

LIVER

Liver Living Donor Transplant Education Book



**Texas Children's
Hospital**

Disclaimer

The purpose of this education book is to give guidelines for pre and post-transplant care at Texas Children's Hospital. It does not provide specific medical advice and does not replace medical consultation with a qualified health or medical professional.

Our education book is updated every two years, but with the rapidly changing healthcare system, this information could be out of date and/or contain inaccuracies or typographical errors. Please consult with the transplant team.

Welcome

Welcome, from Transplant Services at Texas Children's Hospital! We have designed this education book to guide you throughout the living donor process. It is a resource to assist you, but it will not answer all your questions. You will continue to learn from all the members of the care team throughout the living donor process. Please remember, the medical opinions, techniques, and procedures discussed throughout this book are general statements and recommendations that may vary for each patient. If you have specific questions or concerns, please speak directly with one of our physicians, transplant coordinators, or your independent living donor advocate.

Please carry this book to your appointments and bring it to the hospital with you. This book is yours to keep and to refer to at any time. Please write notes in it as you read and learn.

The decision to move forward with the living donor process can be difficult. Choosing to be a living donor requires a long-term commitment. The donor will require life-long follow up care by the transplant team. We recognize that there will be numerous demands placed on your family before and after transplant. These demands can be overwhelming and can take an emotional toll on every member of the family. The transplant team at Texas Children's Hospital is committed to working closely with your family in the face of those demands. We want you to feel comfortable with our team as we move forward with the living donor process. You are not alone in this process. We are a team!

The gift of a new organ gives our patients a second chance at life and hope for a better quality of life. We look forward to moving through this journey with your family. Our goal is to make the living donor process a positive experience for your family. We have high standards of care for our patients and families. If there is anything additional that we can do to make this a positive experience, please let us know.

Sincerely,

The Texas Children's Hospital Transplant Team

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Team Contact Information

TRANSPLANT CONTACTS

Texas Children's Liver Transplant Office _____	832-822-1559
St. Luke's Transplant Financial Counselor _____	832-355-7081/8307
St. Luke's Living Donor Coordinator _____	832-355-5506
St. Luke's Clinic Front Desk _____	832-355-5535
St. Luke's Main Number _____	832-355-2011
St. Luke's Spiritual Care _____	832-355-3258

MONDAY-FRIDAY, 8:00AM - 4:30PM:

Non-Urgent Issues: Contact your Living Donor Coordinator by phone at 832-355-6461 or email.

Urgent Issues: Call 832-355-4146 and request to have your Living Donor Coordinator paged. Calls should be returned within 30 minutes. If you do not receive a return call, please try again as technical difficulties do sometimes occur.

For a true medical emergency, such as difficulty breathing, bleeding, or change in responsiveness, please call 911.

AFTER HOURS, WEEKENDS, OR HOLIDAYS

Urgent Issues: Call 832-355-1400 and request to have the surgeon on call paged. Calls should be returned within 30 minutes. If you do not receive a return call, please try again as technical difficulties do sometimes occur.

For a true medical emergency, such as difficulty breathing, bleeding, or change in responsiveness, please call 911.

OTHER IMPORTANT PHONE NUMBERS

Pediatric Intensive Care Unit- Main Desk _____	832-824-5952
Pediatric Intensive Care Unit- Waiting Room _____	832-824-5949
Texas Children's Page Operator (for urgent issues) _____	832-824-2099
Texas Children's Operator Toll-Free _____	1-800-364-5437

Chaplain Services are available for inpatients. Please ask your bedside nurse to page them if needed.

Section 1: The Liver

The liver is the largest solid organ in the body. It is normally located on the right side of the abdomen, under the rib cage. The liver has two lobes that are divided into sections (lobules). It is connected to the small intestine by bile ducts.

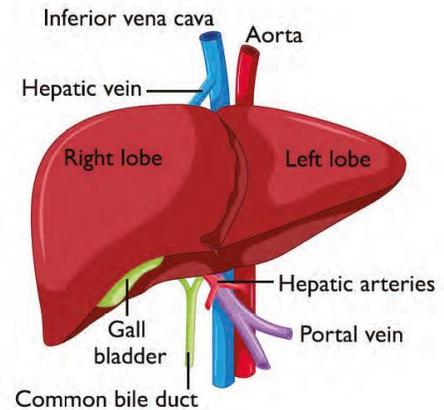
How the Liver Works

Hepatocytes:

- Regulate blood sugar levels
- Regulate hormones and growth factors
- Produces albumin, blood clotting factors, and proteins
- Produces bile, clotting factors, enzymes, proteins
- Bile is important for fat and vitamin absorption
- Breaks down food
- Clears bilirubin
- Remove wastes/toxins and breaks down medications

Bile ducts:

- Bile ducts carry bile from the liver to the small intestine. Bilirubin is changed into bile, which is needed to absorb fat and certain vitamins. The bile system and intestines are connected by the main common bile duct. If bile flow is blocked or slow, this may result in liver damage and problems with absorption of important nutrients.



