Living Organ Donor FAQ

1. What are living donors?

Living donors are healthy individuals who choose to donate a kidney or a portion of their liver to a friend, family member or even someone they do not know who has end-stage organ disease.

There are three types of living donors:

Living related donors – Individuals who are a blood relative to the transplant recipient such as parent, aunt, uncle, brother, sister, nephew or niece.

Living unrelated donors – Individuals who are not a blood relative to the transplant recipient. This may include a spouse, friend, neighbor, coworker, brother-in-law or sister-in-law.

Directed (anonymous)/nondirected (altruistic) donors – Individuals who offer to donate a kidney or portion of their liver to those on the waiting list. Donors and recipients do not know each other, but can meet later if both sides desire to.

2. How great is the need for living donors?

Each year, the gap between those who need an organ and available donor organs widens.

- More than 200 people are on the Nebraska waiting list for a kidney
- More than 100 people are on the Nebraska waiting list for a liver
- Visit this link for a daily updated list from the Organ Procurement and Transplantation Network: https://optn.transplant.hrsa.gov/data/view-data-reports/state-data/#
- Once you've clicked on the link, choose your state, "Waiting List" then "Overall by Organ"

3. Why would I want to be a living donor?

Most individuals do not get many chances to save someone's life. This is a uniquely rewarding experience!

"There are a lot of people that think about donation, but they are not sure they can handle it; they think about donation, but they do not know the person; or they think about donation but they are always worried about something else. Well I can tell you that creating a beautiful gift of donation is something so many people can do and it affects so many more."

Tim Nowak (Anonymous kidney donor)

4. What are the advantages of kidney living donation?

- Outcomes are better in living donation versus a donation from someone who has died
- Surgery can happen when it is most convenient for the recipient and the donor
- All donors get a very thorough medical evaluation to make sure it is safe to donate



- The longer a patient is on dialysis, the higher the rate of medical complications, therefore living donation decreases the wait time and increases the recipient's longterm health and their quality of life
- Surgery happens simultaneously so the kidney is transplanted shortly after being removed from the living donor

5. How successful are kidney and liver living donor transplants?

Living donation is very successful because the living donor team carefully match people to minimize risk to the donor and maximize the benefits to the recipient. As the donor, our team will thoroughly evaluate you to ensure you are in good health from a medical and psychosocial standpoint. The patient survival and organ graft function for kidney is significantly better with living donation than with using an organ of someone who has died. Therefore, patients who receive living donor transplants live longer and have healthier organs that last longer. Living donation in kidney transplant is the best treatment option for chronic and end-stage renal disease.

For liver, the results for the recipients are the same whether the donor is living or deceased. Living donors provide a supply of livers that wouldn't otherwise be available, meaning more people receive the transplant sooner than they otherwise would. In some cases it means receiving a liver before the window where the person is healthy enough to receive a liver completely closes.

6. Will becoming a living donor impact my ability to play sports, work outside or get pregnant?

You can continue to exercise and play sports as you did prior to living donation after recovering from the surgery. Female living donors may get pregnant after living donation but we ask they wait a year before pregnancy and are followed closely by their primary care doctors during pregnancy.

7. What are the medical and surgical risks associated with living donation?

The transplant team at Nebraska Medical Center will comprehensively evaluate your overall health to ensure that is not only a safe surgical procedure, but that we will not put donors at increased medical risk in the future. Our multidisciplinary team meets to discuss each and every individual donor in detail to be certain every person is a good candidate.

8. What if I need a transplant in the future?

The chances of a donor needing another kidney later in life is really small, but should that occur:

 In the event that a living kidney donor develops end-stage kidney disease at any time during their life and is eligible for a kidney transplant, the current Organ Procurrement and Transplant Network (OPTN) policy gives the previous living kidney donor extra points on the transplant list with the goal of shortening their waiting time on the list



INSURANCE

9. As a donor, do I have to pay for this with my own insurance?

We have a financial team and transplant coordinators who will work with your insurance to ensure the maximum coverage possible.

Kidney living transplant – The recipient's Medicare insurance will pay for the cost of your medical expenses for the evaluation, surgery, as well 90 days following the surgery. If some other medical problem is discovered during the pre-surgery evaluation, it would be treated by your own insurance, like any other medical issue your regular doctor might discover during a routine physical.

Liver living transplant – Living liver donation is covered by most private insurers for the evaluation and donation stay. Coverage after the donation may vary with insurance companies. Our financial counselors will be happy to discuss insurance coverage with you.

10. If I choose to donate a kidney or part of my liver, what happens to my insurance rates going forward?

Most living donors do not have problems with insurance as a result of donating. While federal law may protect you from problems with health insurance, after you donate, it is possible that an insurance company may consider you to have a pre-existing condition. If that happens, it is possible that:

- It could be harder to get new health, disability, life, or long-term care insurance
- It could be harder to increase your life insurance coverage
- Your insurance premiums might be higher than they would be without a pre-existing condition
- The transplant team has dedicated financial counselors that living donors will meet with to assist in questions and concerns during the evaluation process

11. Are any of my other bills covered, such as hotel or travel costs?

Lodging and hotel expenses are your responsibility as the donor. There is an assistance fund called the <u>National Living Donor Assistance Fund</u>, which offers grants to living donors that help offset some of the donor expenses. Most donors who apply will qualify. We encourage every living donor to take advantage of this grant. Your living donor coordinator will provide more information and education about the NLDAC. Also, many states have their own policies that can offset the expenses.

