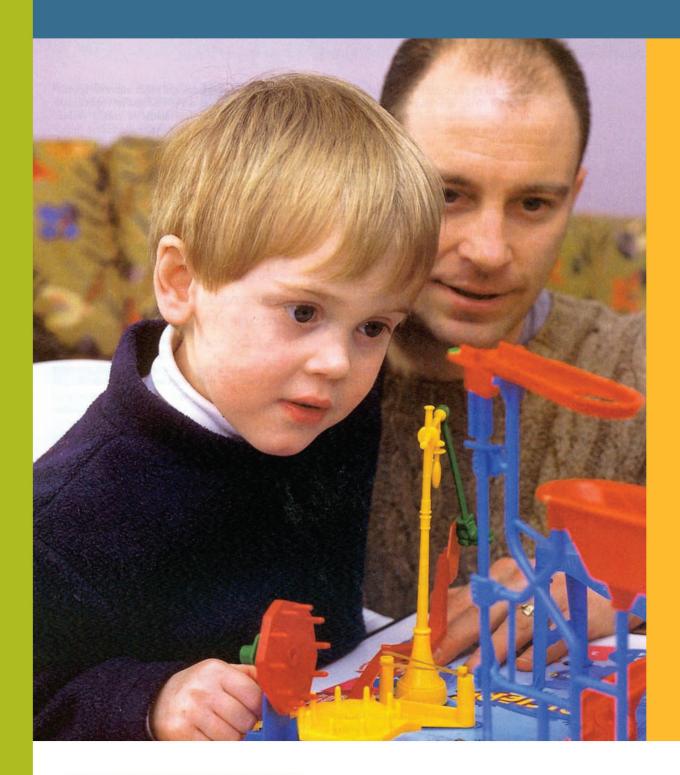
Multi-Organ Transplant Program Living Liver Donation





Patient Handbook

Multi-Organ Transplant Program

Living Liver Donation Program

This handbook provides information about the Living Liver Donation Program at London Health Sciences Centre.

Living liver donation offers an additional option to help patients with liver failure. This booklet will give you information about the risks and benefits of living donation as well as an overview of assessment, surgery and recovery.



Living Liver Donation Program, London Health Sciences Centre 339 Windermere Road, London, Ontario, N6A 5A5 Phone 519-685-8500 · Fax 519-663-3858

Cover photo: Matthew donated part of his liver to his son, Curtis. (Photo by Mone Cheng)

Revised 2014, London Health Sciences Centre

Contents

Overview	Page 1
Deciding to Donate	Page 2
Where to Start?	Page 4
Possible Reasons for being Declined	Page 5
Donor Assessment	Page 6
Surgical Process	Page 8
Recovery after Transplant	Page 9

Appendix 1: Contacting the Transplant Team

Overview

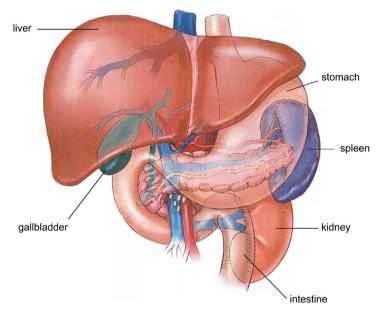
Liver transplantation is an effective treatment for many patients with life-threatening liver failure. Unfortunately, the number of people who could benefit from this procedure exceeds the number of deceased donors, and some people with liver disease die before a donor becomes available. Patients often wait for several years for a transplant and can become very ill by the time a suitable donor is located. Since 1989, many transplant programs have utilized living donors as an additional option to help patients with liver failure.

This booklet will give you information about the risks and benefits of living liver donation, and an overview of the assessment, surgery and recovery.

What does the liver do?

The liver is the largest organ in your body and is located on the right side of your abdomen under the ribcage. A healthy liver provides these functions:

- produces bile to metabolize food and makes protein to build muscles
- processes drugs and toxins so they can be eliminated from your body
- \cdot helps regulate blood sugar
- participates in balancing fluids in the body



Why does the liver fail, and what are some symptoms?

Liver failure may result from dozens of diseases that cause damage to the liver over time. Also, the liver can be affected by viruses such as hepatitis B and C, and by ingesting a large quantity of medications or alcohol.

Patients with liver disease may have jaundice, muscle wasting, life-threatening bleeding, confusion and coma, itch, low blood sugar, and a build-up of fluid in the abdomen, legs or chest. There are some medications and treatments that can help with these symptoms, but a transplant is the only way to permanently address these symptoms if someone has worsening liver failure.



