



Indiana University Health

Donating Partial Liver for Transplantation

Living Liver Donation Patient Education

Donating Liver (partial) for Transplantation

Indiana University Health has a long history in the field of transplantation, and consistently ranks as one of the best liver transplant programs in the nation.

When someone has end stage liver disease, they stand a risk of liver failure when medical therapy does not help, and the only option is liver transplantation. Without timely transplantation, there is a significant risk of death.

Liver transplantation involves replacing the diseased liver with a healthy, donated liver from another person. The liver that is transplanted can come from a person who has died (a deceased donor), or it can come from a person who wishes to donate while alive (a living donor).

You are reading this information booklet since you are considering giving a portion of your liver to another person who has end stage liver disease and needs a liver transplant. This education booklet provides detailed information about the living donation process – including evaluation, surgery and follow-up – that will be discussed with you further throughout the process. We ask that you carefully read the following information and ask any questions you may have before agreeing to proceed. **You will need to sign a consent form to indicate that you wish to proceed with the evaluation process.**

The IU Health Liver Transplant team is available to assist you throughout the entire donation process, from evaluation through follow-up care. The living liver donor coordinators are available Monday-Friday, 8 am - 4 pm, and can be reached at 800.382.4602 or 317.944.4370.

Who Can Donate?

Your decision to donate should be completely voluntary and free of pressure or guilt. In general you must be healthy, in good physical and mental health, and between 18-55 years of age to be a living donor. You will complete a thorough medical and psychosocial evaluation and you will be fully informed of the known risks involved with donation. You must disclose any medical history along with use of drugs, alcohol and smoking. It is critical that you provide, to the best of your knowledge, accurate and complete information about past and present health issues, illnesses, hospitalizations, medications and your mental health, and that you report any changes in your condition during the evaluation and donation process.

Types of Living Liver Donation

- Related – Blood relatives of transplant candidates, including parents, children (over 18 years old), brothers, sisters, half brothers and sisters, aunts, uncles, cousins, nieces and nephews.
- Non-Related – Donors emotionally close to transplant candidates, but not related by blood, including spouses, in-law relatives, close friends, coworkers, neighbors or other acquaintances.
- Non-Directed – Donors not related to or known by the recipient, but who make a decision to donate purely out of unselfish motives. This type of donor is commonly referred to as an anonymous or altruistic donor.

Evaluation Process

Living donors must be chosen carefully to avoid outcomes that are medically and psychologically undesirable. You will be evaluated with consultations, lab tests and various procedures to determine the medical appropriateness of liver donation. IU Health takes all reasonable precautions to provide confidentiality for both the donor and the recipient.

You will interact with many members of the transplant team who may include:

- A **Financial Coordinator** is a nurse case manager who will work with your recipient's insurance so the donation process will be at no cost to you, the donor.
- The **Transplant Coordinator** is a registered nurse who specializes in the transplant and donation process. Your coordinator will provide you with education regarding the donation and transplant process. You are encouraged to ask questions and to become fully informed about the liver donation and transplant process.
- A **Living Donor Advocate (LDA)** is independent of the recipient transplant team and acts solely on your behalf to ensure that your rights are protected and that your decision to donate is informed and voluntary. The LDA is available to you throughout the donation process. Before any evaluation testing is started, you must have an initial interview with the LDA.
- A **Hepatologist** is a physician who specializes in liver disease. The hepatologist will assess the function of your liver and the safety of your donation. You and your recipient will have different hepatologists.
- A **Surgeon** will meet with you and discuss living liver donation, the risks of the surgery and the possible complications after your donation.
- An **Anesthesiologist** will meet with you prior to donation to review your medical history and discuss your risk(s) from anesthesia.
- A **Psychiatrist** or **Psychologist** will conduct an in-depth evaluation and assessment of your psychosocial history, the relationship between you and the intended recipient and your ability to cope with the donation process.
- A **Social Worker** is available to provide support and identify resources that may be beneficial when needed.
- A **Registered Dietitian** is available to perform a nutritional assessment and provide nutrition education and support.
- Some potential donors may be referred to other service(s) for consultation. For example, some patients need to be seen by a pulmonologist (lung doctor) or a cardiologist (heart doctor) to assess for other medical conditions.

Multiple tests are done to determine if you are a suitable donor. The following tests may be included in your evaluation process. Remember, other tests may need to be done based on the results of these tests.

