

Living Liver Donation

The Donor's Guidebook

University of Washington Medical Center

Liver Transplant Program

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About This Guide

We wrote this guide to teach potential donors and their loved ones about living liver donation. This guide explains the benefits of living donation, the donor evaluation process, the criteria we use when choosing liver donors, and the surgery itself.

We also describe what the living liver donor can expect after surgery. We include the risks that may be involved in this major liver surgery.

Please read this guide carefully. If you want to learn more about living liver donation, please call the UWMC Living Liver Donor Program Office at 206.598.0337, or email liverdonor@uw.edu.

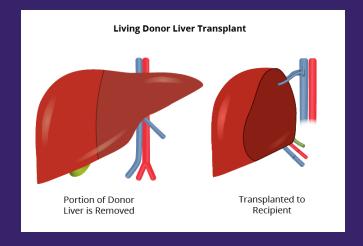
The liver donation process must be started by the potential donor. After you contact us, we will teach, guide, and help you in making the best decision for yourself and your family about living liver donation. Whether or not you become a living liver donor, thank you for your interest in living donation and how it could help someone in need of liver transplant.

What is Living Donor Liver Transplant?

Most liver transplants use a whole or partial organ that is donated by the family of a deceased donor. But in living donor liver transplants (LDLTs), surgeons remove part of a liver from a healthy person for transplant into a recipient. The recipient's whole diseased liver is removed.

The liver has the amazing ability to regenerate (regrow) quickly. This is why both the donor and recipient can readily recover after an LDLT. Most of this liver regrowth happens within 3 weeks of surgery. By 3 months after surgery, the donor's liver has regrown to about 90% of its original size.

Since the late 1980s, over 7,000 living donors in the U.S. have donated their livers to someone who needed a liver transplant. At UW Medical Center (UWMC), we have an expert team of liver surgeons, liver physicians and other medical sub-specialists, nurses, social workers, donor advocates, and other transplant team members who are dedicated to the living liver donation process.



Why is Living Liver Donation Needed?

There are not enough livers donated by deceased donors to meet the needs of everyone who needs a liver transplant. In the U.S., there are almost 13,000 patients currently on the liver transplant waitlist. About 1 in 5 of these patients will die before getting a transplant.

Patients on the waitlist often wait a long time before getting a transplant. By the time they receive a transplant, many recipients are very ill. This slows their healing after transplant surgery.

LDLT offers these benefits:

- A much shorter time on the waitlist. The transplant can be done soon after the living liver donor completes their evaluation.
- Easier recovery. With a shorter waiting time, the recipient is more likely to be stronger and in better health at the time of transplant. This helps them heal more quickly after surgery.
- **Scheduling.** We can schedule the donation and the transplant surgeries at a time that works best for both the donor and the recipient.
- **Higher quality organ.** The liver from a living donor is of high quality. Many of the livers from deceased donors are less than ideal for a variety of reasons. We also may not have the deceased donor's full health history.
- **Better outcomes.** Most times, transplants using a liver from a living donor have better outcomes than those using a liver from a deceased donor.



Nephew and Uncle, Hudson (recipient) and Trevor (living donor)

If You're Thinking About Being a Liver Donor

To help you make your best decision, we want to help you fully understand the liver donation process. Once you tell us that you want to learn more, we will connect you with one of our independent donor advocates. This person is knowledgeable about liver donation and transplant, and will educate you about the living liver donation evaluation process. Please ask your advocate any questions you have. Your advocate is dedicated to your well-being. They are not involved in caring for the intended liver transplant recipient.

To make sure you are a good candidate to be a living liver donor, please ask yourself these questions:

Motives and free will

- Why do I want to donate?
- Is this decision my own? Am I feeling pressured by anyone to be a living liver donor?
- Do I have any unrealistic expectations about being a donor? Am I hoping for a better relationship with the intended recipient? Do I expect publicity, respect, gratitude, or other rewards?

Family and social support

- Will I have enough help from family and friends during my recovery after surgery?
- Do I have a plan for someone who can take care of my children, pets, household, and other duties during my recovery?
- Do my close friends and family understand what is involved with this surgery?
- Do my close friends and family support this donation? If not, what can I do to make sure I get the support I need?

