

Being Evaluated for Living Liver Donation

You've indicated that you're thinking about donating part of your liver. To donate part of your liver, you must first be evaluated to see if you can be a donor.

What is a living donor transplant?

A living donor liver transplant is when someone who's still alive gives part of their healthy liver to a person who needs it.

This is different from a deceased donor transplant, which is the most common type of transplant. Deceased donation is when the liver comes from a person who's already died and the donor's family or the donor (before death) has given their confirmed consent.

Currently, there aren't enough deceased donor livers for every person who needs a new liver. This is one of the reasons living donations are so important.

How can I be evaluated as a living donor?

Before you can be evaluated or even decide to be evaluated as a potential living donor, you need to understand both the risks and benefits of the evaluation, as well as the risks of donating part of your liver. Learning about what you are agreeing to is a process called **"informed consent."**

We've created this document to help you learn what happens when a person decides to donate part of their liver. This includes the process of being approved to be a liver donor, what to expect before and after surgery, and the potential risks and benefits of live liver donation. The process of live liver donation includes:

- evaluation
- approval to donate and surgery scheduling
- surgery
- post-operative follow-up and care.

Donation is voluntary

Donating part of your liver is a completely voluntary decision. You have the right to change your mind at any time during the donation process. You shouldn't feel pressured or obligated to have such a serious procedure. If you have any concerns at any time, talk with your donor team about them. You're always allowed to change your mind. If you do change your mind, the transplant team can simply tell the recipient that you're no longer a donor candidate. None of your health or evaluation information will be shared with the potential recipient.

The sale or purchase of any human body part is a federal crime. It's illegal for anyone to get money or payment of any kind in exchange for a human organ or part of a human organ.

Why do people need liver transplants?

A person needs a liver transplant when their liver is too diseased or sick to be cured. Every person who's waiting for a liver transplant has reviewed all possible alternative treatments with their doctor. A liver transplant is their best option for getting better.

Are there other transplant options besides living liver donation?

The alternative to a living donor liver donation is a deceased donor liver donation. This is when the donated liver comes from someone who's already died. Occasionally, a deceased donor liver may become available for the recipient before the living donor evaluation is complete or before a transplant happens.

What happens if someone needs a liver transplant but doesn't get one?

The progression of their liver disease may lead to death.

What are the advantages of living liver donation?

For the recipient, the greatest advantage of living donation is having a shorter wait time. This is especially important, because there is a risk of dying while waiting for a deceased donor transplant. Here are some reasons that living liver donations are so important:

- At any given time, more than 14 thousand people are waiting for a new liver, but there aren't enough deceased donors to meet this need.
- 1 in 5 patients will die while they wait for a deceased liver donor.
- Living donor livers let someone get the liver they need before they get too sick.
- With a living donor transplant, the operation is scheduled and the recipient does not have to wait as long for a transplant.
- The recipient may have a faster recovery than recipients with deceased donor liver transplants.
 - One reason is because their MELD score (how sick the person is) is often lower at the time of surgery.
 - Another reason is that the piece of the liver from the living donor is put into the recipient as soon as it's taken out of the donor's body. This improves the chance that the liver will work as it should. This is different from a liver from a deceased donor, which may be stored for many hours before it can be transplanted.

- Living donor liver transplants help other people who are waiting for deceased liver donations. This is because live donations increase the number of deceased donor organs that are available for other patients who are waiting.
- Live liver donation is also more convenient than deceased liver donations. Both the recipient and donor are able to arrange the best time for surgery.
- For the donor, there is the added benefit of knowing that they have contributed to another person's life in a meaningful way.

Is it safe to give part of my liver away?

Most people who donate part of their liver recover and lead normal lives after surgery. However, the decision to donate part of your liver is very serious. It's one you shouldn't take lightly. It also comes with risks, which are explained in pages 8-11 of this document.

If you decide that you want to donate part of your liver, know that your health and safety will be our primary focus.

Will there be someone at Vanderbilt to help me through the donation process?

Yes. A person called an independent living donor advocate (ILDA) will be assigned to you. They will work with you and the living donor team to ensure that your health, safety, and interests take priority. You'll meet your ILDA during evaluation.

