the recipient's insurance.

Donation rules **require** that transplant centers follow all living donors for a period of 2 years. You will be contacted by our transplant center at 6 months, 1 year, and 2 years after the donation. Lab tests will be needed at this time.

Donor follow-up information is used to monitor:

- How many donations are done
- How many are successful
- Complication rates
- That you receive all the information you should

If you are found to have an infectious disease or cancer during the follow-up period you will be told about it. The transplant center may also need to tell the recipient, the public health department, and the Organ Procurement and Transplant Network (OPTN).

You should see your primary care doctor every year for routine health check-ups for the rest of your life. You must talk with your doctor about any prescription or over-the-counter medications and supplements that you are taking. Some should not be taken after you donate your kidney. You will be given a copy of this medicine list during your evaluation.

You are encouraged to live a healthy lifestyle.

Right to Withdraw

You should not feel pressured to become a living donor. You will be given a lot of time to think about your decision. You can change your mind and choose not to donate your kidney at any time before surgery.

If you decide **not** to donate your kidney, the transplant program will support you. Sometimes it is hard to share this decision with the recipient. If you wish, the transplant team can let the recipient know that you are no longer a donor candidate. The transplant center will not share details about your decision with the recipient. None of your health or evaluation information will be shared with the recipient. **You have the right to privacy.**

National and Sanford Transplant Center-Specific Outcomes

Recent statistics from the Scientific Registry of Transplant Recipients (SRTR) <http://www.srtr.org/default.aspx> explains national and our transplant center's patient and graft (transplanted kidney) survival rates.

For more information, check the public data available at <http://www.srtr.org/default.aspx>. A most recent copy will be provided to you.

What Facts Do You Need to Know?

Sanford Kidney Services are Medicare and Medicaid approved centers for kidney transplant. Information must be given about all organ transplants to the United Network for Organ Sharing (UNOS). This includes your name, birthdate, sex, social security number, blood type, your relationship to the recipient, and some blood test results. This is kept private and not given to the public or used by researchers. Knowledge gained will be used to teach future transplant donors and recipients. Data is kept to track:

- How many living donor kidney transplants are done
- Success rates
- Complications

Your information is kept private and will not be discussed with the recipient. The transplant team does all it can to preserve your confidentiality. Information cannot be shared without your permission.

It is your decision if you want to share your information and results with the recipient. The recipient also has the right to privacy. They may have risk factors that cannot be told to you.

You have the right to delay or stop the donation process at any time.

Concerns or Grievances

The United Network for Organ Sharing (UNOS) provides a toll-free patient services line at (888) 894-6361 to help transplant candidates, recipients, living donors, and family members understand organ donation. A handout will be provided to you. If you have questions regarding your own medical care you should talk to your transplant center first.

Notice of Medicare Outcome Requirements Not Being Met by Center

Certain outcome requirements need to be met by transplant centers. We are required to notify you if we do not meet those requirements. This information would include how many transplants are done, transplant recipient survival rates, and graft (kidney) survival.

Currently, Sanford Kidney Services meets all of the requirements as a transplant center under the Centers for Medicare and Medicaid Services (CMS) policies. If you donate your kidney to a recipient having a transplant at a facility that is not approved by CMS (Medicare) to do transplant surgery, the recipient's ability to have immunosuppressive (anti-rejection) drugs paid for under Medicare Part B could be affected.

Helpful Resources For Kidney Donors (Websites)

www.kidney.org

The National Kidney Foundation is a voluntary health organization focused on the prevention of kidney disease and improving the health of anyone affected by the disease.

www.unos.org

The United Network for Organ Sharing (UNOS) is the nonprofit organization that maintains the nation's organ transplant waiting list for the fair distribution of cadaveric/deceased organs. The "Transplant Living" section of the website contains living donor profiles, updated statistics on living donation, information about the donation process and answers to frequently asked questions.

If you have any concerns regarding something you see or hear about kidney donation, please contact the Transplant office. Remember that each center may approach the donor evaluation process a little differently, but all have the same goal, the best possible outcome for the donor and recipient.

www.transplantliving.org

Transplant Living is an information and resource website for both donors and recipients. This website provides information on many aspects of living donation including state tax deductions.

<https://www.livingdonorassistance.org/Home/default.aspx>

The National Living Donor Assistance Center was established to provide greater access to transplantation. This is for persons who want to donate but cannot afford the travel, lodging, and meals expense associated with donation.