Am I financially able to do this?

- Can I be out of work for 6 weeks to 3 months after my donor surgery?
- Can I handle the hidden costs of being a donor, such as transportation to the hospital and meals away from home?

Handling the pain and stress of major surgery

- Can I handle the physical discomfort of this surgery? This is major surgery. Pain is common with surgery, but usually eases with pain medicines and with time.
- Can I handle the mental and emotional stress of having major surgery?

Recovery from donation surgery

- Will I be able to follow the advice of doctors after surgery? This includes not lifting anything that weighs more than 8 pounds for 2 months.
- Do I have a plan for transport back to the hospital for my follow-up visits?
- Can I commit to a healthy lifestyle after liver donation?
- Can I commit to the follow-up visits I will need after surgery?

Expectations

- Do I have clear and realistic expectations for my own recovery?
- What do I expect for the recipient's outcome? How would I cope if the liver transplant does not go well?

Who Can Be a Living Liver Donor?

You may be a candidate for living liver donation if you:

- Are 18 to 60 years old
- Have not been pressured to make this decision
- Realize that you will not receive any financial or other material rewards for your act of kindness
- Understand all aspects of liver donation and how it could affect your life
- Have the mental health and capacity to make a clear, informed decision
- Have solid social support and a stable home life

- Are healthy, have no major health concerns, and can commit to living a healthy lifestyle
- Have not had any major liver or abdominal surgery
- Have a body mass index (BMI) of 32 kg/m2 or less
- Do not have any substance use disorders
- Can stop using tobacco, alcohol, and oral contraceptive pills for an extended period before and after the donation

Can I Be an Anonymous Donor?

Yes. Some people want to donate without having a specific recipient in mind. This is called an anonymous or non-directed liver donation.

The evaluation process for a non-directed donor is the same as that for other living liver donors. But, all non-directed donors will also meet with our transplant psychiatrist. We want to make sure that the potential donor is able to make this important decision, both mentally and emotionally.

Non-directed donors must agree to:

- Respect the anonymity of the recipient who receives their liver, and not expect to receive information on the name or status of the liver transplant recipient
- Not seek out or expect recognition, publicity, or financial reward for their act of kindness

We will also respect the anonymity of the non-directed donor. We will not reveal any personal information about the donor to the recipient. If both the recipient and donor wish to meet, we will help them connect in a way that works for both people.

We will talk with the non-directed donor about the different types of liver donor surgeries that can be done. Surgeries differ in how much liver tissue is removed. We will explain to the donor why this difference matters. If a non-directed donor wishes to have a specific type of liver donation surgery, we will abide by that request.

Non-directed donors cannot specify the age, race, gender, or any other traits of the recipient who receives their liver. The transplant team will choose the recipient we feel will benefit the most from this precious gift.

Getting Started: Becoming a Donor

The prospective liver donor must start this process.

Please call the UWMC Living Liver Donor Program Office at 206.598.0337 or send an email to liverdonor@uw.edu.

We will first ask you questions about your health history. Our doctors want to make sure you meet all of the basic criteria before we go further. If they do not feel donation is a good option for you, we will tell you why.

Before you start the evaluation, you will also talk by phone with your independent live donor advocate. This advocate will confirm with you whether or not it is a good idea for you to proceed with testing.

If you meet our criteria, we will ask you to visit your local doctor's office for a basic exam. This visit will include:

- Health history and physical exam
- Blood (ABO) typing
 If your blood type is not compatible with the intended recipient, we can still assess you as a potential liver donor. If this occurs, our team will talk with you about your options.
- Blood draws to measure your blood cell counts, liver and kidney function, and electrolytes
- Routine cancer screening, if needed, based on your age and family history

Formal Evaluation for Living Liver Donation

Our transplant team fully evaluates potential liver donors. We want to make sure that donating your liver will not be harmful to you. During your evaluation, you will meet with these transplant team members:

