



Understanding Living Kidney Donation - FAQ

The most considerate way to help a kidney patient in need.

It can be troubling to learn that someone you care about has (or is approaching) kidney failure. Learning more about their options can help. We invite you to use this information guide to help you discover the various ways you might be able to participate. In this guide, we've answered 13 of the most commonly asked questions. We hope you find this information helpful.



Q: I know someone who needs a kidney transplant. How can I help? ⁽¹⁾

A: Thank you for taking the time to learn more about how you might be able to help a friend or family member (or even a stranger) who has *or* is approaching kidney failure. People diagnosed with end stage renal disease (ESRD) often feel alone, fearful and without hope. Your support can mean the world to them. And though you may feel somewhat helpless in this situation, there are a few things you could do:

#1: Be compassionate. Try your best to understand the patient's challenges as well as their choices. Learning more about their options and the process of how a living kidney donor can help them can be extremely helpful. Sometimes just listening and understanding can be a beautiful gesture.

#2: Increase awareness. Be committed to informing others about this need and living kidney donor options. As more people learn about living kidney donor transplants and the life-threatening wait for a deceased donor's kidney, the greater the chance of finding a living kidney donor. Become a champion "donor advocate" for the person in need.

#3: Consider getting tested. Have you thought about getting tested to see if you might be able to be a living kidney donor for the person in need? Want to learn more about the process? If so, continue reading this information pamphlet and then call the patient's transplant center's "living kidney donor department" to request a telephone interview. During the call you'll be able to ask questions and gain insight about the living kidney donor process.

Q: *Who can be a living kidney donor?* (2)

A: A living kidney donor can be a family member, friend, co-worker *or* stranger providing they are in excellent health between the age of 18 to 65. (Donors over age 65 may also be considered on a case by case basis).

Individuals interested in becoming a living donor can start the process by simply calling the patient's transplant center to schedule a telephone screening. Some centers also receive initial inquiries online through an interactive web-based questionnaire.

If you are found to be an acceptable potential donor, then you will be asked to submit medical records and schedule more thorough tests for a donor evaluation. Though it varies from patient to patient, testing can often be completed in just a couple of days.

Q: *What type of screening tests are involved?* (3)

A: The living kidney donor work-up can include:

- a medical exam
- psychosocial consultation
- chest x-ray, EKG (heart test)
- routine blood and urine tests
- blood compatibility testing.

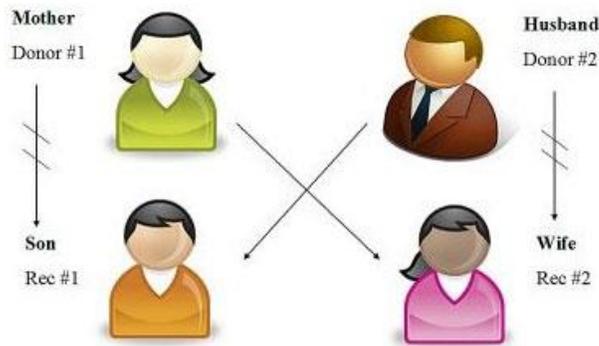
Additional tests may be required. If a donor lives out of state, it may be possible to get the initial blood work completed by a nearby transplant center.

Blood Compatibility Work-Up: As part of the medical work-up, a potential donor will have blood drawn for two levels of compatibility testing: ABO blood typing and cross match testing. In addition, HLA (genetic) testing will be completed.

Candidacy: Following blood tests and the medical work-up, the transplant center's selection committee will review their findings. You will be notified as to whether you are an appropriate living donor candidate. If testing determines you are a qualified,

compatible donor to your recipient, additional tests may be ordered (final CT scan) and arrangements will be made to schedule both you and your recipient's surgery date.

What If I'm not a good match? If you have been approved to donate, but you are not a good match for the recipient, you can consider a Kidney Paired Donation (KPD) program. This program helps find sets of donor/recipient pairs who can "swap" kidneys. This enables you to donate to another recipient, while ensuring your recipient receives the best match from another donors within your paired group.



