

Words we use in this booklet

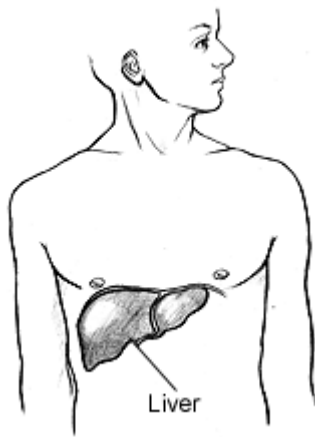
Abdomen	The part of your body that's below your chest and above your belly button; tummy; belly
Bile	A fluid made by your liver to digest fat
Body Mass Index (BMI)	A way to measure body fat by using a person's height and weight
Compatible	Gets along together, mixes well together, or does not cause a problem, reaction or rejection when put together
Independent Living Donor Advocate	Transplant programs are required to identify an ILDA for living donors. ILDAs support the living donor's rights. They help potential living donors understand the consent process, the evaluation process, the surgical procedure, and the need for follow-up after donation.
Psychosocial health	Includes the mental, emotional, social, and spiritual parts of what it means to be healthy
Regenerate	To grow back lost or injured tissue
Risk	More likely to suffer harm, injury, or loss; in danger of
Social Worker	A specially trained person who can help solve problems in your daily life and coordinate care needs after your transplant

What is Living-Donor Liver Transplantation?

Living-Donor Liver Transplantation (LDLT) is an accepted and successful treatment for patients suffering from advanced liver disease who are listed for liver transplant. Currently, in the United States there are over 17,500 people waiting for a liver transplant with the United Network for Organ Sharing (UNOS). Every day more patients are added to the waiting list. More than 6,000 patients receive liver transplants every year. Another 1,700 patients die each year while waiting.

Living-Donor Liver Transplant (LDLT) is possible because of the special ability of the liver to regenerate (regrow) after a section is removed. This means that when a piece of the liver is removed from a healthy living donor, the part that remains in the donor will grow back. The piece of liver transplanted into the recipient will also regenerate.

What does my liver do?

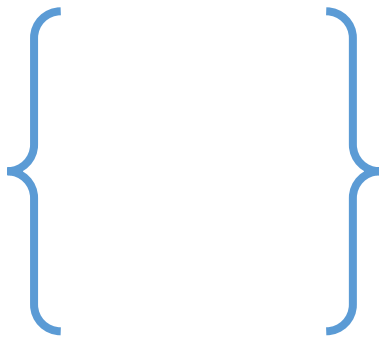


The liver is the largest solid organ in the body. By the time you're an adult, it's about the size of a football. This important organ supports every other organ in our bodies. The liver has two sections, the right lobe and the left lobe. The liver does many things including:

- Cleaning the blood
- Producing an important digestive liquid called bile
- Storing fat, sugars, iron, and vitamins for later use by the body
- Making the proteins needed for normal blood clotting

What are some benefits of donating?

Donating is a very personal decision. You, as the donor, don't receive a direct benefit. But your donation can make a big difference to the receiver.



Liver transplants are given to patients based on how sick they are. Each patient waiting for liver transplant is given a score called the "Model for End-Stage Liver Disease" (MELD). The MELD score is a sign of the recipient's degree of liver failure. The MELD score determines priority on the wait-list. Patients with a higher MELD score are very sick, so they have a better chance of getting a liver transplant sooner.

A living-donor transplant means a patient can have a transplant before their liver failure gets worse. It means a shorter wait time for a liver. Because the surgery can be planned, the chance for a successful transplant may be better. The quality of the liver is usually better, because living donors are usually healthy adults. They have gone through a complete medical evaluation.

What are the first steps to donation?

The person that you would like to donate to must be on the transplant waiting list or approved for listing in order to start your donor evaluation process.

To qualify as a living donor, you must:

- Have a compatible blood type with the recipient
- Be in good general health
- Be older than 18 years of age and younger than 60
- Know the person you would like to donate to
- Have a healthy body weight
 - Body Mass Index (BMI) no more than 35 at initial evaluation
 - Must have BMI of 30 or less at time of donation
- Have no significant physical or mental problems
- Not have active or long-term hepatitis B or C
- Have no serious medical conditions such as diabetes, cancer, or heart disease
- Have active medical insurance

We may need some additional information, if you are between 55-60 or have a BMI between 30-35.

What happens during the donor medical evaluation?

The evaluation serves two purposes: to protect you and to help ensure success of the transplant.