- A liver donor surgeon, who specializes in liver surgery and liver transplant
- A hepatologist, a doctor who specializes in liver disease.
- An independent donor advocate, who will meet with you many times, both before and after donation
- · A living liver donor nurse coordinator
- A social worker

- A transplant infectious disease specialist
- A pharmacist
- A dietitian
- A psychiatrist, for all non-directed donors and donors with a history of depression or other mental health issues

Evaluation Tests

You will have these tests during your evaluation:

- Blood typing (ABO)
- Blood cell counts, liver and kidney function, and metabolic testing including thyroid function, glucose level, and cholesterol levels
- Infectious disease testing
- Urine pregnancy and toxicology tests
- Heart function studies, including an electrocardiogram (EKG) and heart ultrasound (ECHO)
- Heart stress tests if the potential donor is 50 years of age or older
- Lung studies such as a chest X-ray

- Pulmonary (lung) function tests for donors who smoke or used to smoke
- Liver imaging, including a computed tomography (CT) scan to check your blood vessels and liver size, and a magnetic resonance imaging (MRI) scan of your bile ducts and fat content in your liver

We usually do not need to do a liver biopsy. If our team decides a biopsy is needed, we will talk with you before we schedule it.

The Role of the Liver Donor in Their Own Evaluation

Our evaluation of a potential liver donor is only valid if the donor answers all of our questions honestly and fully. We will ask you about certain behaviors that may be linked to a risk for HIV, hepatitis C, hepatitis B, or other infections. We keep all of this information private. We do not share any of your answers or test results with the intended recipient or with anyone not directly involved in your care.

Please feel free to confide in your independent donor advocate. This person is devoted to your well-being and supports your ability to make your own decisions.

We will remind you often that you can stop the evaluation at any time. If you choose to stop, we will thank you for your time. We will tell the recipient that the donor is not medically eligible for liver donation. We will not provide any other details or explanations to anyone.

We know that this evaluation will take a lot of your time, energy, and resources. We will do all we can to make the process move quickly. But, your safety is our top priority. We will not hurry or change any tests or decisions, even if the intended recipient becomes ill.

To be ready for liver donation surgery, we ask that potential liver donors take these steps as soon as they can:

- Stop smoking: Do this at least 4 weeks before surgery.
- Stop oral contraceptive pills: Do this at least 4 weeks before surgery to avoid blood clots.
- Stop taking ibuprofen or other nonsteroidal antiinflammatory drugs (NSAIDS): Do this at least 1 week before surgery.
- Walk at least 1 mile a day: Do this for at least 2 weeks before surgery.

Making a Decision: We Advise, You Decide

We will give you a handout of the Living Liver Donor Selection Criteria. Please read this handout carefully.

After we finish your evaluation, if you want to proceed with donation, we will share all your test results with the UWMC Living Liver Donor Selection Committee. The committee will decide if you qualify to be a liver donor. They will use these criteria:

- You are age 18 to 60 years old.
- You have a recipient who is already accepted for liver transplant listing.
- For non-directed donors, the UWMC Liver Transplant Team will identify a waitlisted recipient who will benefit most from your generous gift.
- You have a strong desire to donate part of your liver, and do not feel like you are being forced to do so. You should feel good about the donation, every step of the way.
- You are healthy, with no major medical or psychosocial issues.
- · Your liver works normally.
- You have a BMI of 32 kg/m2 or less, but our physicians will review each donor individually.
- You are strongly committed to a healthy lifestyle and to having regular healthcare visits after donation.
- You will stop smoking tobacco and drinking alcohol before the donation, as directed by your doctor.

- The transplant team has confirmed that you do not have any substance use issues.
- You do not have any active or past cancers that could be passed along to the recipient.
- You do not have any signs of a chronic infection that could be given to the recipient through the transplant.
 These include, but are not limited to, HIV or hepatitis
- You have not had any surgeries that could make it unsafe for you to donate your liver.
- You have a stable home and good social support.
- · You are not currently in prison.
- You are willing and able to accept blood and blood product transfusions.
- You will be able to donate enough of your liver to benefit the recipient, while also keeping enough to allow you to fully recover. We will decide how much of your liver can be donated during your evaluation.

