

Live Donor Liver Transplant - Information for Donors

Thinking about live liver donation?

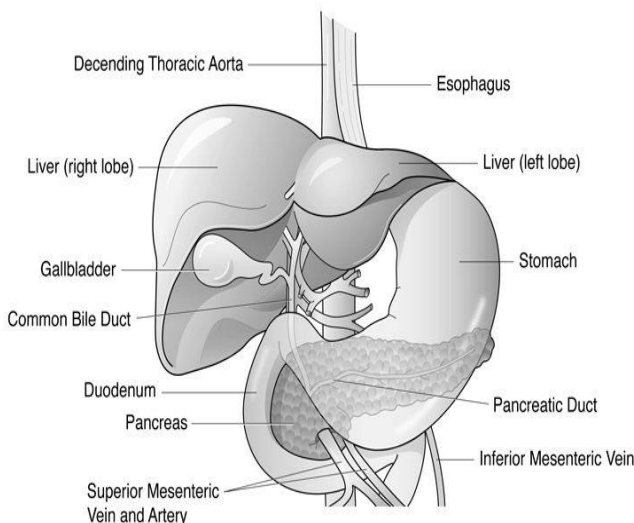
This handout explains the process if you are thinking about donating part of your liver.

You will learn about the reasons for:

- Live donation
- The assessment process
- The operation
- Post-operative care
- Alternatives
- The benefits and risks of this surgery

Please take the time to read this handout carefully. If you are interested in live liver donation, please contact the transplant office at **(608) 263-1384** or **canibeadonor.com**. You may also contact the nurse transplant coordinator working with your intended recipient.

With live liver donation, a piece of a healthy person’s liver is transplanted into the recipient. This can be done because the liver renews itself in both the donor and recipient after the transplant. Both the donated segment and the remaining section of the donor liver will grow to normal size within weeks.



There is a severe shortage of organs for transplant. This means that the wait for a liver transplant can be many years. Patients may die while waiting for an organ. The UW Transplant Program has led the way to find new ways to increase the number of good organs for transplant. Live liver donation is an option that can decrease the waiting time for a patient in need of a liver transplant.

Giving someone part of your liver can be very rewarding and satisfying. Whatever you decide, make the choice that is right for you.

Who can receive a liver from a live donor?

Patients in need of a liver transplant go through their own medical, surgical, and psychosocial evaluation to find out if they can get a transplant. This process weighs the risks, benefits and likelihood of a good outcome. During their evaluation, the transplant team discusses whether live donor liver transplant is an option.

Live donor transplant may not be advised for all patients in need of a liver transplant. It is a more complex surgery and one with different risks and different outcomes. The team makes the decision about whether live donor transplant is an option. If live liver donor transplant is going to happen, the team, the person who needs the liver, and the potential live donor all need to be willing.

The donor work-up does not start until the recipient has been listed for deceased donation. A patient who has a potential living donor remains active on the waiting list while the living donor work-up is being done. Their place on the waiting list is not affected.

Who can be a living donor?

- A living donor can be related or unrelated.
- A donor is most often between 21 and 55 years of age. A donor must be old enough to provide informed consent and young enough to have a healthy liver. Donors between 18-20 years of age, or between 55-60 years of age, may be considered on a case by case basis.
- The donor's main goal should be to help the recipient.
- Living donation must be voluntary.
- The donor must be in excellent physical and emotional health. The donor must be free of major health issues.
- The donor must have a blood type that is compatible with the recipient's blood type.
- The donor cannot have a body mass index over 35. If the donor's body mass index is between 30 and 35, weight loss may be needed prior to proceeding.
- A donor cannot have cancer.
- A donor cannot have any active infections.
- The donor must have normal or near normal liver function and have no history of any liver disease.
- Body differences occur among people. The donor's liver must have a pattern of blood supply and a delivery of bile ducts that are suitable for donation and transplant.

- The donor must have family or friends that can provide support before, during, and after the surgery.
- The donor must be able to plan for up to three months off from work.
- The donor must be able to express understanding of the risks of living liver donation.
- A donor is required to have a primary care doctor.
- A donor is strongly advised to have his or her own health insurance. Lack of health insurance may disqualify a person from being a donor.
- Costs related to donating are billed to the recipient's insurance. Questions about the financial aspects of donating can be direct to the transplant financial planner at **(608) 263-1505**.
- Keep in mind that not all patients that need liver transplant can receive a live donor liver.