**Image from National Kidney Registry
(<http://www.kidneyregistry.org/>)*

Q: What might disqualify someone from donating? (4)

A: Conditions that may prevent a person from donating one of their kidneys includes a history of heart disease, chronic lung or liver disease, kidney disease, hypertension, diabetes, cancer, untreated psychiatric disease—or indications of coercion, financial gain, guilt or pressure. Other health issues, and other factors such as smoking, drug abuse and obesity can also be contraindications for candidacy.

Q: What's involved in the donor surgery, what are the risks and how much pain will I be in? (5)

A: Surgical procedure. The surgical procedure to remove a kidney from the donor is called a donor nephrectomy. The surgery usually takes about 2-3 hours. Surgeons primarily use a minimally invasive technique, using 3 small incisions to insert instruments and a slightly larger incision (8 cm in length) to remove the donor's kidney.

On average, donors spend about 2 days in the hospital before being discharged from the hospital.

A: Risks. With any surgery and anesthesia there are risks. Nationally, the risk of having a life-threatening problem occur when donating a kidney is 1 in 10,000. The risk of minor complications such as a minor wound infection is about 2-4%.

A: Pain. There is pain associated with the surgery, though it can be well controlled with medication. In addition to the pain medication that you receive in the hospital, donors are also prescribed pain medication to have at home as well. For the first few weeks after kidney donation surgery, you may also feel tired with reduced stamina. It's important not to overdo, especially during the first few weeks of recovery.

A: Emotions. You may feel emotional ups and downs throughout this journey. You are encouraged to discuss your emotions with the donor department's social worker and your own support network of friends and family. Sometimes, just talking about them helps.

Q: *What's this going to cost me?* (6)

A: Medical coverage: All expenses for the medical work-up and transplant surgery are covered by the recipient's health insurance. This can include 3 years of related post-donation care under the recipient's special ESRD Medicare policy, if the policy was in force the day of transplant.

A: Employer Compensation: In some states, like California (SB1304)* employers (of any business that employ 15 or more employees) are required to give up to 30 days paid leave for organ donation. It also permits employees to return to the same position *or* an equivalent position. *<http://livingdonationcalifornia.org/how-living-donation-works/who-pays-for-living-donation-and-kidney-transplants/#sthash.TGp3o64c.dpuf>

A: Disability: For donors who worked prior to surgery, most disability coverage allows 6 weeks off for recovery; however, some donors return to work before this time.

Additional expenses can include:

- Travel to the transplant center for testing, surgery and follow up.

- Parking, lodging, ground transportation, meals, bridge tolls and other incidentals.
- Lost wages, if sick time or short-term disability from work is not available.

The transplant center's financial coordinator and social workers can discuss your specific circumstances and advise accordingly.

Q: How much time will I have to take off work? (7)

A: Because the kidney donor operation is a major surgical procedure, donors might find they have less energy after the procedures. It is recommended to take about 4-6 weeks off before returning to full pre-surgical activities. Of course, this is relative to the degree of activity involved.

Two to three weeks following a donor's discharge from the hospital, the donor is asked to return to the transplant center for a medical exam. This will be followed by a 6 month exam and annual visits, in addition to seeing their primary care provider.

Q: How will this surgery affect my life? (8)

A: The chance of the donation affecting the donor's lifespan or lifestyle is extremely low. Much of this is due to the extensive health requirements one must meet in order to become a donor. Nonetheless, it is important to know the facts:

After donating one kidney (and essentially removing 50 percent of your functioning kidney mass), your remaining kidney will compensate its overall kidney function. This happens in about 2 weeks when the remaining kidney increases to approximately 70 percent of baseline function. Long term, the kidney increases to approximately 75 to 85 percent of baseline function.

Published long-term studies* analyzing outcomes of kidney donors showed donor survival were similar to that of the general control population (people who had not had a kidney removed). Again, much of this is due to the health qualifications required to proceed in this process. Simply put, donors are healthier than the general public so it stands to reason that they'd show healthier markers post donation.