We will tell you of the committee's decision about your candidacy as a liver donor. If you are accepted and you wish to proceed, and the intended recipient is willing and medically fit for liver transplant, we will prepare for the living liver donor surgery.

Remember, you can still stop the living donation process at any time. If you make this decision, we will keep your reasons strictly private.

Preparing for Liver Donation Surgery

We will tell you the surgery day and time well before the date. In the days before your surgery:

- Your surgeon will talk with you about the surgery.
 You will learn about the incision site, the part of your liver we plan to remove, and the specific steps of the surgery. Be sure to ask any questions you have.
- You will also meet with your independent donor advocate and anesthesiologist. They will answer any questions you have.
- We will repeat your lab tests to make sure you do not have any new infections.
- The blood bank will reserve blood for you. You do not need to donate blood for yourself.

- You will sign a surgical consent form in the presence of your surgeon.
- You will receive instructions on what to do on the day before and the day of surgery.
- On the night before surgery, follow all directions your surgical team gave you.

Sometimes, an urgent liver transplant must be done at the time of your scheduled donor surgery. This happens about 5% of the time (5 times out of 100). If this happens, we may need to postpone your donor surgery. This is for your safety. We will do everything we can to avoid this delay.

The Morning of Donation Surgery

The day of any surgery is stressful. We hope that knowing what to expect will help ease any anxiety. Here is what to expect:

- Come to UWMC no later than 6 a.m. on the morning of your donation surgery. Tell us right away if you have had any change in how you are feeling, such as a new cough or fever, or other symptoms.
- We will ask you to change into a hospital gown.
- We will record your vital signs.
- A small intravenous catheter (IV tube) will be placed into your arm. We will give you fluids and medicines through the IV.

- You will see these members of the living donor care team:
- Your anesthesiologist will talk with you about placement of a breathing tube and your anesthesia needs during and after surgery.
- The operating room (OR) nurse will ask you questions to make sure you have a safe surgery.
- Your liver donor surgeon will meet with you to answer any questions.

Living Liver Donation Surgery

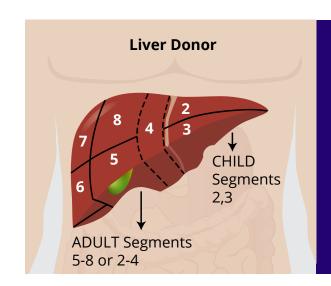
This surgery is called a donor hepatectomy. Here are the basic steps of this surgery:

- Your surgeon will make an incision from just below your breastbone down to just above your navel. We may need to extend the incision to your right side, about the width of a hand.
- We will check your liver and the liver's veins, arteries, and bile ducts.
- We will then remove your gallbladder and place dye into your bile ducts. This helps the ducts show up clearly on an X-ray. If you are donating only a small portion of your liver to a child, we might not remove your gallbladder or take an X-ray of your bile ducts.
- In 2% to 5% of donors (2 to 5 out of 100), the surgeon finds an issue in the liver that makes it unsafe to do the surgery. In these patients, we stop the surgery right away and close the incision. The surgeon will tell the donor about the specific findings. The donor and recipient families will be informed that the surgery is cancelled.
- If all goes as planned, we will then isolate the liver's blood vessels and divide the liver tissue. We always remove the smallest amount of liver that will serve the needs of the recipient. We may not know which part of the liver will be removed until the surgeon reaches this point in the surgery, but this is uncommon.

- After we remove the liver lobe, we will place a small plastic tube through your skin to drain fluid from around your liver.
- The last step of surgery is to close the incision with sutures, just under the surface of the skin. We do not use staples. The sutures will dissolve by themselves. They do not need to be removed.
- Most times, the surgery takes about 6 to 8 hours.
 Your anesthesiologist will remove your breathing tube before you leave the OR.