Reasons a Transplant May Be Needed

A liver transplant may be needed if liver failure cannot be improved by medical therapy or surgery.

Common Reasons for Liver Transplantation

- Biliary Atresia
- Metabolic Disorders
- Liver Cancers
- Fulminant Hepatic Failure
- Genetic Disorders

Section 2: Before Donation

What is a Liver Living Donor?

A living donation occurs when a living person donates part of an organ for transplantation to someone in need.

Who can be a Living Donor?

Living donors can be a family member or friend who meets the following criteria:

- Can pass a full medical and psychological evaluation
- Healthy with no chronic liver disease
- Voluntarily willing to donate (without being pressured by others)
- Blood type compatible (in most cases)
- Between the ages of 18 and 60
- Non-smoker
- BMI \leq 35
- Free from alcohol or substance abuse
- Willing to accept blood products if needed
- Fully informed of risks

Possible reasons a living donors can be declined:

- Blood type incompatible
- Liver is too small or too big for donation
- Technical concerns (surgical concerns like blood vessel abnormality)
- Abnormal test results
- Substance or alcohol abuse
- Age < 18 years old
- Positive for HIV or Hepatitis B or C
- Malignancy (cancer)
- Suspicion that a donor is being pressured to donate
- Infection
- Prior living liver donor

What are the Benefits of Living Donation?

- Shortens waiting time for the liver recipient
- Shortens the time the donated liver is without oxygen/blood flow (cold ischemia time)
- Great organ quality due to intense donor evaluation and good health
- Frees up an organ from a deceased donor for someone else on the waiting list

Are Transplants from Living Donors Always Successful?

Although living donor liver transplant has a good 1- year organ survival rate, problems may occur. Sometimes, the transplanted liver is lost due to rejection or other complications. In certain cases, the original disease that caused the liver failure may re-occur in the recipient, causing the donated liver to fail.

What Happens During a Living Donor Evaluation?

Your donation evaluation is strictly confidential and no private information will be revealed to anyone, including the possible recipient.

Medical Tests and Procedures:

- **Lab Tests**
 - Medical: Liver function, Kidney function, Blood count, Blood type, Coagulation (blood clotting)
 - Infection: HIV, Hepatitis
 - Toxicology: Tests for drugs or alcohol
 - Urine tests
 - Other:
 - Pregnancy test for women of childbearing age
 - Pap smear and mammogram for women >40 years old
 - Prostate testing for men > 50 years old
- **Radiology Tests**
 - Ultrasound: Evaluates the donor's liver size and blood vessels
 - Electrocardiogram: Measures rhythm and regularity of your heartbeat
 - Echocardiogram: Ultrasound the donor's heart and shows how well your heart is pumping
 - Stress Test: Test to see how the heart responds to stress (depends on donor health and history)
 - Chest X-ray: Evaluates lungs and chest cavity for abnormalities
 - CT scan: A scan that helps the surgeon determine the size and shape of the liver
 - MRCP: Magnetic resonance cholangiopancreatography evaluates the bile ducts
- **Medical Tests**
 - Vital Signs: Heart rate, blood pressure, and respiratory rate are checked for evidence of medical problems
 - Physical Exam: All potential donors must have a physical examination to evaluate their health and ability to tolerate major surgery

Consultations with team members:

During the living donor evaluation you will meet the members of our team. The following is a list of people you are likely to meet during the evaluation and their role in the transplant process:

- **Hepatologist:** A liver doctor who medically evaluates potential donors and will monitor you after donation. The hepatologist will discuss risks/benefits of donation, review labs and test results, and answer your questions related to donation.
- **Transplant Surgeon:** Performs the actual donation surgery and leads the surgical management after donation. The transplant surgeon will review the surgical process and answer your questions related to transplantation and the transplant surgery.
- **Donation Coordinator:** Serves as your initial point of contact for questions related to donation. The coordinator will coordinate the evaluation, educate your family about donation, and provide support throughout the donation process.
- **Dietitian:** Performs a complete nutritional assessment of the potential donor and works with the physician to develop an appropriate nutritional program if needed.
- **Social Worker:** Reviews your social situation to ensure there is a good support system for donation. They can assist you in finding resources, programs, and other forms of support as needed. May recommend a psychiatric or psychological consultation for a more in-depth look at readiness.
- **Pharmacist:** Reviews your medications and can teach you what medications to avoid after donation.