**The New England Journal of Medicine and Journal of the American Medical Association, 2009/ 2010. One study followed 80,000 live kidney donors matched for age, sex, and race or ethnic group, dating back to 1994; another studied 3,698 individuals who donated a kidney between 1963 and 2007.*

Q: Why can't the patient get a deceased donor's kidney? (9)

A: Currently, there are over 100,000 people waiting on a list for a kidney transplant from a deceased donor. With an average wait of 5 years (and more than 9 years in some regions), patients will require dialysis, just to stay alive. While dialysis is the only option for mimicking kidney function while waiting, it's not the ideal option long term.

Living kidney donation, however, offers a faster-track to transplant. It does this by removing the need to wait for a deceased donor's kidney. Living donation also offers better survival rates and reduced risk of rejection over deceased donor kidney transplants. On average, kidneys transplanted from living donors last nearly twice as long as kidneys transplanted from deceased donors—sometimes up to 30 years or more.

Q: Why shouldn't the patient get on (or stay) dialysis? (10)

A: While dialysis is a lifesaving treatment, it performs only about 10 percent of the work a functioning kidney does. Therefore, those who qualify for transplant are encouraged to seek a transplant as their preferred *long term* quality-of-life option.

Although transplant is not without risks, dialysis can pose a more significant hardship on daily living. Inconveniences, health problems and complications associated to dialysis can include:

- Depression
- Fatigue
- Pain
- Anemia
- Bone disease
- High Blood Pressure
- Heart Disease
- Nerve Damage
- Infection

As a result, the average life expectancy for a patient on dialysis is generally five years. On the other hand, patients who receive a kidney transplant typically live nearly three times longer than those who stay on dialysis.

Also, a living donor's kidney transplant functions on average, 12 to 20 years, which can be as much as double that of a deceased donor's kidney.

Patients who get a kidney transplant *before* dialysis live an average of 10 to 15 years longer than if they stayed on dialysis.

Younger adults benefit the most from a kidney transplant, but even adults as old as 75 gain an average of four more years after a transplant, than if they had stayed on dialysis.

Spending a long time on dialysis does not necessarily take away the chance of having a kidney transplant. Yet, research shows getting a transplant sooner (rather than later) is generally the best approach due to health problems dialysis can cause over time.

Moreover, spending a long time on dialysis before transplantation may also compromise the life of the new kidney graft once transplant occurs*.

**Published medical data has shown that the kidney will work much longer in patients transplanted before they start dialysis.*

Q: What's the "upside" of donating a kidney? (11)

A: While there are no trophies or medals, parties *or* parades, suitcases of money *or* live captures of video getting mega hits on the internet; there's a lot to be said about the perpetual joy that comes from knowing you risked your life to save another.

It is said, the opportunity to witness the "human-life gain" resulting from donating a kidney, can be the most extraordinary *payback* of all.

While this personal sacrifice may appear to fall into Life's "Unsung Heroes" bucket from the outside— Inside, there can be no greater "Life Achievement" for this extraordinary act of human kindness.

Q: Should I save my kidney for one of my children or my spouse? (12)

A: Often times this decision comes down to trusting that someone else will come forward in the future should a child or spouse be in need later in life. It makes sense to consider family members who hold a high risk for kidney disease.

The cross-roads of this decision is often more about helping someone who is in need now. It also had to do with the donor's ability to donate when they are healthy enough or at an appropriate age to do so. *The transplant psychologist or social worker can help you address these concerns and think through your decision before moving forward.*

Q: Is it possible to change my mind? (13)

A: Yes, of course. Your decision to donate a kidney must be one that you are completely comfortable with and that is made free of any pressure, guilt or coercion. You can decide not to donate at any time throughout the evaluation process and the recipient will never know the reason, unless you choose to tell that person. The transplant center will simply tell the recipient you were not a good match.

You can also ask to pause your evaluation process until you are ready to continue. As difficult as it might be, it will be important to tell your potential recipient, so they can consider testing other potential donors without delay. If you decide you are not able to donate, please let the living donor nurse coordinator be aware of this change as soon as possible.

Thank you for taking the time to learn more about how you might be able to help a friend or family member (or even a stranger) fast-track their way to transplant & secure their best life possible.

Your Friendship & Support Speak Volumes.

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EMPOWERING KIDNEY PATIENT
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