About your independent living donor advocate

- They're an employee at Vanderbilt. But they don't work for the transplant team.
- They work on your behalf and will be your partner through the entire transplant process.
- They'll be an important part of the support system at Vanderbilt that helps you and your family throughout the donation process
- You may contact them any time you have questions or concerns.
- Everything you talk to them about is confidential. They won't share information with the transplant team members unless it's needed.

What your advocate does

- They decide if you're able to understand the donation process and its risks.
- They make sure your rights are protected throughout the transplant process.
- They promote your best interests.
- They talk with you in detail about the risks and complications of donating, including death
- They're available to you and your family at any time during the donation process.
- They're here to answer any questions you have about donating part of your liver.

What will happen to the recipient if I change my mind?

- The liver transplant team at Vanderbilt will continue to care for them.
- They'll remain on the waitlist for a deceased liver donation.

What happens during evaluation?

You'll have different types of tests

The tests will find out if:

- you and the recipient are a compatible match
- you're medically, surgically, emotionally, and mentally able to donate
- you have the social support you need to go through the donation process
- your financial situation is strong enough for you to go through the donation process.

The tests you'll have are based on your situation

Not every person will need all the tests that are listed in this section or even the same tests. Your tests are based on you.

- Every test will be carefully explained to you in detail and in advance.
- If a test has risks, we'll explain them to you in advance and ask you to sign a consent form that outlines the risks in detail.
- It's possible that we'll find out you have medical issues, a serious medical condition, a reportable infection, or a genetic finding that you didn't know about. If this happens, we'll refer you to your primary care provider for follow-up.

General medical tests

Tests you may have include:

- a review of your health history
- an MRI with IV contrast of the abdomen to check the structure of your liver and blood supply (Tell your nurse or liver doctor if you've ever had a bad reaction to IV contrast dye.)
- a CT scan with IV contrast of the abdomen to check the structure of your liver and blood supply (Tell your nurse or liver doctor if you've ever had a bad reaction to IV contrast dye.)
- an EKG (electrocardiogram), to measure the electrical activity of your heart
- additional heart testing, including an echocardiogram or stress test to make sure your heart is healthy enough for surgery
- a chest X-ray to see if your heart and lungs are healthy
- blood tests to determine your blood type and make sure it matches the recipient, and to check to see if you are immune to or have certain viruses, including HIV (human immunodeficiency virus).

Medical tests if you're older than 50

If you're older than 50, your tests will include:

- a colonoscopy to look for polyps and bleeding in your colon
- a prostate cancer screening blood test if you're male.

Medical tests if you're female

If you're female, we'll need the results of your last pap smear and mammogram, if they were completed in the past year. You can have these results faxed to us. If you haven't had a pap smear or mammogram in the past year, you'll need to have both tests done.

Psychological and social evaluation

This evaluation will help us:

- find out if you're capable of giving your informed consent for liver donation
- confirm that you haven't been pressured into donating
- review and talk with you about the reasons you want to be a donor
- determine if you and your family or support person(s) will be able to manage the emotional, financial, and physical stresses of this type of surgery.

It's important for you to know that these tests can sometimes uncover psychosocial issues that may need further evaluation.

Risk evaluation

In addition to the medical risks relating to surgery, donating a liver has risks that are psychological, emotional, social, and financial.

We'll talk with you about these risks in great detail to help us decide if you can safely donate part of your liver. We also want to be sure you're making an informed decision.

What happens after all the tests are done?

Once the tests and evaluation are complete, the living donor transplant team will review them. Together, the team will decide if you're a suitable living donor candidate.

If you are NOT accepted as a candidate

If the team decides that you're not a candidate for any reason, you and your recipient do have the option of going to another transplant center to be evaluated. Other programs may have different exclusion criteria.

If you ARE accepted as a candidate

If the team decides that you're a good candidate, we'll tell you, but not your recipient. It's up to you to share the good news! If you choose to go ahead with the transplant, we'll work with you and your recipient to schedule surgery.

What happens during surgery?

The surgery you'll have is one in which part of your liver is removed. The medical name for it is "partial hepatectomy."

The surgery is done through an open incision in your belly. Your surgeon will talk to you about all the details of the procedure and answer all the questions you have.