Deciding to Donate

Things to consider before volunteering to donate

The surgery to remove part of your liver is a serious operation with a number of risks. You will be required to undergo numerous tests to ensure that you are healthy and that your liver is large enough to support the recipient and yourself. During the course of the assessment, it is possible that we could discover that you have a serious illness, such as cancer or hepatitis. Although we would ensure that you get the medical care you require, this diagnosis may impact your ability to get insurance or a mortgage. On a positive note, in the unlikely event that we find you have a medical problem, these tests may lead to early treatment of the illness and be very beneficial to your health.

Liver donors need to come to London for part of the assessment. After the surgery, they remain in hospital for six to ten days and are required to stay in town for two weeks after they leave the hospital. Donors are off work for three to four months, and are not able to drive a car for four to six weeks or lift more than ten pounds for at least two months.

Costs and non-medical issues involved in transplantation

Organ donors are not paid for giving a portion of their liver. There will be some additional expenses because of the trips to London for the assessment and surgery. Also, donors are unable to work while recovering from surgery. The Ontario and Manitoba governments have recently passed legislation to partially reimburse donors for some of the expenses associated with having this surgery.

People considering liver donation should think about getting life insurance prior to donating because it may be more expensive and difficult to get after the surgery. Anyone undergoing major surgery is also encouraged to consider making out a will and power of attorney prior to the operation. The cost of housing and travel to London are the responsibility of the donor. With a scheduled surgery date, Air Ambulance is not required so you will need to pay for your airfare or other transportation costs to London.

Benefits of living donation

Living donation may prevent the death of the person with liver disease and significantly reduces the time on the waiting list and the likelihood that the recipient's condition will deteriorate. Since the donor and recipient will be in the same city, the donated piece of liver will be transplanted immediately. This lowers the chances of complications, which can result when liver tissue is cut off from its blood supply. Finally, living donation is scheduled ahead of time, and therefore everyone involved knows when the surgery will take place. It is important to note that living donation is not usually considered in emergency situations. Patients with rapid decline (fulminant liver failure) require urgent transplants and this does not allow adequate time for living donors to be assessed or to consider the risks.

Risks of living donation

Any type of surgery has some risk, but the donation of part of the liver is a major operation with several risks. The donor may develop problems with bleeding, infection, blood clots, or bile leaks from the cut edge of the liver. Liver donors may experience an adverse reaction to the anesthetic. They will have some pain during the recovery phase, although every effort will be made to control the pain. The risk that a donor might have a minor complication is approximately 15%, and the possibility of dying as a result of this surgery is less than 1%.

It is important for anyone who is considering liver donation to know that several living liver donors from around the world have died from postoperative complications. Fortunately, there have been no deaths amongst Canadians who have donated. Also, several donors in other countries have required a transplant after donation because too much liver tissue was removed. Finally, liver transplantation has an 80% success rate, and living donation does not guarantee that the recipient will do well.

Risks to the recipient

The recipient who is given a partial liver may risk developing bleeding, infection, blood clots and bile leaks from the cut edge of the liver. Also, the fact that the donor is a relative does not reduce the risk of organ rejection. Having said that, however, the partial liver that the recipient receives from you should begin to grow to normal size, and be capable of performing all liver functions.

Where to Start?

If you are interested in being a living liver donor, please contact the Recipient Coordinator who is working with your family member or friend. (Contact information is provided in Appendix 1.) Because of the amount of work involved in assessing potential donors, we are only able to evaluate two people at a time. If there are several people interested in donating, please discuss with your family and decide which two people are in the best situation to donate.

The Coordinator will ask the potential donor some general information about his or her health and can arrange for the initial blood tests. People who are considering liver donation are asked not to drink alcohol or use marijuana or narcotics as these substances may injure their liver.

Who can donate?

A living donor is a relative or friend who has the following characteristics:

- · compatible blood type with the recipient (see the table below)
- · between 18-55 years old
- large enough to donate sufficient liver tissue (approximately as tall as the recipient, or taller)
- excellent physical and psychological health
- within 8-13 kilograms (20-30 pounds) of their ideal weight. People who are quite overweight may have a fatty liver, which is not suitable for donation.

If you have blood type:	You can donate to someone with blood type:
0	O, A, B, or AB
A	A or AB
В	B or AB
AB	АВ

Liver Donation Handbook



Reasons why you may be declined as a liver donor

As a potential donor, you will need to have a number of medical tests as outlined in the donor assessment section. Following these tests, you might not be able to donate a portion of your liver if...

- Your blood type is not compatible with the recipient's blood type.
- Your liver is too small to give enough tissue to the recipient, while ensuring that you are left with an adequate liver mass.
- There are technical concerns, such as an unusual blood supply or bile system in your liver. This is not a risk for you, but this can make it very difficult to connect a piece of your liver with the recipient's anatomy.
- Abnormal test results, such as heart tests, that indicate you would be at an unacceptable risk during the operation.
- · Your alcohol or narcotic use is excessive.
- · Donating would jeopardize your psychological well-being.