What are some things to think about?

Donor safety is the most important issue during the assessment. Donation will not be offered if the medical and surgical team believes the risk of harm to the donor outweighs the expected benefits to the recipient.

A different group of medical providers from those caring for the recipient evaluates the donor to avoid conflict of interest. Donors are assigned a donor team. These members are in charge of ensuring their interests are being met. They also make sure the risks and benefits of living donation are understood.

Previously undiagnosed medical conditions may be found during this medical assessment. A new diagnosis could affect the ability to obtain insurance and/or cause emotional distress.

Your medical assessment, and every aspect of the donation process, is part of your personal, private medical record. This means that the recipient cannot be told by the transplant team anything about the work-up. This includes if you decide to walk away from donation.

As your assessment grows and you better understand the donation process, you may decide donation is not something you want to do. The transplant team helps you stop the donation process at any time.

What are the benefits of living donor transplantation for the person who gets the transplant?

Live liver donor transplant offers several advantages to the recipient, most notably around timing. The transplant can be done sooner, before the recipient's health worsens. Likewise, if the recipient has symptoms that are worse than their score reflects. It can help the recipient get relief from these symptoms and return to a better quality of life.

What are the costs for the donor?

There is no cost to the donor for the medical evaluation, the surgery, hospital stay, or after care. This is also true for evaluation costs. Even if the potential donor is not able to donate or chooses not to donate. However, most donors do have some costs.

These can include:

- Time off work that may or may not be paid.
- Travel costs to get to Madison, or stay in Madison. Ask the donor social worker about a grant that may help cover these costs.
- Other costs, such as childcare or costs of snow removal when the donor is healing and unable to do these tasks.

Are outcomes the same for live donor liver transplant versus deceased donor liver transplant?

Outcomes for the patient who receives a live donor liver are like the outcomes for the patient who receives a deceased donor liver. But there is an increased risk of surgical problems for patients who receive part of a liver from a live donor. Most problems can be treated. Medical problems such as rejection or disease relapse are not more or less common for patients that receive a live donor liver. However, there is a risk that problems will lead to graft loss or death.

Living Donor Evaluation

Step One: Contact the transplant office.

Call the liver transplant office at **(608) 261-1996**. You can also call the nurse transplant coordinator working with the recipient.

The first step is to make sure the recipient can get a live donor liver transplant.

Blood type matches must be known before any other testing is done. The transplant office can help you learn your blood type if needed.

Then, a nurse transplant coordinator will get some basic health information from you and review it with a surgeon. **It is your duty to submit an honest and complete health history to the donor team.**

General health care and cancer screening tests should be done through your primary care doctor. This includes things such as dental work, PAP/pelvic exams and mammography for females, PSA screening for men, colonoscopy screening if needed. We prefer this testing be done before you come for your visit.

Step Two: Work-Up Testing

The team assessing you is focused on protecting the donor's interests and well-being. The screening tests are planned by the transplant office. You will have a nurse transplant coordinator that will help guide you through the work-up. They will answer any questions you may have.

Your work-up can be complex. There are many steps. It may take days, weeks, or sometimes months to complete all the needed tests and to confirm that live liver donation is a fitting and safe option for everyone.

Testing is done in a step-wise approach to try to avoid having tests done that are not needed.

The rest of your testing will be done at the UW Hospital. We attempt to get all the testing done in two to three visits. We try to allow for a one to two-week reflection period between each visit.

These visits will include:

1. A clinic visit with a liver transplant surgeon to discuss the surgery in detail. The surgeon will discuss risks and benefits of live donation. They will perform a physical exam and review your history.
2. Blood tests are done to confirm normal liver function and test for several viral diseases including but not limited to Hepatitis B and C, HIV, and syphilis. Please note that some viruses are reportable by law to the Public Health Department. You may be contacted by Public Health if you have tested positive for these viruses.
3. You will be assigned to a donor team. Each member of the team will help you to better understand the risks and benefits of donation. They will ensure you are making an informed choice. You will meet with each member of the team separately. This includes:
 - a. Social worker - will cover the potential effects of donation on family, work and activities, finances, and mood. The social worker will also discuss how to plan and prepare for recovery.
 - b. Live donor advocate – talks with you about the decision to be an organ donor. They will assess whether you feel under pressure to donate. Also, if you understand potential risks and benefits. The advocate can also help you walk away from donation if it doesn't feel right.
 - c. Transplant Coordinator is a nurse that helps guide you through the donation process. They also help explain the risks and benefits to you. They will ensure that you are making an informed choice.