- Blood tests are done to determine your blood type and identify reasons that you might not be able to donate part of your liver. These tests will screen for your immunity to or the presence of specific viruses, including human immunodeficiency virus (HIV). Additional blood tests may be used to determine how well other organs are functioning.

- A chest X-ray helps identify any problems with your lungs.
- A urine test is used to screen for the presence of urinary tract infections and kidney disease.
- An EKG, echocardiogram and/or stress test will show how well your heart is functioning. This will help your physician decide if your heart is strong enough for surgery.
- A CT scan will be done to identify anatomy, blood flow to and from your liver and the presence of tumors.
- An MRCP/MRI will help determine anatomy of the bile ducts.
- A liver biopsy may be performed if BMI is 30 or higher, or if an abnormality is suggested by imaging. This is a test in which a needle is used to remove a small portion of your liver. The tissue is then looked at under a microscope to identify any abnormalities and fat content. There are risks involved with a liver biopsy that will be discussed with you prior to the procedure.
- Pulmonary function tests may be required, especially if you have a history of smoking or a history of lung disease. This is a breathing test to analyze your lung capacity and function.

Donors with Risk Criteria

All potential living donors must be assessed for criteria that would put organ recipients at risk for acquiring HIV, Hepatitis B (HBV) and Hepatitis C (HCV) infections according to the U.S. Public Health Service (PHS) guideline recommendations. Screening will be done during the initial donor intake process and again within 28 days of scheduled donation

- At time of screening: within the past 30 days
 - Sex with a person known or suspected to have HIV, HBV, or HCV infection
 - Man who has had sex with another man
 - Sex in exchange for money or drugs
 - Sex with a person who had sex in exchange for money or drugs
 - Drug injection for nonmedical reasons
 - Sex with a person who injected drugs for nonmedical reasons
 - Incarceration (confinement in jail, prison, or juvenile correction facility) for ≥72 consecutive hours
- Transplant hospitals must educate recipients about donor risk criteria, and while the specific criteria will not be shared, the transplant hospital must inform an intended recipient when their donor has any risk criteria. In most circumstances, the intended recipient will be informed prior to proceeding with the living donor evaluation.

Potential Risks of the Living Donor Evaluation Process

Health information obtained during the evaluation is subject to the same regulations as all medical records and could reveal conditions that must be reported to local, state, or federal public health authorities. During the evaluation process, risks that a donor may encounter include:

- Allergic reactions to contrast (dye used in some testing)
- Discovery of reportable infections
- Discovery of serious medical conditions
- Discovery of adverse genetic findings that may be unknown to you
- Discovery of certain abnormalities that will require more testing at your expense or create the need for unexpected decisions on the part of the transplant team

Routine donor evaluation tests are paid for by IU Health Transplant. **PLEASE NOTE:** If you seek evaluation testing outside of the IU Health system, we cannot guarantee that the outside hospital will accept or follow the billing process required for IU Health Transplant to pay the claims. If this occurs, you may be financially responsible for those bills. In addition, if medical issues are identified during the evaluation processes that are unrelated to donation, you will be referred to your primary physician for further follow-up. Financial responsibility for any testing or care you receive that is not related to the living liver donation will be yours and/or your insurance provider.

The IU Health Transplant team may determine that you are not a candidate for living donation at this center. If this occurs, you may choose to pursue evaluation by another transplant hospital that might evaluate you using different selection criteria.

Information Regarding Transplant Candidates/Recipients

- Each transplant hospital determines candidacy for transplantation based on existing hospital specific guidelines or practices and clinical judgment
- It is possible that a deceased donor liver could become available for a recipient who is listed on the United Network for Organ Sharing (UNOS) waiting list before the living donor evaluation is completed or the living donation/transplant occurs
- The recipient has the option of being listed for transplant at multiple transplant centers and has the ability to transfer waiting time to a different transplant center without loss of the accrued waiting time
- Any transplant candidate may have an increased likelihood of adverse outcomes (including, but not limited to graft failure, complications, and death) that:
 - Exceed local or national averages
 - Do not necessarily prohibit transplantation
 - Are not disclosed to the living donor due to privacy laws
- IU Health Transplant can disclose to the living donor certain information about transplant candidates only with the permission of the candidate, including:
 - The reasons for a transplant candidate's increased likelihood of adverse outcomes
 - Personal health information collected during the transplant candidate's evaluation, which is confidential and protected under privacy law

- Alternative treatments or therapies may be available for the recipient's medical condition such as medical management or deceased donor liver transplant. Please feel free to discuss liver disease and/or any possible alternative therapies with the healthcare team.

