

*Living Liver Donation
Patient Education Handbook*



Charles O. Strickler Transplant Center

Charlottesville, Virginia



Living Liver Donation

Introduction

This handbook was developed to provide information to those individuals considering donating a portion of their liver to a family member or friend. This handbook is intended to supplement discussions with the health care professionals involved in your care. It is important that you fully understand the risks involved and how donating a portion of your liver may affect you and your family. Our staff is available to answer any questions you may have with regards to donating part of your liver, as well as to explain any procedures and test results. Please do not hesitate to contact the Transplant Team members at any time if you would like more information about living liver donation.

The Liver Transplant Team

Transplant Surgeons

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Transplant Office Access

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Hours of operation: Monday- Friday 8:00 AM-4:30 PM

The Normal Liver

The liver is the largest organ in the body and plays a vital role in regulating many life processes. The liver weighs approximately 3-4 pounds and is roughly the size of a football. It is made up of a sponge-like mass of wedge-shaped sections called lobes. The liver is located in the right side of the abdomen and is protected by the ribcage.

The liver is a very complex organ that performs many functions that are essential for life. These functions include:

- Storing energy in the form of sugar
- Storing vitamins, iron and other minerals
- Making proteins, including blood-clotting factors, to keep the body healthy and growing
- Processing worn out blood cells
- Making bile, which is needed for food digestion
- Helping "clean" the blood by breaking down and removing many medicines and toxins, such as alcohol
- Regenerating its own damaged tissue
- Maintaining hormonal balance
- Aiding in digestion by helping in the absorption of fat and certain vitamins, including vitamins A, D, E and K
- Helping the body resist infection by producing immune factors and by removing bacteria from the bloodstream

A healthy liver also has a remarkable ability to regenerate (grow back), which no other organ in the body is able to do. There are illnesses, however, that can cause severe and irreversible damage to the liver.

Liver Failure and Transplantation

Liver failure occurs when the liver is unable to perform its normal functions. A diseased liver can result from an acute failure as a result of an infection or drug reaction. Liver disease may also result from chronic failure due to an ongoing viral infection, alcoholism, injury due to elevation in bilirubin, or an autoimmune disease. Liver failure can also result from having a primary liver cancer.

A liver normally has a great ability to heal itself and can overcome most injuries it experiences on a short-term basis. Occasionally the liver is so injured, however, that there are not enough cells left to

regenerate and scar tissue forms in the liver. When all normal liver tissue is replaced by scar tissue, the liver is said to be cirrhotic and a liver transplant may be the only available option.

Why Living Donation?

Each year, thousands of people die from complications of chronic liver disease and cirrhosis. There are currently over 17,000 persons awaiting a liver transplant from a deceased donor in the United States. Only slightly over 4,500 liver transplants from a deceased donor are performed in the United States each year. Because of the severe national organ shortage, alternative solutions to using deceased donors have been sought. Living liver donation is one of those solutions that has proven to be successful for some patients.

The first living donor liver transplant in the United States was performed in 1989. Since that time, nearly 3000 living donor liver transplants have been performed in this country. The majority of these procedures have been done in children, using a smaller portion (usually the left lateral segment) of the liver. Because of the growing need for adult livers, much larger portions have been removed (total right and left lobes) for transplantation.

There are several advantages for a transplant candidate to receive a living liver transplant as opposed to receiving a liver from a deceased donor. The living donor transplant surgery can be scheduled ahead of time, for example. More importantly, it can give patients an opportunity to be transplanted before the onset of life-threatening complications of their liver disease, thus leading to better outcomes. Another important advantage to living liver transplantation is the emotional satisfaction that donors share with recipients when a life is saved.

Who Can Be A Living Donor?