- d. Internal medicine doctor- this is a doctor that is not part of the transplant team. They will do a physical exam and help to make sure it is safe for you to donate.
4. A CT scan is done. This is a special x-ray that makes detailed pictures of internal organs and bones. It uses a computer to create the images. The CT is a very useful tool that helps the doctors look closely at certain sites. Images obtained in the CT scan help the team decide if the donor's body is suitable for transplant surgery. This also helps to get a map of your bile ducts to help guide the surgeons.



5. An MRCP is done which is a special MRI that helps the transplant team look at your bile ducts.
6. You will have an electrocardiogram and a chest x-ray to confirm normal heart and lung function.
7. You will meet with a dietician to review any diet or nutritional needs or concerns related to donation.
8. A clinic visit with a liver disease expert to review your health history. This ensures it is safe for you to give part of the liver.

They will also discuss the medical risks that can go with a live liver donation. Sometimes, this doctor will say that more testing needs to be done.

9. An echocardiogram is done. This is a safe and painless way to view the heart for problems. Depending on your history, more heart testing may be needed. This testing may include an exercise stress test.
10. A liver biopsy may be done to see if the liver tissue is healthy. During a liver biopsy, a small piece of tissue is removed from the liver. It is checked under a microscope for signs of disease. The biopsy takes only a few minutes. The donor remains in the hospital for 4 hours after the test. The transplant team will provide more information to help prepare the donor for the biopsy.
11. There will be a pre-anesthesia screening visit to review the medical testing and to assess risks of anesthesia for you.
12. You may have other tests or consults to ensure it is safe for you to donate.

What if the tests are abnormal?

If the tests uncover something of concern, you will be informed. The assessment is stopped. The results of the tests done during the assessment are sent to your home doctor with a request that they follow up on these tests. Some abnormal findings can be treated. After treatment the assessment can be restarted.

It is the transplant team's job to be careful about any would be risks to you. The team may decide it is not possible for you to proceed.

If this happens, the reason is discussed with you in detail.

Can I change my mind about being a donor?

Some people may decide live donation is not a good choice for them after starting the assessment. People going through a live donor are supported in every decision they make. At any stage, you may decide to stop the process. This decision is honored and kept private. The reason will not be shared with the recipient.

You must be in direct contact with us about questions or concerns about your assessments. We will not discuss information or test results with family members, friends, recipients, etc. Unless we have your written okay to do so.

What other resources do you offer?

We offer a mentor program. It links people by phone who have already donated an organ with those who are wanting to donate. We believe our donors know better than anyone what donation is like. They can be a valuable source of support, help, and information for those going through the process.

What are some items to keep in mind while going through the process?

There is a risk of spreading infections via organ donation. You should report any fever, flu-like illness, or nerve symptoms right away. If you have an active infection, you should not donate part of the liver. This illness could be given to the recipient. To lessen the risk of disease spreading we do blood tests to check for infections.

You should also:

- Take steps to avoid disease spreading through sexual contact by using condoms or avoiding sex.
- Avoid being bitten by mosquitoes, which could transmit the West Nile virus. The donor needs to wear long sleeve shirts and pants. Use mosquito repellent prior to a scheduled surgery.

This is because UNOS Policy 4.1.1 (Communication of Donor History) requires us to assess all potential live donors for risk of infectious disease spreading. You will be asked to complete a set of questions taken from the USPHS guideline about increased risk behavior.

This set of questions are like the ones required for blood donation. For live donation, if you are at higher risk, the team is required to provide the transplant recipient a general statement about your risk status per USPHS guidelines. The donor coordinator and the donor social worker would talk with you about this ahead of time.

Avoid alcohol completely for 4 weeks before surgery and for 6 months after the surgery. The medical team will inform you when it is safe to have alcohol again. Alcohol is toxic to the liver. It is important that the liver be in the best condition before and after surgery.

Stop smoking: Smoking can lead to blood clots after surgery. As a result, we strongly advise you to quit for at least one month before donation.



Birth control pills or hormone medicine may need to be stopped. These can lead to blood clots after surgery. If you are on these medicines, talk to your team about whether you should stop them before surgery, and when they can be safely restarted.

Maintain a stable weight. It is vital that you do not have big changes in your weight. This affects the volume of liver you will need after donation and may impact your ability to safely donate. Be sure to tell your coordinator if you have big changes in your weight as you go through the process.