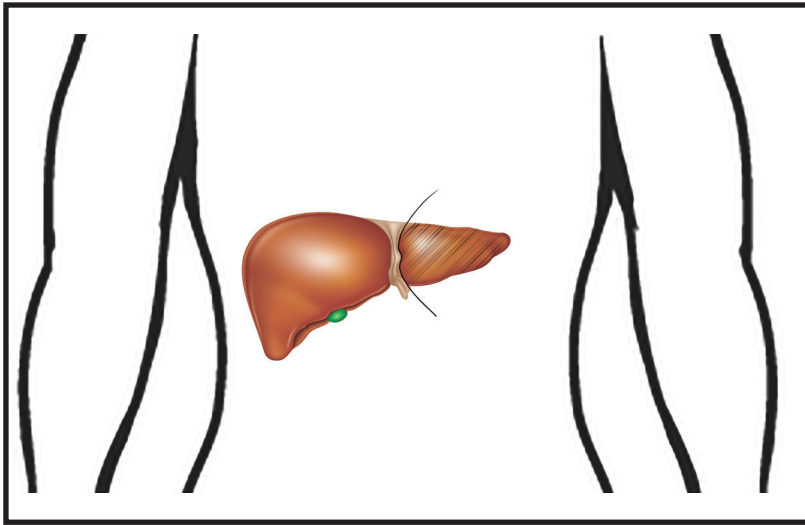


Figure 1

If you're donating your liver to a child, the surgeon usually takes about 25 percent of it. In this situation, the cut is made on the left side of the organ. You may hear your surgeon call it the "left lateral" side.

The shaded area and the black line give you an idea of where the surgeon may cut for this type of donation.

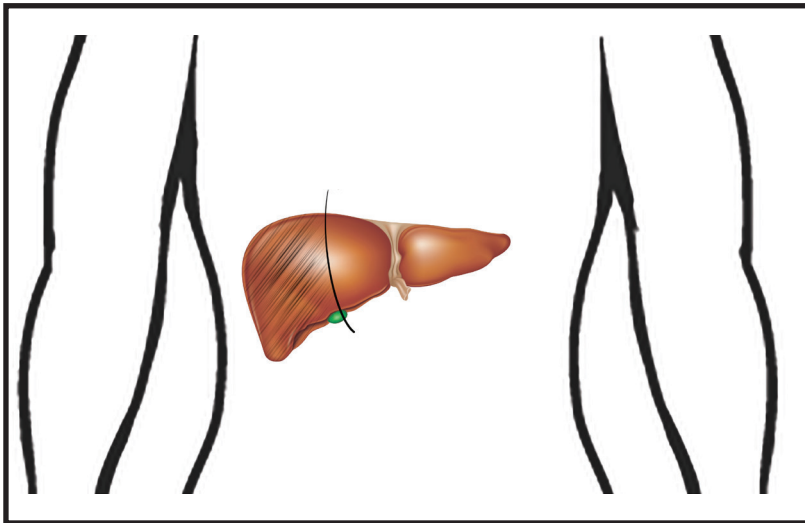


Figure 2

Here you can see where the liver may be cut if the recipient needs more than 25 percent. If you're donating part of your liver to an adult, the surgeon may take as much as 60 percent of it out. The line and shaded area give you an idea of where the surgeon would cut if they take from the right side of your liver.

Will my liver grow back?

Yes. After surgery, the liver you have left after donation will grow back to close its normal size in about 2 to 3 months.

What happens after surgery?

For 1 or 2 days after surgery:

- you'll be in the **surgical intensive care unit**
- you'll have a **catheter** in to help drain urine from your bladder
- you'll have an **IV** for fluids and medicines
- you'll breathe air through an **oxygen mask** on your face or through small tubes that run to your nose for the first 24 hours
- you'll need to **breathe deep and cough** every 1 to 2 hours
- your mouth and throat may feel dry (other than rising out your mouth, no drinking or eating until we tell you it's OK and until after we've taken out your **NG (nasogastric)** tube
- you'll have **pain**, which we'll give you medicine for
- you'll have **drain tubes** coming out of your belly that we'll watch closely.
- we'll ask you to **sit up and move** as you can.