In addition to parents, children, siblings, and other relatives, living donors can also include in-laws, friends, co-workers, etc. The potential donor and recipient must have compatible blood types, the donor must voluntarily offer to donate and he or she must be in excellent physical and psychological health. Individuals with a history of high blood pressure, diabetes, heart disease, cancer or liver disease will not be considered as donors because of the potential health risks. Obesity and prior abdominal surgeries may also exclude a donor because of the increased surgical risk. Donors must also be between 18 and 55 years of age.

The Decision to Donate

Being a living donor can be a very rewarding experience. Living donation is a sharing of life, a giving of oneself to someone that you care about. Donating a portion of your liver, however, is also a choice that *only* the donor can make. It is very normal to have second thoughts regarding the decision to donate and to experience feelings of guilt about not wanting to donate. The Transplant Team is always available to ensure all of your questions are answered thoroughly. Our responsibility is to protect the privacy and rights of each potential donor. At any time in the process, it is acceptable to say "No," regardless of the circumstance. Remember that the only "right" decision is the one that makes the potential donor the most comfortable.

The Liver Donor Evaluation

If someone is interested in learning more about being a liver donor to a patient at the University of Virginia, he/she should contact the Transplant Office to speak with one of the nurse coordinators. The nurse will ask a series of health history questions over the phone.

Blood Typing

The first step in the process is determining if your blood type and the recipient's blood type are compatible. The chart below illustrates blood type compatibilities.

DONOR		RECIPIENT
O	→	O
A, O	→	A
B, O	→	B
O, A, B, AB	→	AB

Medical and Psychological Evaluation

Once it is determined that the potential donor and the recipient have compatible blood types, the donor will be referred to the **Donor Advocacy Team**. The Donor Advocacy Team (DAT) is a group of UVA family medicine physicians, psychologists, and a social worker that meets and evaluates each donor. A review of past and present medical problems and surgeries is done to be sure that there are no concerns identified that would place the potential donor at increased risk.

Please note: Only one potential donor will be evaluated for a given recipient at a time. At any point in the evaluation process, if a potential donor is deemed inappropriate for donation, another potential donor may begin the evaluation.

The other evaluation tests and studies included in this evaluation are listed below:

1. Blood studies- will include blood chemistries, blood counts, immune system function, and tests for certain infectious diseases
2. Chest x-ray- to determine the health of the lungs and respiratory tract
3. EKG of the heart- to determine how well the heart is working and it may reveal damage that was previously unsuspected
4. MRI of the liver- to determine the size and shape of the liver and major blood vessels
5. Ultrasound of the liver- to determine the openness of bile ducts and major blood vessels

Additional tests maybe necessary depending on a donor's age and individual medical history.

Once the DAT evaluation is complete, the Liver Transplant Team will review the recommendations and test results. Abnormal test results may warrant further testing or may prevent you from donating altogether. If the test results are considered normal, our office contacts the potential donor to set up an appointment to meet with a liver transplant surgeon to specifically discuss risks of surgery and to answer any further questions. After this visit with the surgeon, each

donor is given a “two-week cooling off period/or time-out.” This two-week time is required for the potential donor to think about all of the information that has been shared and re-consider his/her decision to donate. After the two-weeks have passed, the donor then contacts the transplant office to let the coordinator know of his/her decision. The transplant surgery can then be scheduled if it has not already been done.

At this point in the evaluation process, women who are on the birth control pill maybe asked to stop taking this medication prior to the surgery due to the increased risk of developing blood clots.

Risks of the Donor Operation

Although living liver donation surgery is relatively safe, the operation does involve certain risks. Unlike living kidney donation, in which death related to the operation is rare, there have been at least three deaths reported after living liver donation as of December 1999. Currently, the chance of death from this surgery is about 1 out of every 500 liver donors. This is a major operation and it should be discussed thoroughly with your family and Family Physician as well as with the Transplant Team. Below is a list of possible problems and risks associated with liver donation surgery.