To see videos of living liver donor surgery, please visit one of these websites:

- **Right lobe donation:** http://pie.med.utoronto.ca/ TVASurg/project/transplant-rightlobedonor
- **Left lobe donation:** http://pie.med.utoronto.ca/ TVASurg/project/transplant-lefthepdonor
- Left lateral lobe donation (donating to a baby/small child): http://pie.med.utoronto.ca/TVASurg/project/transplant-leftlateraldonor



RIGHT LIVER LOBE DONATION:

Segments 5-8 and gallbladder are removed.

LEFT LIVER LOBE DONATION:

Segments 2-4 and gallbladder are removed.

LEFT LATERAL LIVER LOBE DONATION:

Segments 2,3, the gallbladder is usually not removed.

What to Expect During Your Hospital Stay

- After surgery, we will move you to the intensive care unit (ICU). In addition to the surgery team, the ICU nurse, nurse practitioner, and critical care doctors will care for you.
- We will control your pain with several medicines. Some
 of these will be given on a set schedule. We will provide
 opioid pain medicines for severe pain, if you ask for them.
- Most times, liver donors move to a regular hospital unit 1 day after surgery. This depends on how recovery is going.
- We will remove the bladder catheter and arterial line (both of which were placed while you were asleep in the OR) 1 or 2 days after surgery. Removing these devices should not cause much pain.
- Over the next 3 to 5 days, your appetite, bowel function, and ability to move around should improve. We will keep treating your pain. Most donors feel much better after the 3rd day.

- We will help you get up and walk starting the morning after surgery. Getting out of bed and moving around are vital to your recovery. They help lessen your risk of having blood clots in your legs and getting a lung infection (pneumonia). Walk as much as you can after this surgery. It is the most important thing you can do for yourself.
- We discharge living liver donors when they:
- Can eat and drink normally
- Have normal bowel and bladder function
- Can get out of bed and walk safely without significant help
- Have normal vital signs and temperature
- Do not need extra oxygen
- Can control their pain with oral medicines
- Have a caregiver ready to help them at home

Most donors are able to leave the hospital 4 to 6 days after their surgery.



Friends Jamie (living donor) and Kailyn (recipient)

Risks and Potential Problems

Our goal is for your surgery and recovery to go smoothly. But, this is a major surgery, and problems may occur.

Your surgeon will have a long talk with you about liver donation, including how we manage any problems after surgery. Most problems after donor surgery occur within a few days or weeks after surgery. Most of these issues are short-term and are not life-threatening.

The risk of problems depends somewhat on the amount of liver removed in the surgery. Please know that:

- The risk of long-term disability, liver failure, or death from living liver donation is about 1% (1 out of 100 donors).
- The overall mortality rate is about 0.2% (1 in 500 donors).

Possible Problems After Liver Donation Surgery*

- Bleeding inside the abdomen
- Bile leak or bile duct injury (less than 5%)
- Need for blood transfusion (less than 5%)
- Diaphragmatic hernia
- · Keloid (prominent) scar
- Bowel blockage
- · Bad reaction to the anesthesia
- Pancreatitis
- Liver donation surgery stopped because of a finding during surgery (2% to 5%).
- Acute liver failure, requiring a liver transplant (very rare)
- Nerve injury to arms or hands from lying on the OR table

- Injury to the intestine, spleen, stomach, or other organs in the belly
- Infection in the wound, bladder, abdomen, lung, or blood
- "Orphan liver" (the donor liver is removed, but the recipient cannot receive the transplant)
- Blood clots in the legs or lungs
- Pneumonia or fluid around lungs
- Need for another surgery (less than 5%)
- Stroke
- Heart attack
- · Hernia or numbness in the incision
- Depression

^{*}This list includes the most common or most important problems. Other problems not listed may also occur.

When to Call

You can call the living donor liver team at any time, any day of the week. We want to hear from you if you are having any problems. Please do not wait to be seen at your scheduled visit.

Weekdays from 8 a.m. to 4:30 p.m.: Call 206.598.4920 and press 4.

After hours and on weekends and holidays: Call 206.598.6190 and ask for a liver transplant surgery team member. A member of the team will call you back.

If you have any trouble reaching us, please go to the Emergency Room (ER) at UWMC (preferred) or to your local hospital. Tell the ER staff to call the UWMC Liver Transplant Team.