How long will I be in the hospital?

You'll be in the hospital for 5 to 7 days after surgery.

Can I drive myself home from the hospital?

No. You need to arrange for a ride from the hospital. We won't let you leave on your own.

Remember that for as long as you're taking prescription pain medicine, it won't be safe for you to drive, even short distances.

How long will it take to recover?

Every person recovers at a different rate. Some people are back to their normal behaviors very quickly, while it may take longer for other people. Most donors are back to their normal state of health by about 3 months after surgery.

When will my liver go back to normal size?

Your liver should return to its normal size within 2 to 3 months after surgery. The part of the liver that was taken out won't grow back. Instead, it's the liver that's left that will grow to fill the space of the part that was taken out.

Will I have many doctor's appointments after surgery?

You'll need to follow-up with the Vanderbilt Transplant Center for the first 2 years after donor surgery.

We're required to keep track of you and report certain clinical information to the United Network for Organ Sharing.

We also want to make sure you continue doing well.

You'll have 2 years of follow-up forms and lab tests

You'll need to complete a follow-up form and lab test 3 times after surgery. This will happen:

- 6 months after surgery
- 1 year after surgery
- 2 years after surgery

These tests will be done at no cost to you. If you're not able to come to Vanderbilt for your lab tests, we can arrange for you to send the forms and test results to us.

Remember! After 2 years and for your entire life after donation, it's important for you to have a regular primary care provider who manages your routine medical care.

If any infectious disease or malignancy is found during your 2 years of follow-up care

If any problem is found during your care:

- you'll be told about it
- it will be reported to local, state, or federal public health authorities, if it's required
- your recipient's transplant center will be informed
- it will be reported through the OPTN Improving Patient Safety Portal.

We need your contact information

Make sure we have your correct contact information so we're able to follow-up with you.

What are the risks of live liver donation?

Risk of having part of your liver removed

Most of the time, healthy people who donate part of their liver recover and lead normal lives. However, the risk of having some type of complication ranges from 15 to 30 percent. Most complications are minor and get better on their own. In some cases, they are serious enough to require another surgery or medical procedure.

Risk of bile leakage

The most common serious complication is **bile leakage**. Bile is a fluid made by the liver that helps with digestion. Bile may leak from the surface of the liver where it was cut or where the bile duct was cut. This happens to about 3 to 5 percent of donors. Most leaks resolve without surgery, but some will need surgery to correct the leak.

Risk of infection

Infections can happen when bacteria enters your body. This can occur at the surgical incision sites or where tubes are placed in your body (tubes to help you breathe, tubes to provide or remove fluids, or tubes to measure body function).

Infections can develop at specific sites or they can be more widespread, like in your bloodstream.

Risk of future liver disease and only having part of your liver

- Even with a complete medical evaluation, your lifetime risk of developing liver disease cannot be predicted.
- If you do have future health problems, they may not be covered by your recipient's insurance.

Risk of hernia

This is when the muscles of the belly that the surgeon had to cut through don't heal back together the way they should.

Risk of death

The death rate in the United States for a living liver donor is less than 0.5 percent, or about 1 in 300.

Risk of other medical complications

Other problems that can happen include:

- allergic reaction to the contrast dye used to evaluate your liver
- belly or bowel symptoms, such as bloating, feeling sick to your stomach, or developing a bowel obstruction
- injury to structures in your belly

- pressure sores on the skin caused by the way your body is positioned during surgery
- nerve damage
- burns caused by the use of electrical equipment during surgery
- damage to your arteries and veins
- pneumonia
- heart attack
- stroke
- permanent scarring at the site of the belly incision.

Interrupted surgery

Your evaluation as a potential liver donor continues through surgery. Your surgery may be interrupted if the surgical team decides you're at high risk or that your liver is not right for transplant.

Risk of bleeding and blood transfusion during surgery

There can be some bleeding during the surgery since the liver has a very rich blood supply. If you bleed more than we expect, we may have to give you blood from a blood bank. However, the chance that a living donor will need a blood transfusion is very low.

Risk of blood clots

This surgery may cause blood clots to form in your legs. This is dangerous since clots can travel to your lungs and make it hard for you to breathe.