Minor problems:

- Nausea and vomiting for several days after the surgery
- Pain at the incision site
- Allergic reactions
- Minor bleeding at the incision
- Abnormal scar formation
- Temporary jaundice, which is a yellow color to the eyes and skin
- Delay in return of intestinal function (about 1 out of 10 cases)

Major problems:

- Bile duct problems
 - Leaking bile (about 1 out of 10 cases) usually stops by itself, but sometimes additional medical attention or even surgery is needed to control the bile leak
 - Bile stricture (narrowed bile duct, about 1 out of 100 cases), can occur quite some time after the operation; may need a tube placed in the duct to keep it open or another surgery to correct the problem
- Serious bleeding requiring blood transfusion
- Liver failure (about 1 out of 1000 cases), if your remaining liver does not grow enough after surgery

Other risks related to having any major operation:

- Infection at the surgical site
- Hernia at the surgical incision
- Fluid buildup in the chest
- Bowel obstruction
- Blood clot

All of the risks will be explained to you in greater detail at the time of your visit with the liver transplant surgeon so that you can make an informed decision regarding donation.

Preparing for Surgery

Blood Donation (autologous transfusion)

Today, all blood is screened thoroughly for infectious diseases and the likelihood of contracting a disease is very small. Because liver donation is a major surgical procedure, however, you may require a blood transfusion. Since this specific type of surgery is scheduled ahead of time, it is possible in most cases to donate and store your own blood prior to the surgery so it can be used for you in the event that you do require a blood transfusion. Your nurse coordinator will speak with you regarding autologous blood donation before the scheduled surgery date.

Psychosocial Support

The Transplant Team has a dedicated social worker available to answer questions or assist you and/or your family throughout the donor process. Many potential donors have questions and concerns that come up as they begin the evaluation process. Common issues include worries about financial responsibilities when work is missed, childcare, housing for family during your hospitalization, and support after surgery during the recovery phase. It is common for potential donors to have some stress associated with considering donation. Whether one is a family member or friend, the decision to consider donation can raise many conflicting emotions. The Transplant Team is very committed to addressing these concerns in a completely private and confidential manner. The social worker is available to meet with you and your family to talk about any questions or concerns both in the clinic and at any time throughout your hospitalization.

It is very important to remember that a donor can change his/her mind about going through with surgery at any point before the surgery, even the day of surgery. The transplant team will support whatever decision a donor makes at whatever point in this process.

Before the surgery

Living donor transplants at the University of Virginia are done on Thursdays. About a week or two before the scheduled surgery, both the donor and the recipient will come to the transplant clinic for a pre-operative visit. During this visit the donor will have a history and physical exam performed by a surgeon, receive pre-operative instructions, and have pre-operative blood drawn. Consent for the donation surgery will also be obtained at this clinic visit. You will also be evaluated in the Pre-Admissions Assessment Center where anesthesia screening will occur.

A nurse from the pre-operative area will contact you the evening before surgery to tell you what time to report to the hospital for your operation. You will not actually be admitted to the hospital until the morning of the surgery. If you live far away and want to stay in Charlottesville prior to surgery let us know and we can help you find accommodations.

It is important not to eat or drink after midnight the night before your surgery. If there are medicines that you take each day, you will be instructed of which one(s) to take and not to take on the day of surgery. You should avoid taking aspirin or medicines that contain aspirin for 10 days prior to your surgery, unless directed to do so by your physician.

The Surgical Experience

The day of surgery you and the recipient will be instructed to present to the Surgical Family Waiting Room on the first floor of the main hospital. Any family members and friends who accompany you to the hospital can wait in this waiting room where the doctors will speak to them after your surgery is complete. The donor and recipient will then go to the Surgical Admission Suite to prepare for surgery. The staff in the surgical admission suite will start an intravenous (IV) line through which medications will be given to you during surgery. You will then be taken to the operating room where the anesthesiologist will give you a medication through your IV line to put you to sleep. You will be under general anesthesia throughout the entire operation and a member of the surgical team will be at your side at all times.

