

The Johns Hopkins Hospital

Comprehensive Transplant Center

Living Donor Liver Transplant Handbook

Patient Guide



JOHNS HOPKINS
MEDICINE

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Living Donor Liver Transplantation at The Johns Hopkins Hospital

Comprehensive Transplant Center

The Johns Hopkins Hospital has been performing living donor liver transplants since 1992, and is proud to offer this unique option for patients who have loved ones who are willing and able to donate. As a living donor, you entrust us with your safety. We therefore conduct a comprehensive evaluation and offer post-donation care to ensure that the donation has a successful long-term outcome for you and for the recipient of your liver.

This handbook is a comprehensive tool that will outline what you may expect as you go through the living donor process. We hope this information is helpful in making a decision regarding living donation. Though this handbook focuses mainly on the donor aspect of liver transplantation, it will also be beneficial to read for potential liver recipients. Questions may be directed to the Living Donor Liver Transplant Team, who can be reached at 410-614-2989. Thank you for your interest in our program. We look forward to working with you.

Liver Transplantation

Dedicated to the management of advanced liver disease, the liver transplant program at the Johns Hopkins Comprehensive Transplant Center has continued its outstanding work with liver transplant patients and their families since 1986. The liver transplant team is committed to providing excellent care for patients at every stage of their transplant journey.

Collaborative medical and surgical efforts have helped to create a dynamic and thorough evaluation process. By working together in a multidisciplinary fashion, combining the expertise of pre- and post-transplant teams, our goal is to make the process more efficient and comprehensive.

Contact Us

The Johns Hopkins Hospital Liver Transplant Office

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410-614-2989 T
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Living Donor Advocate

Alana Williams
410-955-1771

Visit us online:

hopkinsmedicine.org/transplant

The Living Donor Transplant Team

At Johns Hopkins, we have a dedicated staff of people who work with living donors. This multidisciplinary team ensures that all potential living donors are thoroughly evaluated both medically and psychosocially. All information that is shared or learned by our team regarding donors is completely confidential.

Living donor evaluation nurse coordinator: This nurse will guide you through the evaluation process. There are many tests to complete, which he or she will help to arrange and coordinate. The nurse coordinator also works closely with transplant surgeons and hepatologists.

Patient services coordinator (PSC): The PSC works with the nurse coordinators and other members of the transplant team to schedule testing, collect test results and answer your questions about the donation process.

Living donor advocate: The donor advocate is an individual whose responsibility is to help ensure the safe evaluation and care of living donors. The donor advocate provides an additional resource for the donor and the transplant team members. The donor advocate promotes the donor's best interests and assists the donor in obtaining information and understanding the donation process.

Transplant surgeon: The surgeon will explain the donor operation, including the risks involved, and will answer any questions you may have regarding the operation. The surgeon also performs your operation and works with the donor team to oversee your post-donation healing.

Transplant hepatologist: The hepatologist (liver doctor) medically evaluates potential donors and will counsel you regarding the risk of donating a portion of your liver. The hepatologist is also part of the team that monitors your liver function after donation.

Post-donation nurse practitioner (NP): The nurse practitioner helps take care of you while you are in the hospital and provides you with post-donation support after discharge from the hospital. The NP monitors your liver function after donation and serves as a valuable long-term resource.

Social worker and psychologist: The psychologist and social worker help you gather information, weigh options and make an informed choice. They will complete a psychosocial evaluation to determine eligibility to proceed with donation. This evaluation is used to measure psychological, emotional and social

stability, as well as establish whether the potential donor is competent to give informed consent and to assess donor motivation. (The degree to which the decision to donate is being made freely, without undue pressure, coercion or financial incentive to donate.) Another purpose for this discussion is to give you an opportunity to express yourself freely and to discuss any concerns you may have about donation.

Who can be a living donor?

Living donors can be an immediate family member, a relative or a close friend. Donors must be medically and psychologically healthy, willing to donate and between the ages of 18 and 60. There are some medical conditions that may make a donor ineligible, such as diabetes, certain cancers, kidney or heart disease, substance abuse, hepatitis and elevated body mass index.

As a donor, you must be fully informed of the risks involved and complete a full medical and psychological evaluation. Your decision to donate should be completely voluntary and free of pressure and guilt.

All potential donors have questions about the donation process. How much discomfort is associated with the surgery? How long will it take to get better? How much time will I need to take off of work? Will the donor incur any costs? Some donors express fear. Some even feel guilty about being afraid. Whatever concerns you have, the transplant team is available to help you get the answers you need. Your team can even connect you to a "donor mentor"—someone who has previously donated and can share their personal experience with you. The transplant team encourages you to learn all that you can about donation to ensure that it is right for you.

Benefits of Living Donor Liver Transplantation

In the United States, more than 17,500 patients are on the waiting list to receive a liver transplant. Although more than 6,000 liver transplants are performed each year, at least 1,700 patients die each year waiting for a transplant. Livers are allocated to patients based on how sick they are—their MELD score—with the sicker patients having priority. Living donation offers patients the option of transplant prior to getting very sick, regardless of MELD score, and it significantly decreases the time they wait for a liver. It is an elective operation that is planned well in advance and results in a very short cold ischemia time—the time that the liver is without blood and is being preserved. Livers from living donors are usually of excellent quality, because donors are extensively evaluated prior to donation and are only allowed to donate if they are in very good health. Living donation not only saves the life of the intended recipient, but also frees up a liver for a patient on the waiting list who does not have a living donor option.