Call us if:

- You have a fever of 101°F (38.3°C) or higher
- Your incision is red, leaking fluid, or hurting more
- You have nausea, vomiting, or growing pain in your belly
- You are short of breath
- Your eyes are yellow (jaundice)
- You don't feel well or think that you need to see a doctor

Discharge Instructions

Medicines

You will likely be sent home with these medicines:

- Acetaminophen for incision pain
- Colace to prevent constipation
- Oxycodone, or similar medication, for incision pain if the acetaminophen is not enough
- An acid-blocking medication, such as a proton pump inhibitor, to help prevent ulcers and stomach upset

Nutrition and Diet

- · Please eat a normal, healthy diet.
- Drink lots of water, at least 2 liters a day.
- Eat plenty of vegetables and fruit to help avoid constipation.
- Do not drink alcohol for at least 3 months after donation surgery.
- · Avoid fatty meals for at least 3 weeks.

Activity

- Do not lift anything that weighs more than 8 pounds for 2 months after your surgery. (A gallon of water weighs more than 8 pounds.)
- Walk and climb stairs as much as you can. Increase your activity a little bit every day.
- · Resume sexual activity when you feel OK doing so.

Return to Work

- If you have a job where you sit most of the time, and do not lift anything heavy, you can most likely return to work by 6 to 8 weeks after surgery. Talk with your surgeon about this.
- If you need to do heavy lifting or other physical work on your job, wait at least 8 weeks after surgery before you go back to work. Before you do, please get an OK from your surgeon.

Travel

- It is best if you stay in the greater Seattle area for at least 2 weeks after discharge.
- For the first 6 weeks:
- You must drink a lot of fluids.
- For any travel where you must sit for long periods, get up and walk for at least 10 minutes every hour.
 While sitting, please extend and flex your legs at least 10 times an hour.
- Do not travel to other countries.
- Please talk with your doctor or liver donor team before going on any trip that will last more than 2 hours. We might prescribe blood thinners for a long trip.

Your Schedule for Follow Up Visits

If you can, please go to UWMC for all of your follow-up visits. We understand that this may be hard to do if you live outside the Seattle area. If needed, we will work with you to make sure you have a healthcare team in your area to handle your follow-up care.

Here is what to expect at your follow-up visits:

When	Who	What
Week 1	Meet with your surgeon or nurse practitioner	Lab tests
Week 2	Meet with your surgeon or nurse practitioner and your liver donor advocate	Lab tests
Week 4	Meet with your surgeon or nurse practitioner	Lab tests and Liver Ultrasound
3 months	Talk with your nurse coordinator by phone	Check-in
6 months	Meet with your surgeon or nurse practitioner	Lab tests
1- year	Meet with your surgeon or nurse practitioner	Lab tests and Liver Ultrasound
2- year	Meet with your surgeon or nurse practitioner	Lab tests

Getting Back to Normal

- Everyone recovers at a different pace after major surgery. About half of living liver donors feel like they are back to normal about 6 weeks after their donor surgery. The other half feel back to normal over the next several months.
- There is a lot of buildup and excitement before, during, and just after a liver donation. Some liver donors report feeling "down" or even having mild depression within a few weeks or months after the donation. If you have these feelings, please talk with your living donor nurse coordinator, independent donor advocate, or surgeon. We want to know how you are feeling, and to support you in whatever ways we can. Most times, these feeling ease as your body heals.

Your Life as a Living Liver Donor

- Most living liver donors return to the same or better physical and mental health state that they enjoyed before becoming a donor. Surveys show that more than 95% of living liver donors (more than 95 out of 100) would donate again if given the chance.
- We do not require follow-up visits at UWMC after 2 years. But, if you have any ongoing issues related to the donation, please see us for your follow-up visits. Remember that most problems related to liver donation occur fairly soon after the donation. Very few issues related to the liver donation will start after 2 years.
- We have great respect and admiration for you. We honor your selfless and generous act of living liver donation.
 We are here to help with any healthcare needs related to your donation.

University of Washington Medical Center Liver Transplant Program

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