Can the evaluation be done more quickly?

Quick workups for urgent living donation are only done in special cases. These are most often for an adult with acute liver failure or a child with rapidly failing liver function where there is an increased risk of death in a very short period of time if no transplant is done. Quick donor assessments **are not** the standard of care and require very careful thought. It should include, but is not limited to:

- Donor safety remains most important. The transplant team will not reduce safety by taking short-cuts.
- Live donation for recipients with a poor prognosis will not be offered when it is believed that the probability of recipient survival is less than 50%.

Step Three: Schedule the Surgery

If the evaluation went well, you are offered a target surgery date. This date depends on the available resources, staff and schedule of you and the recipient. Please be aware that the date can change due to changes in the donor or recipient status.

Surgical Risks and Complications

Live liver donation has major risks no matter how carefully the donor surgery and work-up is done. It is vital that people who are thinking about being donors have a good understanding of these risks.

- Liver donation is a complex process. Donors may die or have severe problems even when the very best care is given. The risk of death is estimated a 0.5% (1 in 200).
- The surgery is done through a large incision across the stomach. It can cause mild, permanent weakness and numbness in that area. It will leave a scar.
- The remaining liver grows back to its original size in about 6 weeks. It is expected that liver function will return to normal. If it does not, this surgery could be fatal to the donor.
- Potential risks of this surgery include, but are not limited to, the list below.
 - Reaction to the anesthesia given during the surgery.
 - Stroke or heart attack.
 - Blood clots in the legs or lung.
 - Fluid around the lung or collapse of a lung.
 - Fluid retention.
 - Mild or severe infections, such as pneumonia, urinary tract infections, or wound infections.

- Uncontrolled bleeding that would require blood transfusions.
- Repeat operations.
- Bile leakage or bile duct complications.
- Injury to other organs such as the spleen, stomach, or intestine.
- Injury to the remaining liver blood vessels or bile ducts resulting in liver failure and the chance of needing a liver transplant.
- Pain in the incision that doesn't go away.
- Problems with wound healing.
- Hernia.
- Bowel problems such as slow or blocked bowels.

Non-Medical Risks and Costs

Financial strain and potential impact on your job: You should plan on being off work for 8 to 16 weeks. It is possible that donating part of your liver will affect your job status long term. Your social worker will talk with you about whether your job will be protected during this recovery. Also, whether you will be able to get any pay.

Problems getting insurance in the future: This can include health insurance and life insurance.

Changes in your mood: This includes things such as adjustment disorders, anxiety, or depression. This is especially true if your recipient has a hard time, medically, after the surgery.

Body image trouble: You will have a scar on your stomach.

Some people describe changes in how they feel about their body because of the scar.

Lifestyle changes: In addition to an impact to your job, donation may impact your activities and family life during recovery. For example, you will not be able to drive for a while and will have to limit what you lift.

The Donor Surgery

The target surgery date is always subject to change.

- You may opt out of donation at any time.
- The liver transplant program may change the target date if they believe it is necessary to delay the transplant.

Preparing for Surgery

About 2 weeks before your surgery, you will come to UWMC transplant clinic for the pre-operative evaluation. You will receive a reminder in the mail for this appointment.

During this evaluation, you will have an updated physical, blood tests and an anesthesia appointment. You will be taught **deep breathing** and **coughing exercises**. This helps prevent pneumonia.

If you do not live nearby, hotel lodging the night before surgery will be provided. If you live outside of Wisconsin we ask that you complete your air travel at least 2 days before the surgery. Sitting in an airplane for a prolonged time increases the risk of blood clots during and after the surgery.

The evening before surgery, your evening meal should be clear liquids only. You will take a medicine to clean out your bowels. Then, you will shower using a special soap. You should not eat or drink anything after midnight.

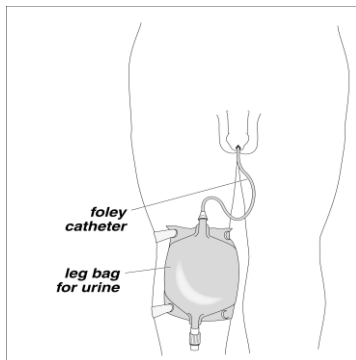
The Day of Surgery

The day of your surgery you will be admitted to the hospital.