Making an Informed Decision

It is important to be fully informed about the living donation process and to be honest with the transplant team about your feelings, concerns and fears about being a donor. Consenting to be a donor is completely voluntary. You have the right to change your mind at any time during the process. All communication with the transplant team is strictly confidential. Consider how donation may affect your physical and emotional health, as well as your daily life and financial situation.

Financial Considerations

In addition to the clinical aspects of donation, there are financially based questions that often arise. Below is a summary of information that may be helpful regarding your decision to donate.

Financial responsibilities: Services that are associated with donation and that are ordered by our transplant staff, including lab work and physician bills, are paid for by the Transplant Center. For this reason, we request that if you have a test done in your local area, you give your provider our billing information. In most cases, they will be willing to send the bill for your services directly to us for payment. However, in some cases, labs require payment up front. If this occurs, you can come to The Johns Hopkins Hospital for testing or pay the bill and immediately forward it to us for reimbursement.

Donation-related travel to Johns Hopkins: If you live outside of the Baltimore area, you will need to be prepared to travel to Johns Hopkins for an on-site evaluation appointment (generally two to three days) and for the donor surgery (generally one day prior to surgery and one week after discharge from the hospital following surgery). You may also want to have a spouse, family member or friend accompany you during the donation period. Some insurance companies may cover the expenses associated with traveling. You should talk to your potential recipient to determine if they have this insurance benefit. Additionally, the Johns Hopkins living donor social worker and advocate may be able to help you identify programs that can assist with these expenses. If you would like to find out more about these programs, please call Mary Kaiser at 410-614-2819 to determine qualification.

Testing – evaluation versus treatment: Your nurse coordinator will request that you have certain diagnostic tests performed in order to determine medical/surgical suitability for donation. In some cases,

the tests may identify potential abnormalities that we recommend you have further investigated by your personal physician. The transplant center will pay for the diagnostic testing related to the donor evaluation; however, the transplant center is not financially responsible for any testing that may be recommended as a result of an abnormal finding. For example, a lab may come back with an abnormal result. At that point, the transplant team may determine that you are not a candidate for donation. It will be your responsibility to follow up with your primary care physician regarding the abnormal test result.

Insurance and insurability: Johns Hopkins does not require that a donor have insurance in order to donate. The costs associated with the testing required for evaluation, the donor surgery and the hospital stay are billed by the transplant center to the transplant recipient's insurance carrier. Although it is not a prerequisite, Johns Hopkins strongly recommends that a donor maintain health insurance.

If donors need supporting documentation for health or life insurance purposes following donation, the transplant center is prepared to provide a letter to the insurance company explaining the long-term data on live liver donation.

Post-donation wellness: The transplant team recommends that donors visit their primary care physician annually for a routine wellness exam. However, the transplant center is not financially responsible for these checkups. The transplant center has a program through which laboratory data is collected after donation, and post-donation liver function is monitored. Testing ordered under this program is paid for by the transplant center.

If a donor experiences a complication related to donation, the transplant team may order or approve additional testing post-donation. If this testing or

treatment is ordered or approved by the transplant team, the transplant center will cover the cost. As an example, a donor is discharged following donation, and upon returning home, experiences a surgical site irritation. The donor calls the transplant coordinator, and the coordinator instructs the patient to go their local emergency room. The transplant center is responsible for the bill related to the emergency room visit.

The Living Donor Process

The Living Donor Process is divided into five phases:

- I. Initial call about living donation**
- II. Screening tests**
- III. Donor evaluation**
- IV. Scheduling the donor surgery**
- V. Recovery from surgery**

The donor evaluation is comprehensive. In order to make the very best decision about candidacy, our team must complete a thorough evaluation. Donors are required to meet strict criteria for consideration. This allows our team to get all the necessary information about you to protect you from any foreseeable problem or issue. Specific criteria used by the transplant center are based on scientific findings and past experience.

The evaluation process involves a medical, surgical and psychosocial component. A determination will be made following medical/surgical consultation and testing, in addition to a consult with our staff psychologist and social worker. One golden rule exists with living donation: Nothing is more important than your health. Living donation is a process and is done at a pace that is comfortable for the donor. During all steps of the process, living donors have a nurse coordinator as their guide.

I. Initial Call About Living Donation

People who are interested in becoming a living donor must contact the living donor office. The living donor team will help answer any questions or concerns you may have regarding the process. Should you wish to proceed, you will work with the living donor patient services coordinator to collect your basic demographic information and complete forms needed to start the screening process. When the forms are received, the donor team will contact you to schedule a call with your independent living donor advocate.

II. Screening Tests

Once the potential donor has completed the initial paperwork and has been deemed a potential candidate, the donor needs to volunteer to proceed with the medical screening. This information is not provided to the recipient. It is the donor's decision whether or not they wish to proceed. Before proceeding with testing, the potential donor must schedule a call with the independent living donor advocate.