- **Living Donor Advocate:** Promotes the donor's best interest and ensures the potential donor understands the donation process; Responsible for ensuring the safe evaluation and care of the living donor.
- **Financial Counselor:** Verifies that insurance includes coverage for donation to assist you in making a plan to cover costs.

What Happens After a Living Donor Evaluation?

- Medical Review Board
 - Results from your evaluation are presented to the Medical Review Board, which usually meets once a week. This board consists of a Transplant Surgeon, Hepatologist (liver doctor), Donation Coordinator, Living Donor Advocate, Registered Dietitian, Pharmacist, and a Social Worker. Based on the information presented, the board and transplant team will decide if you are an acceptable candidate for donation. You will be notified of the Board's decision by the Donation Coordinator and you will be mailed a letter.
- Placement in the UNOS Database
 - Living donors are placed on the UNOS donor registry. Their follow up care is tracked.
- Your Family's Part in the Decision
 - The decision to move forward with donation can be difficult, as there is some risk involved. There can be numerous demands placed on a donor's family before and after donation. While transplant centers approve or deny a candidate for donation, families also have a decision to make. If a donor is approved, they will need to decide if it is the best option for the family.

How does living donation affect the donor?

The remaining part of your liver will grow and resume normal function within a few weeks. A living donation does not change your life expectancy. You can generally resume normal home and working activities within 6-8 weeks.

What if you decide not to donate?

Living liver donation is a difficult decision. You are free to change your mind about the donation at any time before surgery. If you decide not to proceed with the surgery, the recipient will remain on the waiting list for a deceased donor transplant. The transplant team can let the patient know that you are not a suitable donor for medical reasons.

What Is the Organ Donation Process?

- **United Network for Organ Sharing (UNOS)**
The United Network for Organ Sharing (UNOS) provides a toll-free patient service line to help transplant candidates, recipients, living donors, and family members understand organ allocation practices and transplantation data. For more information, call 1.888.894.6361.
- **LifeGift**
LifeGift is a local, federal-designated, non-profit organization that serves Houston, Fort Worth, and Lubbock to promote organ donor awareness. Individuals who have a family member or friend with liver disease are usually more aware of the need for organ donors than the general public. If you or anyone you know want more information about organ donation, call LifeGift at 713-523-4438.

What are your Responsibilities?

- Communication with the transplant team is very important pre and post-donation
- Contact the transplant team immediately:
 - If your insurance changes
 - If your address or phone numbers change
 - Please contact your transplant coordinator directly with this information
 - If your medical status changes

Section 3: Donation

When will the surgery be scheduled?

Once you are approved for donation, the Donation Coordinator will contact you to schedule the surgery. Most of the time, surgery is scheduled 4-6 weeks in advance. This is so you can arrange time away from work, child care, or other daily responsibilities.

How will I be prepared for surgery?

- You and the recipient will be scheduled to meet with the team for pre-op:
 - To review and sign surgical consent, consent for blood transfusion, and discuss the risks associated with the surgery
 - Updated blood tests, a chest X-ray, and ECG will be done
- Inform the Donation Coordinator of any signs of infection as soon as possible before surgery
 - The surgery may need to be postponed if the donor or recipient are showing any signs of illness

What happens during the donation surgery?

- Donors are admitted the morning of the surgery
- Donors cannot eat or drink anything after midnight the night before surgery
- Hospital staff will check your vital signs and insert an intravenous catheter (an IV)
- An anesthesia team member will speak with you to obtain consent and discuss pain control
- Family members may wait in the surgery waiting area when you go to the OR
- The donor goes to the OR first and then the recipient is taken to the OR
- You and the recipient will have separate operating rooms and surgical teams
- You will receive medicines such as antibiotics to prevent infection
- After you are asleep from anesthesia, special lines may be placed to:
 - Drain your stomach contents or bladder
 - Give fluids
 - Monitor blood pressure
- Surgery will begin after all necessary lines are placed and will last 4-6 hours
- A large incision is made in the donor's abdomen to remove a piece of the liver
- An ultrasound and careful examination of internal organs will be done
- Your gallbladder will be removed
- The surgeons will examine the organ, blood supply, and bile ducts
 - There is a chance that the donation surgery may be cancelled if the surgeon finds something concerning during this initial exam of the donor's anatomy
- After confirming the donor's anatomy, the recipient's surgery can start
- Removal of a portion of your liver is called a partial hepatectomy
 - For an infant or child recipient, the left lobe of the liver may be used
 - For an adult recipient, the right lobe is removed for transplant.
- The remaining liver segment will grow and resume normal function within a few weeks
- Once the portion of your liver has been removed, the surgeon will complete your surgery and close the incision with staples or sutures
- Pain is common after surgery and we work to minimize your pain with medications by IV

What Should You Expect After Donation Surgery?

