

Thinking about being a living donor? *This is what you need to know first.*

This paper explains what you need to know before you may agree to be a living organ donor. It is a patient version of the OPTN (Organ Procurement and Transplantation Network) informed consent policy. This paper explains:

- What it means to give your consent
- That only you can decide to donate
- You have the right to privacy as you get tested and make your decision
- The role of an Independent Living Donor Advocate
- What the transplant hospital staff must do before, during and after donation
- The risks of living organ donation, including the medical, mental, social, and financial risks
- How your health might be affected by donation
- What information you must be given about how well transplant recipients do after their transplants
- What information about your organ recipient you do not have the right to receive
- Your need for medical follow-up after donation

A living donor can donate a:

- Kidney
- Portion of their liver, pancreas, or intestine
- Lobe of their lung

Some words used in this paper and their meaning may be helpful.

- A person who needs an organ transplant is called a “**transplant candidate**”. A transplant candidate must be on the national waiting list to receive an organ transplant from a deceased donor or a living donor.
- After a transplant candidate receives an organ transplant they are called a “**transplant recipient**” or “**recipient**”.
- If the living donor knows the recipient it is “**directed donation**”.
- If the living donor does not know the recipient it is “**non-directed donation**”.

You will meet with the hospital staff who will help you decide if you can be a living donor. The hospital staff must get your informed consent. Through informed consent, the hospital staff gives you information so that you understand the benefits and risks of donor testing and organ donation, and that you agree to the testing and donation. Informed consent will include all the items below.

Consent for Living Donation

To become a living donor you must be able to state that:

- You want to donate.
- No one forced you to donate.

- No one said they would give you something of value for donating.
- You know that you can decide not to donate at any time.

The hospital staff will ask you to sign a paper for your medical record to show you understand these things.

Living Donation is Your Choice

You Have a Right to Privacy as You Get Tested and Make Your Choice

It is your choice to donate an organ. It is against the law for you to receive something like cash, property or a vacation for donating an organ.

If you become a living donor, the hospital staff must keep your personal and medical information private. The hospital staff must also keep the recipient's personal information private. If you want to be a non-directed donor, the hospital staff must keep your identity private. The hospital staff must also keep the identity of the recipient private.

If you decide not to donate, the hospital staff will keep your decision and reasons private.

The Independent Living Donor Advocate (ILDA)

The hospital staff will provide an independent living donor advocate (ILDA). An ILDA is a person who understands the organ donation process and who will:

1. Promote your best interests.
2. Check that you have received information about the following topics:
 - The informed consent process.
 - The tests needed to be a living donor, and the risks of these tests.
 - The surgery, and the care you will get after the surgery.
 - The need to have follow-up care after donation.
3. Help you get more information about these topics as needed

The ILDA should not be involved with the transplant candidate.

Hospital Staff Responsibilities

The hospital staff will tell you about the donation process. The staff must give you information using words that you understand so that you can ask questions.

To be a living donor, you must have medical tests to make sure you are healthy enough to donate an organ. The hospital staff will help you understand the medical tests that will be needed. The hospital staff will also make sure you are ready mentally to be a donor and have a plan for your recovery (for example, whether you can take time off from work and who will help you while you recover). This is called a psychosocial evaluation. Your ILDA will make sure you understand the steps in these evaluations. Your ILDA will get answers to any questions you have about testing, the use of personal information and any other questions you have about donating.

After the tests, the hospital staff may decide that you should not be a living donor. If this happens, the hospital staff should tell you that you could be evaluated at a different hospital. Another hospital might decide that you may donate because every hospital uses its own guidelines and judgment.

During the tests, the hospital staff may find that you have a medical condition that you did not know about. You could need to be treated for this condition. Also, the hospital staff could find that you have an infection or sexually-transmitted disease that you did not know about. It is the law that hospitals must report some of those conditions to local, state or federal public health authorities. They must report them privately, meaning that no one else will be told.

The hospital staff must tell you that transplant candidates have other options for treatment. A transplant candidate could get an organ from a deceased donor instead of from you. A transplant candidate who needs a kidney transplant could continue to get dialysis if they do not receive a transplant.

After you donate an organ, your hospital must continue to check on your health. Depending on the type of organ you donate, the hospital must report information about your health and personal status (e.g. ability to work) for two years after you donate. You must agree to take part in this follow-up. Ask the hospital staff how you will receive follow-up and who will pay for the follow-up.

A group called the Scientific Registry of Transplant Recipients (SRTR) collects and keeps information for every transplant hospital in this country. The information shows how well recipients do on average after getting transplants. The hospital staff must give you information about how well recipients do at the hospital performing the recipient's transplant, if the transplant hospital is known in advance. The information must include

- Percent of transplant recipients at that hospital still alive one year after transplant.
- Percent of transplanted organs at that hospital still functioning one year after transplant.
- Percent of transplant recipients alive and transplanted organs functioning after one year in the country overall

If the transplant center is not known, staff at your donation hospital must give you information about:

- the percent of transplant recipients across the country who are alive after one year
- the percent of transplanted organs functioning after one year across the country

Ask your ILDA if you need help understanding this information.