A living donor liver transplant actually involves two overlapping surgeries between the healthy donor and the recipient. The operating rooms are side-by-side. A portion of the donor liver, usually the right lobe, is removed with its blood supply intact in one operating room while the recipient's diseased liver is removed in its entirety in another operating room. The healthy portion of the donor liver is then sewn into place in the recipient. During the donor's surgery, the gallbladder is also typically removed as part of this procedure.

The donor operation usually takes between 6 and 8 hours.

You will wake up in the Recovery Room where your blood pressure and other vital signs will be closely monitored by the nursing staff. You will feel very groggy and may have some discomfort. A catheter will be draining urine from your bladder and frequent urinary output measurements will be taken.

Once you are sufficiently awake and your vital signs are stable, you will be transferred to 5 West, the in-patient Transplant Unit. Your family members may visit with you. The IV will remain in place until you are able to take in fluids and food by mouth. Medicine for pain will be available when you need it. You will have sequential compression devices on your legs to prevent blood clots in your legs. Also upon awakening you will be asked to take deep breaths, and to cough and turn to help keep your lungs free from infections. Once able, you will be encouraged to get out of bed, usually on the evening of surgery or the following morning. During your hospital stay, you will be encouraged to move around as much as possible. You may have some discomfort the first couple of days, which is completely normal. You will remain in the hospital for approximately seven days and will be given an appointment to follow up in the Transplant clinic before you go home.

The Recovery Process and Follow Up After Discharge

You should anticipate being out of work for 6 to 8 weeks after your surgery to allow your body time to continue healing itself properly. This will depend on your individual recovery as well as the type of work you do. Lifting will be restricted to no more than 10 pounds for the first two weeks following surgery, and then can gradually be increased as you heal. Walking will be advised and you will be encouraged to slowly increase the amount of walking each week.

You will need to come back to the Transplant Clinic approximately 3-4 weeks after your discharge for a physical exam and blood work to monitor how your body is adjusting after the surgery. Because of its amazing capacity to regenerate, the liver is restored to its original size in the donor, and grows to a comparable size in the recipient, in approximately 12 weeks.

You should notify each of your local health care providers of any problems that develop once you are discharged home, and they should be given the number to the Transplant Office in the event they need to contact us to discuss a problem related to your surgery.

When to Notify the Transplant Office:

It is important that you notify your Transplant Nurse Coordinator if you develop any of the following symptoms once you have been discharged home:

- Fever of 100.5 or greater,
- Shortness of breath,
- Cough that produces a yellowish or greenish substance,
- Prolonged nausea,
- Vomiting or diarrhea,
- Persistent or worsening pain,
- Drainage, redness or swelling at the incision site,
- Unusual lightheadedness or weakness,
- Any emergency room treatment or hospitalization

Frequently Asked Questions

Is every patient in need of a liver transplant a candidate for receiving a liver from a living donor?

Not every patient on the liver transplant waiting list is a candidate to receive a liver from a living donor. As liver disease progresses, and the recipient becomes more ill, it becomes more likely that he/she will require a whole liver for transplant. A whole liver can only come from a deceased donor. If a recipient qualifies for a living donor liver transplant, the transplant team will encourage that as an option and provide the necessary information.

Who pays for the evaluation and surgery?

The costs of the evaluation and surgery for donors are covered by the recipient's insurance company. Costs that are *not* covered include, but are not limited to, loss of salary due to time off from work, hotel and transportation costs, and personal expenses. Donors should explore their employer's sick leave policy, since they will not be able to return to work for approximately six to eight weeks. If you have financial concerns you should discuss these issues with the Transplant Team prior to donation. It is the responsibility of the potential donor to make the Transplant Program aware of any financial concerns prior to the surgery date.

Will I have much pain after this surgery?