We may give you special devices, such as plastic boots that inflate and deflate to keep the blood in your legs flowing during and after surgery. This will help keep blood clots from forming.

Anesthesia risks

This surgery will be done under general anesthesia. This is a medicine that will help you sleep and keep you from feeling pain during surgery. This medicine always comes with risks. An anesthesiologist will explain these risks to you and give you a separate consent form to sign before surgery.

Emotional and social risks

Most donors say they feel very good about the decision to donate. They benefit emotionally and mentally from the process. However, there is the possibility that donating part of your liver may create or increase stresses related to your emotional well-being, such as body image or family, social, employment, or financial situations. There's also the risk of :

- depression
- post-traumatic stress disorder (PTSD)
- generalized anxiety
- anxiety regarding dependence on others and feelings of guilt
- feeling unhappy if expectations about your donation and the transplant aren't met.

We'll discuss the emotional and social risks with you in advance so you'll be as prepared as possible to go through the process. Your donor team, especially your living donor advocate, is available to give you ongoing support before and after donation. If you have any concerns, it's important that you share them with your advocate or someone on the donor team.

Financial risks

Getting a transplant can affect your finances, both now and in the future.

- During your evaluation, you may find out that you have some health problems you didn't know about. You may have to spend money to treat these problems.
- You won't be responsible for out-of-pocket expenses for the donation surgery and hospitalization. The recipient's insurance will be billed for the surgery and hospitalization. However, if there is a denial of claim, your insurance may be billed.
- After you recover from surgery, it's important that you have routine, life-long care with a primary care provider, either through your insurance or at your own personal expense.
- You may be responsible for personal expenses associated with your donation, including travel, housing, child care, and lost wages. There are some resources available for those who meet the criteria, which can help you cover some of these costs.
- It's always possible that donating may negatively impact your current or future employment.

Health insurance risks

After donor surgery, your health insurance company may identify you as a person with pre-existing liver disease or abdominal-related problems.

- Future liver disease or abdominal problems may not be covered by your health insurance.
- You might have to pay more for your health insurance than you did before donating.
- You may not be able to receive health insurance at all.

Disability and life insurance risks

- You might have to pay more for disability and life insurance.
- You may not be able to receive disability or life insurance at all.

Learn more

UNOS (United Network for Organ Sharing)

Get more information about live liver donations from UNOS.

- You can go to the website at UNOS.org.
- You can also call the UNOS toll-free patient phone line at (888) 894-6361. This resource:
 - is available to help transplant candidates, recipients, donors, and family members understand the way livers are matched with the patients who need them
 - can help you find transplant data, information, and statistics
 - is for you to use if you need to talk about any problems you're having with your transplant center or the transplant system in general.

National and local transplant data

During your evaluation, we'll give you data and information about national and Vanderbilt-based transplants, also known as the SRTR. This information will help you learn about the number of transplants that are done across the country and at Vanderbilt, including the results of those transplants.

Information sharing and your privacy

Throughout the transplant process, members of your transplant team may access and share your medical information as permitted by law and Vanderbilt University Medical Center policies.

If you do end up donating part of your liver, information about you, which will include your identity, will be shared with UNOS.

This information may also be sent to other transplant-related agencies or companies as permitted or required by law.

Information-sharing is an important part of the success of the overall transplant program, nationally and locally. Other than these instances, all communication between you and the transplant center will remain confidential.

Medicare-approved centers

If a transplant center is not Medicare-approved, it may affect the ability to have immunosuppressive drugs, which are needed by the recipient, to be paid for by Medicare Part B.

Vanderbilt Transplant Center is currently a Medicare-approved center. Our status is reevaluated on a regular basis. If there's ever any change in this status, we'll let you know.

Financial support

Financial support may be available to you if you need it. The National Living Donor Assistance Center (NLDAC) is an organization that helps donors pay for some of the costs associated with living organ donations. This helps people who want to donate but might not be able to without financial help.

The NLDAC may be able to help you with the cost of things insurance doesn't cover, such as:

- transportation
- lodging
- food.

Both the donor and the recipient have to fill out an application. To learn more, go to LivingDonorAssistance.org.