While in the First Day Surgery Center, an IV will be inserted into one of your veins. Through the IV, placed in the arm or hand, you will be given fluids.

About an hour before surgery, you will get a shot. This will relax you and dry the secretions in your lungs. It will make your mouth feel dry, and you will become sleepy. After the shot, we will ask you to stay in bed.

During surgery, a small rubber tube (**Foley catheter**) will be placed in your bladder. This allows us to watch your urine output. It remains in place until the day after surgery.



The surgery will last 6-8 hours. An incision will be made across your upper stomach. The liver will be cut. A portion of the liver will be prepared for transplant into the recipient.

At the end of your surgery, the incision will be closed and a temporary drain (plastic tube) may be placed to exit through the skin. This will be removed in 3–5 days.

It is possible, although very rare, that the surgeons may find reasons not to proceed with the donor surgery and the incision is closed.

You will be in the recovery room for 1–2 hours before being taken to your room on the transplant unit.

What to Expect While in the Hospital

You can expect to be in the hospital for 5–7 days.

When you arrive in your room, you will still be quite sleepy. You will still have the IV and Foley catheter in place. Your nurse will take your blood pressure, pulse, and temperature. Your urine output will be measured often.

You will be asked to **cough and deep breathe** at least hourly while you are awake. Anesthesia can increase your lung secretions. These can stay in your lungs and may lead to pneumonia. By deep breathing, air reaches the area where the secretions collect. Coughing helps to bring them up. A small plastic tool called an incentive spirometer will be used to help you take deep breaths.

Most often you will get up and **walk** about 6 hours after you return to your room. Walking will help prevent many problems that can occur after surgery, including pneumonia, blood clots and constipation. You should walk at least every 1–2 hours during the first few weeks.

You may be given elastic socks (TED stockings) to help the blood flow to and from your legs to help prevent blood clots.

Your doctor will decide when you can resume eating. Surgery and pain medicines can slow the wave-like action of your bowels for a short time. As bowel activity and sounds return and you start to pass gas, you will be given liquids. Slowly, you will advance to eating regular food. Walking as early as you are able will help your bowel function return to normal.

If drainage tubes were inserted during your surgery these are removed after the first few days.

You should look at your incisions daily. Watch for signs of infection such as redness, swelling, or drainage.

Your doctor will prescribe pain medicine for you. Until you are able to drink, you will receive medicine through the IV. The pain medicine should be taken to help decrease incision pain. It will be easier to walk and take deep breaths if your pain is under control. Once you are able to eat, you will take a pain pill.

Blood tests are done to check your liver function.

You may develop mild jaundice after the donor surgery. The jaundice most often improves without any treatment. If it does not, you may require more tests.

You are started on a blood thinner after surgery. This will require a daily shot for up to 2 weeks.

Donor Follow-Up Care

After You Leave the Hospital

- You will come to the transplant clinic for a doctor's visit in about 1-2 weeks. At your clinic visit, you will have blood work done and will be seen by your transplant surgeon. If you live far away, you will need to stay in Madison at least until this first visit. Based on your healing, you may be asked to stay longer.
- You will go home with pain pills to help control your pain. Your doctors will advise you on over-the-counter pain pills that you can use as well.
- You may continue to need a blood thinner through a daily shot for two weeks.
- You will come to our transplant clinic again at about 4 weeks, 4-6 months, one year and two years after donation.
- You should see your regular doctor yearly.
- You should plan on being off work for 8 to 16 weeks.
- You will have activity limits. They may include not being able to drive or lift heavy objects for several weeks.
- It may take 3 to 4 months before you return to normal routines and energy level. It will be important to have a specific plan in place before the surgery. You will need help and support you during this time.
- It is common to have a "letdown" or mild depression while healing. This most often improves in a short time. The donor social worker is available to talk. **Please contact the transplant program for help.**



NO LIFTING



NO DRIVING

Phone Numbers

Transplant office number
(608) 263-1384

Fax Number
(608) 262-5624

Main Hospital Number
1-800-323-8942.

Ask for the transplant office telephone number listed above or the department you want to reach.

The Gift of Life

Donating part of your liver is not an easy choice. It is not for everyone. You should consider the emotional, physical, and financial factors. The choice to donate should be made free from any feelings of family pressure, duty, need for credit, or financial gain. Feeling anxious and afraid is very normal and common. It is our hope that this handout helps clear things up for you. Our entire staff is happy to answer any questions.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 6/2019 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#6839.