It is common and expected for donors to experience some mild pain and discomfort after the surgery, which may persist for several weeks. Pain medications will be made available to you during your hospitalization to keep you as comfortable as possible. Pain medication does not always take away all of the pain, but you should feel comfortable. It is important to let your doctors

and nurses know if your pain is not well-controlled or is worsening over time. You will be given a prescription for pain medication to take by mouth once you are discharged from the hospital as well.

How will this surgery affect my lifestyle?

Because of the unique ability for the liver to regenerate (grow back), it will return to its original size in approximately 12 weeks. The transplant team will recommend to you that you avoid alcoholic beverages for the first several months up to a year, following liver donation surgery. After recovery, which is typically 6 to 8 weeks, you can work, drive, exercise and participate in sports as usual. You can continue all types of occupations, including military duty. There is also no evidence to suggest that female donors suffer any effect on their ability to become pregnant or bear children.

What if I change my mind about having this surgery?

A potential donor should never feel pressure to donate. At any point in the evaluation process, you have the option to change your mind. Even if you get through the entire donor evaluation, you still have the opportunity to change your mind. You can put a stop to the surgery up until the point you are put to sleep in the operating room! The transplant team will support whatever decision you make, at whatever time you make it.

****Thank you for taking the time to carefully read the information in this handbook. Please contact our office with any questions you might have about living liver donation and/or if you wish to be evaluated as a donor.****

Patient Rights and Responsibilities

The University of Virginia Health System is committed to providing an environment, which fosters quality health care for its patients as described below. Employees are expected to assist patients in understanding and exercising their rights. Likewise, patients are expected to understand their responsibilities to their caregivers and other individuals attempting to provide services to them.

Patient Rights

- The UVa Health System is dedicated to giving you the best health care and service possible. As a patient here, you may expect to receive considerate and respectful care. We will honor your rights to be informed and to be involved in making decisions about your care. You have the following rights as a competent adult patient:
- You have the right to know about your illness and proposed treatment and to participate in the development of your plan of care. Information will be given to you by your doctors and other members of your health care team in language you can understand.
- You have the right to make decisions about your care, including the right to know why you need an operation or treatment and who will perform that operation or treatment. This includes the right to refuse care or treatment and to know what may happen if you do not have this care or treatment.
- You have the right to develop Advance Directives and to have hospital staff comply with those directives.
- You have the right to access all information contained in your medical record. This includes the right to know the name of the doctor who is in charge of your care and the names of all other Health System staff taking care of you.
- You have the right to have a family member or representative and your own physician notified promptly of your admission to the hospital.
- You have the right to receive treatment in a safe, abuse-free environment without discrimination as to race, color, religion, sex, national origin, disability, sexual orientation, or source of payment.
- You have the right to personal privacy while in the hospital and to have all information about your illness and care treated as confidential.
- You have the right to be free from restraints of any form that are not medically indicated.
- You have the right to receive appropriate assessment and management of pain.
- You have the right to agree or refuse to take part in any study or experiment related to your care or treatment.
- You have the right to review your bills and have any questions you have about them answered.
- You have the right to discuss your concerns or file a complaint with the hospital's Patient Representative Office regarding your experience as a patient of the Health System and to receive a response in a timely manner. You also have the right to an internal appeal to any response that you receive and a right to file a complaint with an external agency.

Patient Responsibilities

In order to receive optimal care, you and your family are responsible for:

- Providing accurate information about your present illness and past medical history and wishes for your medical care.

- Seeking clarification when necessary to fully understand your health problems and the proposed plan of care.
- Following through on your agreed plan of care.
- Considering and respecting the rights of others.
- Being courteous.
- Providing accurate information for insurance claims and working with the Health System to make payment arrangements when necessary so that others can benefit from the services provided here.
- Following visitation policies of University Hospital.
- Following the rules and regulations of the Health System and of the Commonwealth of Virginia which forbid:
 - Engaging in verbal or physical abuse,
 - Using alcohol or illegal substances,
 - Carrying weapons of any kind.