Surgical Procedure

For living liver donation, a portion of the liver will be removed based on the size of the recipient. Care will be taken to leave at least 30% of the donor's liver, and the part of the liver left behind is expected to grow back to normal size within a few weeks. If at any point, even after the donation surgery has started, the surgical team believes that you are at risk or that the segment of your liver is not appropriate for transplant, the donation process/surgery will be stopped. Removal of a portion of the liver may lead to temporary liver dysfunction of the remaining liver, but this is expected to recover with supportive care.

During surgery, drains may be placed to help the healing process. You will be in the Transplant Intensive Care Unit for 1-2 days after surgery. It is possible that you may need to be on a machine to help you breathe for a short time after surgery. When the doctors feel it is appropriate, you will be moved to the Organ Transplant Unit. You will remain in the hospital as long as necessary, but donors are usually discharged 4-7 days after surgery.

Your recovery time at home is generally 4-6 weeks, but could be longer. You should be able to do most of your usual activities within 2-4 weeks, and return to all activities in 3 months.

Potential Risks of Living Donation

A living donor undertakes risk and receives no medical benefit from the operative procedure of donation. Surgical, medical, psychosocial and financial risks associated with living donation which may be temporary or permanent include, but are not limited to, all of the following:

- **Potential Surgical and Medical Risks**

There are inherent risks in all surgeries, especially surgeries conducted under general anesthesia. Many complications are minor and get better on their own. To reduce some of these risks, IU Health living donors are encouraged to discontinue use of all nicotine, including nicotine replacement products, alcohol and illicit or recreational drugs. Potential complications and risks will be discussed with you further during the evaluation process; these include, but are not limited to:

 - In some cases, the complications are serious enough to require another surgery or medical procedure, and although rare, there is the risk of death.
 - Donor-specific pre-existing conditions, age, obesity or hypertension may impact the morbidity and mortality of the donor.
 - Bleeding during or after surgery may require blood transfusions or blood products that can contain bacteria and viruses that can cause infection. Although very rare, these infections include, but are not limited to, human immunodeficiency virus (HIV), hepatitis B virus (HBV), and hepatitis C virus (HCV).

- Despite efforts to prevent them, blood clots may sometimes develop in the legs and can break free and occasionally move through the heart to the lungs. In the lungs, they can cause serious interference with breathing, which can lead to death.
- The abdominal incision is a potential site for infection. Infections at the sites where tubes are placed in your body (tubes to help you breathe and tubes in your veins to provide fluids, nutrition and to monitor important body functions) can cause pneumonia, blood infections and local infections.
- Damage to nerves may occur. This can happen from direct contact within the abdomen or from pressure or positioning of the arms, legs or back during the surgery. Nerve damage can cause numbness, weakness, paralysis, and/or pain. In most cases these symptoms are temporary, but in rare cases they can last for extended periods of time or even become permanent.
- Other possible complications include: injury to structures in the abdomen, burns caused by the use of electrical equipment during surgery, damage to arteries and veins, pneumonia, heart attack, stroke, permanent scarring at the site of abdominal incision, pain, fatigue, hernia, bowel obstruction, and abdominal or bowel symptoms (such as bloating and nausea).
- Surgical risks may be temporary or permanent and include, but are not limited to
 - Acute liver failure with need for liver transplant is very rare
 - There is a small but significant risk of dying, as with any major operation; based on experience in the United States, the risk is approximately 0.1%
 - Complications such as bleeding, bile leak or bile duct strictures are more common and may need another procedure to resolve them. Over the years, there has been increasing understanding of this operation, and measures will be taken to minimize the risk to the donor.
 - Bile leak is a common liver complication after surgery
 - Most bile leaks get better without having to have another surgery, but may need to be treated with tubes or drains that pass through the skin and into the liver to drain bile from the liver into a bag worn outside the body for a period of time
 - Bile duct strictures (narrowing of the ducts that drain the liver) are rare, but can happen
 - Some can be fixed by placing a stent (a thin, hollow tube) in the area of the stricture using a scope through the mouth or through the skin; if not, surgery could be needed
 - Temporary liver dysfunction can occur, and may depend on the amount of the total liver removed for donation; however, in most cases it recovers within weeks
 - Post-donation laboratory tests may result in abnormal or false positive results that may trigger additional tests that have associated risks.
- After liver donation:
 - Donation related complications that occur, even after discharge, may require the donor to return to IU Health to receive treatment

PLEASE NOTE: If you seek medical treatment related to the donation surgery that is outside of the IU Health system, we cannot guarantee that the outside hospital will accept or follow the billing process required for IU Health Transplant to bill the claims to your recipient's Medicare. If this occurs, you may be financially responsible for those bills.