The evaluation includes a physical evaluation and a psychosocial (syeh-ko-SO-shul) evaluation. The psychosocial evaluation looks at the mental, emotional, social parts of what it means to be healthy.

You will need to answer all the questions we ask. This includes questions about any history of “high risk” behaviors. The transplant staff will ask about your financial situation and talk about who can give you physical help and emotional support throughout the donation process.

We’ll ask you to describe your reasons for donating and how it might affect your lifestyle (such as employment and family relationships). Involving your loved ones in the educational part of the evaluation process can be helpful. They can learn about the donation surgery and recovery process and support you in your decision.

Our evaluation process has **3 parts**:

1

Screening

- Health history
- Phone interview and education
- Blood test to see if you are compatible with the intended transplant candidate.
If you are not compatible with that person, you may have other options to donate.

2

Medical, Surgical, and Psychosocial Evaluation

This part can take two to three days to complete. It includes:

- Blood and urine tests
- Discussion about weight loss, if your Body Mass Index (BMI) is more than 30
- Tests that provide pictures of organs inside your body, called imaging tests
- Tests to see how well your heart, lungs, and kidneys are working
- A review of the surgical procedure and the risks of surgery
- Meetings with mental health and social work professionals
- Meeting with an Independent Living Donor Advocate (ILDA)

3

Preparation for Surgery

If you've been approved for donation:

- Education with the donor coordinator
- Physical exam
- Consultation with anesthesia and preparation for admission
- Meeting with an infectious disease specialist (an expert in detecting and treating illnesses caused by bacteria, viruses, fungi, and parasites)
- Surgical planning

Can I be turned down as a donor?

Yes, it's possible. Only about two or three out of 10 people who are interested in donation will actually become donors. Some reasons are:

- Your blood type is not compatible with the recipient's blood type.
- Your liver is too small to give some away, and still be sure that you have enough for your own body.
- You may have an uncommon blood supply or bile system in your liver. This is not a risk to you. But this can make it very difficult to ensure a successful transplant.
- Abnormal test results, such as heart tests or blood tests that show an operation would be too risky for you.
- Drinking too much alcohol or using too many opioid drugs.
- You don't have enough support at home after you leave the hospital.
- Donating would be harmful to your mental health.

What are the risks of surgery?

Most living donor liver transplants involve removing the liver's right side. The right side makes up more than one-half of your entire liver. The remaining liver can grow back to normal size and return to normal function following surgery.

The specific risks are similar to other major liver surgeries, including:

- Bleeding and infection
- Complications from general anesthesia (for example, sore throat, nausea and vomiting)
- Complications of the bile duct, such as bile leaks that may require on-going medical care or medical procedures
- Common risks associated with blood transfusion (for example, fever, infection, and allergic reactions)
- Rarely, poor liver health, possibly leading to the need for a liver transplant yourself
- Blood clots
- Hernia at the place where the incisions (surgical cuts) were made
- Heart attack
- Nerve injury to your arms, legs, or abdomen

The risk of dying because of living liver donation is 2 in 1,000. Liver donors are not at any greater risk of developing liver disease than people who never donate.

What else should I be thinking about?

How will donation affect me emotionally?

- Sometimes people feel overwhelmed by emotions. These feelings are more common when the recipient does not do well after donation. You may need the care of mental health professionals to help you.
- You might feel and think differently about your body. You will have scar on your abdomen. You might not like your body as much as you did before.
- You might feel bad about the added stress on relationships and loss of independence as you heal.

How will donation affect me financially?

- You may be out of work 8-12 weeks. You might lose income. Does your employer provide disability coverage? You should check. If necessary, do you have enough money in the bank to carry you through?
- The recipient's health insurance will pay for many of the health care cost related to the evaluation, surgery, and after-surgery care. The recipient's insurance might not cover all of them. This could mean additional expenses for you.

There are some programs available that could provide financial help. The social worker will talk with you about these during your meeting.

- If your job requires physical effort, what happens if you can't do it anymore after surgery? There's a chance you could lose your job.
- You might find it harder to get health insurance or life insurance. Or your insurance could cost more. In some cases, you may lose your insurance.
- There are added expenses related to follow-up appointments. These could include hotel and travel costs.
- You may need to consider additional expenses related to childcare, as you recover.

Always remember, this decision to donate is voluntary. It's OK for you to stop the donation process at any time. We will keep your decision confidential.

What about my hospital stay?

Donors usually stay in the hospital 5-6 days after surgery.