Immediately after surgery, you will be taken to a recovery area, and then to your hospital room. The length of your recovery time depends on the care you may need and your progress. Visitors can come to see you based on the visitation policies for the unit you are on.

As you recover, you can expect to:

- Have the tubes placed during surgery removed
- Begin eating a few days after surgery
- Have your pain medicines changed from IV to by mouth
- Have blood drawn for monitoring
- Have an ultrasound done before discharge
- Be sent home from the hospital 5-7 days after surgery (without complications)

After the surgery, you will use the following medical equipment:

- Oxygen Cannula or Oxygen Mask: Provides additional oxygen as needed
- Pulse Oximeter: Measures the saturation of oxygen in the blood through a sensor
- Incentive Spirometer: Helps to expand the lungs and prevent pneumonia
- Foley Catheter: Placed within the bladder during surgery to drain urine from the bladder
- Intravenous Catheter (IV): Placed in your vein to give fluids and medications
- ECG (Heart Monitor): An electronic device attached to the skin to monitor your heartbeat

What are Possible Complications after Donation?

Donating part of the liver is a major operation and has certain risks, such as:

- Bleeding
- Infection
- Bile leaks
- Adverse reaction to the anesthetic
- Pain
- Possible death (although risk is low)
- Blood clots
 - It is important to walk frequently after surgery in order to reduce the risk of forming blood clots
 - Due to the increased risk of blood clots, we ask donors to:
 - Avoid air travel or prolonged car trips for 2 weeks after surgery
 - When traveling after donor surgery to take time to walk every hour for about 15 minutes to promote blood flow in your legs

When Should You Contact the Transplant Team after Donation?

Donors must contact the donor office immediately if you develop new abdominal pain, redness or swelling around their incision, yellow skin, a fever, a cough or shortness of breath. If the donor office is closed go immediately to the nearest Emergency Room. Signs and symptoms to look out for will be reviewed during your discharge teaching.

Section 4: After Donation

How Long Will You Need to Stay in Houston After Surgery?

Unless there are complications after surgery, most donors are discharged from the hospital 5-7 days after surgery. You should expect to stay near in the transplant center for 1-2 weeks after discharge.

How Often Will the Living Donor Need to Have Follow-Up Appointments after Transplant?

- Follow-Up
 - Two weeks post-donation:
 - Labs & Clinic appointment to follow up with your surgeon
 - Ask your surgeon when you can go back to your hometown (if applicable)
 - Six, 12, and 24 months post-donation:
 - Vital signs, labs, and medical examination
 - Can be done in your hometown and results sent to transplant team
 - After your two-year follow-up visit, we recommend that you continue to see your personal physician yearly

What Are the Activity Restrictions after Donation?

The team will continue to follow you closely through the first year post-operatively. Most donors are off work from 6-12 weeks depending on the nature of their employment. It usually takes 3-4 months before patients are able to return to all of their normal activities at their usual stamina level.

Other activity restrictions:

- Do not lift anything heavier than 20 pounds for 6 weeks
- Do not drive or operate heavy machinery for 2-3 weeks
- Walk frequently to decrease your risk for blood clots
- If you have small children, get help in caring for them as you will be unable to lift them for approximately 6 weeks
- Most people can return to work 6 weeks after surgery, depending on their type of work

What Should You Communicate to the Transplant Team?

Donors must contact the donor office immediately if you develop new abdominal pain, redness or swelling around the incision, bleeding, yellow skin, a fever greater than 101°, shortness of breath, or unexplained swelling of the legs. If the donor office is closed go immediately to the nearest Emergency Room.

How Can You Balance Your Family's Needs after Donation?

Caring for a living donor after surgery can disrupt the family's daily routines. Everyone will need some time to get used to these changes. As your independence increases post-donation, family dynamics will be able to return to a more normal feel.

It is normal to feel emotional after donation. These feelings are usually short-lived. If you or your family members are struggling with your emotions after donation, please let a member of our team know. We can help you find needed resources.