- **Potential Psychosocial and Financial Risks**

Choosing to donate a portion of your liver can give you the opportunity to enrich the life of someone in need. There are, however, possible personal risks to you as a result of donation which include, but may not be limited to:

- Problems with body image
- Post-surgery depression or anxiety
- Feelings of emotional distress or grief if the recipient rejects the transplanted organ, has recurrence of disease, or dies
- Changes to your lifestyle
- Personal expenses of travel, housing, food, child care and lost wages related to live donation (some assistance may be available for qualifying individuals)
- Future health problems of a living donor following donation may not be covered by the recipient's insurance or your insurance
- Loss of employment or income
- Negative impact on your ability to obtain future employment
- After you donate a portion of your liver, health insurance companies may consider you to have a pre-existing condition and refuse payment for certain medical care, treatments or procedures
- After the surgery, your health insurance and life insurance premiums may increase and remain higher
- In the future, your ability to obtain, maintain or afford health, disability and life insurance could be negatively affected; this risk can be minimized by avoiding any gaps in your insurance coverage or maintaining continuous coverage

Reporting Requirements and Donor Commitment to Medical Follow-Up

We are required to provide information about all organ transplantation to United Network for Organ Sharing (UNOS). This includes information about the living donor, including name, birth date, sex, social security number, blood type, the donor's relationship to the recipient and some blood test results. UNOS then assigns a case number to the transplant recipient and the donor. The identifying information is not accessible to the public or to other researchers.

We are also required to obtain and report information on all living donors at the time of donation, and at six months, one year and two years after donation. We will ask you to commit to post donation follow-up testing, and will send you a kit to have blood samples collected and returned to IU Health for processing, as well as a brief health questionnaire for you to complete. IU Health Transplant will cover the costs related to these tests.

This information is collected to determine how many living donor liver transplants are performed, how many are successful and if there are any donor complications. Your participation in completing

the follow-up supports the benefit and need of tracking outcomes nationally to impact future policies and safety in living donation.

It is important for you to be aware that any infectious disease or malignancy discovered during the first two years of follow-up that is relevant to the care of the recipient of your liver will be shared with you, the recipient's transplant center/care team, and reported through the Organ Procurement and Transplantation Network (OPTN) Improving Patient Safety Portal. Additionally, some infections may need to be reported to local, state, or federal public health authorities.

IU Health Transplant is required to obtain a blood specimen from you before donation and store it for ten years, to be used only for investigation of potential donor-derived disease in the recipient.

You will need life-long follow-up after liver donation. We strongly recommend regular follow-up with your primary care physician at least yearly. The financial responsibility of the follow-up is yours, the donor.

National and Transplant Center-Specific Outcomes

We will provide you with the current national and IU Health Liver Transplant survival statistics from the Scientific Registry of Transplant Recipients (SRTR). These can also be found at srtr.org. The SRTR is a national database of statistics related to solid organ transplantation, and program specific reports are available for each transplant program in the U.S. Specific survival outcome requirements must be met to be an approved transplant center by the Centers for Medicare and Medicaid Service. IU Health Transplant meets these requirements and is a Medicare-approved transplant center.

Right to Withdraw

You have the right to withdraw your participation as a donor at any time during the process, and we will assist you in doing so in a manner that is protected and confidential. Information about your medical evaluation, diagnostic test results, etc., will not be discussed with the potential transplant recipient. It is up to you what information you discuss with the potential recipient.

Sale or Purchase of Human Organs

The sale or purchase of human organs is a federal crime and it is unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration (anything of value including, but not limited to, cash, property, vacations) for use in human transplantation.

Additional Information

We recommend that you visit the websites listed below for additional information regarding living liver donation and liver transplantation.

- IU Health Transplant: iuhealth.org/transplant
- Donate Life America: donatelife.net/living-donation/
- United Network for Organ Sharing (UNOS): transplantliving.org