You will have a tube in your abdomen after surgery. The purpose of the tube is to drain fluid from your abdomen. We will remove the tube according to the surgical plan we develop for you.

You'll need to stay close to the hospital for 1-2 weeks. That means you'll need to be able to get to the hospital within 30 minutes, from wherever you are.

If you live further away than 30 minutes, our social worker can help you find a short-term, local place to stay.

Will I have much pain after surgery? Unfortunately, live liver donors have significant pain after the surgery. You will be very uncomfortable for at least the first week. You will have less pain as each day goes by.

Most of our live liver donors have significant discomfort for 2-4 weeks after surgery. Most pain medicines make you sleepy, can affect your breathing, and may cause nausea and constipation. We will work to find the right balance of pain medicine to make you comfortable.

What restrictions will there be after surgery?

- Don't lift anything heavier than 10 pounds (that's like a gallon of water) for one month. You will have other lifting restrictions for the first 6 months.
- Talk to us before you take any new medicines, herbal supplements, or vitamins.
- Continue doing your deep breathing and coughing exercises.
- You'll be able to take a shower, but no tub baths or swimming until your incision (cut) is healed.
- Eat a variety of healthy foods and drink plenty of fluids.
- We'll talk about an exercise and activity plan. Walking is always good.
- No driving until we say it's OK.
- It's OK to have sex whenever you feel ready. However, we recommend not getting pregnant for one year after surgery.

- Were you using birth control pills (BCPs) before surgery? BCPs contain ingredients that are not good for you while you're recovering. We recommend using a barrier type of contraception after surgery. Examples include the cervical cap, diaphragm, or copper IUD.

How long until I'm fully recovered?

Plan on 8-12 weeks for recovery after surgery. You may need weekly visits and frequent blood work for the first few months. These visits include physical exams as well as lab tests.

We'll do imaging tests (CT or MRI scans) 3 months after the surgery to see how well the liver is regenerating.

You'll need to come back to University of Rochester at 6 months, 12 months, and 24 months for long-term follow up.

Can I change my mind?

You can change your mind any time. You do not need to provide us with a reason. The only information we'll give to the potential recipient is that you have been excluded from donation. We can provide advice on how to speak with your recipient after they receive the news that we have excluded you from donating

Please remember, our job is to support you. This includes protecting your privacy and your decisions. If you want to stop or wait, please call your coordinator, social worker, or donor advocate. We can help you with any questions.

People often feel guilty about changing their minds. We don't want anyone to feel that way. Liver donation is a wonderful gift, but it is also major surgery. In order to be a donor, you must have a solid support system and be physically, mentally, emotionally, and financially ready.

The decision to donate

The decision to donate a portion of your liver is an individual voluntary and confidential act. You may experience mixed emotions. You may want to help someone, but what does this mean for you?

Take time to think carefully about your decision. It's important to discuss this with your support people and those that will be directly impacted by your decision to donate.

You should never feel pressured to donate.

We encourage you to bring your primary support person with you to your evaluation. The person you choose to help you cannot be the recipient or the recipient's caregiver.

Yes. I want to donate!

For each recipient, we evaluate one donor at a time.

Anyone interested in donation should speak with our living donor coordinator.

Call us

(585) 275-5875

Monday – Friday, 8 a.m. – 4:30 p.m.

Useful websites

If you'd like more information about being a living donor, here are some helpful resources.

<p>United Network for Organ Sharing (UNOS) Organ availability information, education materials, and policies</p>	<p>https://unos.org/ https://transplantliving.org/</p>
<p>UNOS' "Stories of Hope" by living donors and transplant recipients</p>	<p>https://transplantliving.org/community/stories-of-hope/</p>
<p>U.S. Department of Health and Human Services Government Information on Organ Donation and Transplantation</p>	<p>https://www.organdonor.gov/about/process/living-donation.html</p>
<p>Transplant Awareness Organization of Greater Rochester (TAO) A network of people that have had transplant surgery</p>	<p>http://www.tao-rochester.org/</p>
<p>American Liver Foundation</p>	<p>https://liverfoundation.org/</p>
<p>National Living Donor Assistance Center</p>	<p>https://www.livingdonorassistance.org/</p>
<p>American Society of Transplant Surgeons</p>	<p>http://asts.org/</p>
<p>Scientific Registry of Transplant Recipients A national database of statistical information for solid organ transplantation</p>	<p>www.srtr.org</p>
<p>Organ Procurement and Transplantation Network Member Directory</p>	<p>https://optn.transplant.hrsa.gov/members/member-directory/</p>