Information You Do Not Have a Right to Receive

The hospital staff can only give you some information about the transplant candidate if the candidate agrees. This information includes:

- Any reasons why the transplant candidate may have increased risk for a bad result after getting the transplant.

- Any personal health information about the candidate that the law says is private.

The transplant candidate could have a bad result after the transplant. A bad result could be, for example, that the organ transplant does not work, the recipient has new medical problems, or the recipient dies. The chance of one of these things happening to the recipient of your organ might be higher than it would be for other transplant candidates. The hospital might decide that the recipient would still benefit and that the transplant should happen anyway. The hospital staff is not allowed to tell you about the transplant candidate's chances of having a bad outcome unless the transplant candidate agrees to share the information. Each hospital chooses potential donors and transplant candidates based on the hospital's own guidelines, practices and judgment.

Risks of Donation

The hospital staff must make sure you know about the following risks. Ask your ILDA to explain any risks you do not understand.

Potential medical risks that could happen during the evaluation:

- Being allergic to a test and having a bad reaction.
- Discovery of an infection the hospital staff need to report.
- Discovery of a serious medical condition that could require more medical tests or treatment that you will have to pay for.
- Discovery of a genetic health risk factor or issue that you did not know about.

Potential surgical or medical risks that could happen if you donate an organ:

- Death or disease (being very overweight, older or having high blood pressure or other medical conditions could make you more likely to die or have a problem).
- Scars, hernia, infection, blood clots, pneumonia, nerve injury, pain, tiredness, and other symptoms that are common when people have surgery.
- Abdominal symptoms like bloating, nausea, or having a bowel obstruction.

Potential mental or social risks *after* donating:

- Problems with how you feel about your body or what it looks like.
- Problems with depression or fear and stress.
- Feeling sad if the transplant recipient becomes ill or dies.
- Changes in your lifestyle because you donated an organ.

Potential money problems after donating:

- Paying for travel, short-term housing, and child care, and not being paid while you were away or recovering from surgery. Some money may be available to help you with such non-medical donation-related costs.
- Having to pay for costs of lifelong follow-up visits.

- Losing your job or your income.
- Having a hard time finding a job in the future.
- Having a hard time getting, keeping, or paying for health insurance, disability insurance, and life insurance.
- Future health problems that may not be covered by the transplant recipient's insurance.

Effect on Your Future Health

Living Kidney Donors

If you donate a kidney, hospital staff must tell you about how living kidney donation relates to ongoing or chronic kidney disease and kidney failure. Your ILDA should help you understand these terms.

If you are thinking about donating a kidney, you should know that:

- On average, you will permanently lose 25-35% of your kidney function after donating.
- Your risk of having kidney failure later in your life is not any higher than it is for someone in the general population of a similar age, sex or race. However, you are more likely to have kidney failure than healthy people who are not donors.
- Chronic kidney disease most often starts in the middle of your life (40-50 years old). Kidney failure most often starts after age 60. If you get tested when you are young, doctors cannot predict how likely you are to have chronic kidney disease or kidney failure later in life.
- If you damage your other kidney (the one you did not donate), you may have a higher chance of having chronic kidney disease, which could go on to become kidney failure
- You will need medical treatment if you start to have kidney failure
- Current policy gives living donors priority on the national waiting list if they need to get a kidney transplant in the future. You can ask your ILDA or another transplant hospital staff member of about this policy.

These events and others could happen **during or after** surgery, and they could be **short-term or permanent**:

- You will lose some of your kidney function.
- You could have kidney failure and need dialysis.
- If you become pregnant after donating, you are more likely to have high blood pressure during pregnancy. This is called "preeclampsia".

Living Liver Donors

If you are thinking about donating part of your liver, you should know that these events and others could happen **during or after** surgery, and they could be **short-term or permanent**:

- You could have immediate liver failure and need a transplant.
- You could have temporary liver problems while you recover. This may depend on how much of your liver you donate.

- You may need a blood transfusion.
- Your liver may leak and you may need another operation to fix the leak.
- You may need more tests after you donate, which might also have risks.

After You Become a Living Donor

You must agree to give information about your health and general status to the hospital where you donated for two years after donation. The reason you need to have this medical follow-up is to check your health and to give you medical treatment as needed.

During this follow-up, like during any medical checkup, tests might show that you have a medical problem that could need to be treated, and the cost of the treatment might not be covered by the recipient's insurance. Also, if an infectious or sexually-transmitted disease is found, the hospital staff may need to report it, in confidence, to local, state or federal public health authorities, the transplant recipient's hospital and to the OPTN. The hospital staff will not share this information with your recipient, your family or any other person the staff is not required to tell by law.

If you have any questions or concerns about any step of living donor evaluation, donation or follow-up, ask your transplant hospital team or ILDA.

The United Network for Organ Sharing (UNOS) directs the nation's organ transplant system.

UNOS has a toll-free patient services phone number: 1-888-894-6361

Call this number to:

- Find a transplant center in your area that does living kidney or liver transplants.
- Learn more about organ donation and transplantation policies and data.
- Ask questions or talk about concerns or problems.