12. What is the process for becoming a living donor at Nebraska Medical Center?

All individuals are encouraged to complete the <u>kidney donor screening form</u> or the <u>liver donor screening form</u> to determine if you qualify. If you are interested, but have additional questions, please call us at 800.401.4444

After you have completed a kidney or liver living donor form, you will then undergo a thorough medical and psychosocial living donor evaluation. This will include multiple consultations with the living donor team, lab work and radiology tests to ensure donor eligibility and safety.



SURGERY

Kidney donor surgery

In most cases, the kidney living donor surgery is performed laparoscopically, resulting in less pain after surgery, a shorter hospital stay and quicker recovery.

Laparoscopic kidney surgery uses two to three small incisions where the surgical instruments and a tiny camera are inserted. A larger four to six inch incision is required to remove the kidney. The surgery typically takes about two hours. Most patients spend two to three days in the hospital and can return to normal activities within six weeks.

Liver living donor surgery

The liver living donor surgery is performed through an incision along the midline or upper abdomen. The surgery usually takes four to six hours. Most patients spend five to seven days in the hospital, and can return to normal activities within six to eight weeks.

Following a living donor surgery, a living donor coordinator will help you schedule the required follow-up visits at six months and one year. Our team will also contact your primary care doctor to discuss appropriate follow-up care.

13. What factors can disqualify me from becoming a living donor?

To become a kidney living donor you need to be at least 19 years old and relatively healthy. You can't have any major chronic medical conditions like diabetes or morbid obesity or be a smoker. Those over the age of 65 are considered on a case-by-case basis. The living donor team encourages all individuals who are interested in kidney donation to fill out the online form as each potential donor will be screened by living donor team

To become a liver living donor you need to be at least 19 years old and relatively healthy. You cannot have a body mass index over 30. There are a variety of medical conditions that could impact your ability to donate. You will be asked to complete a medical questionnaire to determine if you qualify to become a donor. Those over the age of 50 are considered on a case-by-case basis.

14. Do most religions support organ donation?

Most major faiths support organ donation and consider it a final act of love and generosity toward others. If you are unsure, the federal website, OrganDonor.gov provides religious views on living donor transplants.

15. What if I don't have a family member or relative with a matching blood type?

A living donor does not have to be a relative. We have evaluated friends, coworkers, spouses and even strangers as potential donors and have had much success in having individuals donate to their loved ones even if they have a different blood type. There are certain factors that will determine if this is an option for you. There has also been an increase of altruistic, nondirected organ donation, in which individuals donate to a recipient that they do not know.



Individuals looking for a kidney donor may be eligible for our internal paired exchange program, one of the largest programs in the Midwest. A paired exchange involves an individual who wishes to donate to a relative or friend but cannot because of incompatible blood types or other medical reasons. If another pair is found in the same circumstance, an exchange may be possible between the two pairs. Many compatible and incompatible living donor pairs welcome the opportunity to participate in our exchange program to donate on behalf of their loved one and help other recipients at the same time. Over the past two years, more than 30% of living donors have participated in the living exchange program. The largest kidney chain at Nebraska Medical Center involved nine people who received living kidney organ transplants. Our internal exchange program accounted for 43 living kidney donor transplants from 2017 to 2019.

16. What if I feel pressured to donate?

Donations should be made freely, with no pressure and with no expectations of financial gain. If you feel pressured to donate, the team will not let you donate. You can withdraw from the process at any time, even up to the day of the surgery. The living donor team completely supports the donor.

Every potential living donor will work with an independent living donor advocate. The role of this person is to ensure safety for all our potential living donors. The independent living donor advocate is present for each phase of donation and for our potential donors to assure there is no pressure or coercion and the donors understand that they can say no at any time and for whatever reason and they will have full support of the living donor team. The independent living donor advocates are also present to assure that each potential donor is adequately educated and making an informed decision to donate.

17. What are the short and long term outcomes of living with one kidney?

Most people can live a normal life with just one kidney. Kidney function usually stabilizes 70 to 75% of previous function in a few months after surgery. Risk of kidney failure is not any greater if you have one versus two kidneys. The donor will not have to avoid certain kinds of food or beverages. We recommend the donor maintain a healthy lifestyle and weight. Risk for high blood pressure may be higher as one gets older compared to a nondonor but it can be managed with medications. We ask that each living donor follow closely with his or her primary care doctor. Your living donor coordinator will continue to be your coordinator after donation. They will be your resource for life and have trained staff that work alongside them such as pharmacists and dieticians that are a resource for all our individuals that have donated in the past.

18. What are the short and long term outcomes of living with a partially donated liver?

Your liver will function normally immediately following the surgery. The part of the liver that was removed will grow back.

19. How to become a living donor.

To learn more about living donation at Nebraska Medical Center, visit NebraskaMed.com/Kidneydonor for kidney or NebraskaMed.com/Liverdonor for liver.