Initial required tests may include, but are not limited to:

- History and physical exam from primary care provider (if available)
- Chest X-ray
- Recent lab work and diagnostic tests
- EKG
- Echocardiogram
- Cardiac stress test (based on risk factors)
- Mammogram (if female and over 40)
- Pap smear (females over 21)
- Colonoscopy (if over 50 or sooner if increased risk factors)
- ABO verification

Upon receipt of the above information, the potential donor's chart will be reviewed by the living donor nurse coordinator. If the individual is still deemed a potential donor, they will then be scheduled for an evaluation appointment. If an individual is deemed not a candidate for donation, they will be notified by the living donor nurse coordinator.

Prospective living donors moving forward toward donation will be required to have their initial serologic tests for HIV supplemented with repeat testing with an ultrasensitive HIV and hepatitis C serologic test no longer than 14 days preceding organ donation, per CDC guidelines, to prevent the inadvertent transmission of HIV from donor to recipient. All living donors need to avoid behaviors that would place them in a high-risk situation for acquiring infectious diseases. These diseases include, but are not limited to HIV, hepatitis B, hepatitis C and syphilis. These diseases are infectious and could be transmitted to a recipient through donation. Additionally, a donor who tests positive for an infectious disease is automatically disclosed to governmental authorities, such as the Department of Health. Behaviors that need to be avoided are new tattoos, injection drug use, sex with injection drug users or other high-risk, unprotected sexual activity.

III. Donor Evaluation

If concerns are not identified during the initial screening, a two-day donor evaluation is scheduled at the Levi Watkins, Jr., M.D., Outpatient Center. We encourage you to bring a family member along to meet your living donor team—this should ideally be your significant other or the person who will most likely be helping you during your recovery period. You may not bring your recipient to your evaluation appointment.

Day 1

Day 1 will consist of lab work, diagnostic testing and meeting with the living donor nurse coordinator.

- Lab work
- CT scan of the abdomen/pelvis with contrast
- Chest X-ray
- Cardiac testing
- Consultation with living donation nurse coordinator

Day 2

Day 2 will consist of meeting individually with various members of the living donor team. Disciplines may include the following:

- Living donor advocate
- Social worker
- Hepatologist
- Surgeon
- Psychologist
- Dietitian

You may choose to complete your testing locally. Please discuss this option with your coordinator.

IV. Scheduling the Donor Surgery

Additional testing may be required once the results of your donor evaluation are complete. The donor's case will then be presented to a multidisciplinary committee. This committee will decide if the donor is indeed a good candidate to proceed with donation. It is important to know that donors may be excluded at any point during the donor evaluation process. Upon completion of testing and approval from the committee, and only if you wish to proceed, a surgery date will be selected in preparation for the transplant. In most cases, the transplant is scheduled four to six weeks in advance. This allows you to arrange time away from work, child care, school schedules and other daily responsibilities. Donors are usually in the hospital for approximately seven days following their surgery.

Donors should plan to stay in town for one week after discharge at a minimum.

V. Recovery from Surgery

Inpatient stay: During the early recovery period, you will experience some pain and discomfort from your incision, which is usually well-controlled with pain medications. You are monitored very closely after surgery for all the appropriate signs of recovery and liver regeneration. Your liver will begin to regenerate immediately after surgery and will be back to normal size in six to eight weeks. Once your pain is well-controlled, you are eating and drinking well, and you are up and walking around without too much difficulty, you are discharged from the hospital.

At home: After discharge, you are advised not to lift anything heavier than 20 pounds for at least six weeks. You are instructed not to drive while on sedation medications, which are used at least two to three weeks after discharge. You are encouraged to walk several times a day. If you have small children, you may need initially help in caring for them. Your recovery after discharge will be closely monitored with routine clinic visits and laboratory tests.

Returning to work: Depending on the type of work you do, you may be able to return to work six to eight weeks after surgery. This is variable and will be different for each donor.

Post-Donation Follow-Up

Medical health: After you return home, the post-donation nurse practitioner will be your central contact person and long-term resource for answering health-related questions and coordinating lab work to monitor your liver function post-donation. The nurse practitioner is also there to assist you have any complications or issues related to donation.

Psychological health: There may be some negative psychological symptoms experienced post-donation. You may have feelings of regret, resentment, anger, anxiety or depression. If you encounter any negative psychological symptoms following donation, the living donor social worker and the post-donation nurse practitioner are resources you can contact for assistance.

Additional Resources

The Johns Hopkins Comprehensive Transplant Center

hopkinsmedicine.org/transplant

United Network for Organ Sharing

unos.org

Visit the Johns Hopkins Medicine YouTube channel to view transplant-related videos.

youtube.com/user/JohnsHopkinsMedicine

Financial Resources

Donor Shield

donorshield.org

Natural Living Donor Assistance Center

livingdonorassistance.org

**Call the Comprehensive Transplant Center
to discuss living donor liver transplantation today:**
410-614-2989 or 1-800-706-1046
hopkinsmedicine.org/livertransplant