In order to minimize the risk to both the donor and recipient, several tests will be done to ensure that the donor is healthy and has a compatible liver. Some tests can be done at your local healthcare centre or hospital, but you will still need to come to London. Depending on what tests you need, all attempts will be made to organize them over three to five consecutive days while you are in London.

The results of the donor's tests will only be given to the donor and are not revealed to the transplant patient. Please call the Coordinator once your blood work has been done so that those results can be forwarded to the transplant team.

Blood Tests: Several vials of blood are taken from the donor to check the blood type and how well the liver is functioning. We also want to ensure that the donor does not have a serious infection that could be passed on to the recipient.

Ultrasound: This is a painless scan to look at the donor's liver and the blood vessels that supply the liver. An ultrasound is usually completed in less than 30 minutes.

Echocardiogram: This is an ultrasound of your heart that shows how well your heart is pumping. The test is completed within 30 to 45 minutes.

Stress Test: Potential donors over 50 and any donor with a family history of heart disease may be required to undergo this test to examine how their heart responds to stress. A medication is given during the test to see how the heart reacts, and this helps to determine if it is safe to undergo surgery.

Physical Health: All potential donors must have a physical examination to evaluate their health and ability to tolerate major surgery.

Volumetric CT Scan: This is a painless type of scan that gives more information about the size and shape of the liver and whether it is suitable for donation. Before the CT scan, you will be required to drink a dye solution and you will have an I.V. inserted to give more dye; however, the test itself takes only a few minutes. Rarely, an individual may be allergic to the dye and have an adverse reaction. If you or a family member has reacted to dye in the past, please inform the transplant team prior to the scan.

MRCP: Magnetic resonance cholangiopancreatography (MRCP) is a type of scan. It is a noninvasive technique that is used to evaluate the bile ducts in the liver. Because some of these bile ducts must be joined to those in the recipient, it is necessary to review the anatomy before surgery. The MRCP takes approximately 30 minutes.

Liver Biopsy: If there is any concern about the suitability of your liver, a liver biopsy may be required. This involves inserting a needle through your right side to obtain a small piece of the liver. You would be required to remain in the hospital for several hours to make sure you have no bleeding after the test.

Psychological Health: All potential donors are interviewed in private to ensure that they understand the risks of liver donation, are making a decision without coercion, and are aware of their right to refuse to be a donor. Donors should discuss their intentions with all family members and individuals who will be affected by their decision.

Consultations: During the course of your assessment, you will meet with the Transplant Recipient Coordinator, Social Worker, Physician and Surgeons. These appointments are necessary to review your health history, to educate you on what to expect with the surgery, and to answer all of your questions.

How long does it take to be assessed and to book a date for the surgery?

The assessment is usually completed within four to eight weeks. At that point, the surgery can be booked although it may be a few weeks before the surgery date is finalized. We will do our best to book the assessment in a convenient manner and consider your wishes about when you would prefer to have the operation.

What if you decide not to donate?

The decision to offer part of your liver to someone is very difficult and is not appropriate for everyone. After learning about the risks involved in living donation you may decide that you would prefer not to be an organ donor. In that case, the transplant team can let the patient know that you are not a suitable donor for medical reasons. Your assessment for organ donation is strictly confidential and no private information will be revealed to anyone, including the transplant patient. Even if you decide to proceed with the surgery, you are free to change your mind at any time; the patient will remain on the waiting list for a deceased donor until the day of the surgery.



Surgical preparation

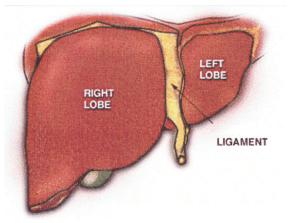
Both the recipient and donor are seen at London Health Sciences Centre a few days before the surgery. This final visit is necessary to re-check blood tests, review your health and sign the surgical consent form. This is done in the Pre-Admission Clinic and is also an opportunity to speak with an anesthetist regarding your surgery and post-op pain management. You will be given instructions for the day of your surgery and will likely be in the pre-admit clinic for a couple of hours.

Day of surgery

Both the donor and recipient must not eat or drink anything after midnight. You will be advised to register at the Surgical Preparation Unit at 6:00 a.m. and will be checked to ensure that you are fit for surgery. Your surgery could be cancelled if there was a concern about your health or, rarely, if there was an emergency or unscheduled transplant with another patient.

Surgical procedure

The removal of a portion of your liver is called a partial hepatectomy. The left lobe of the liver may provide sufficient tissue if the recipient is a child or small adult. In most cases if the recipient is an adult, the right lobe is removed for transplant.



A large incision is made in the donor's abdomen to remove a piece of the liver. The surgery lasts between four to six hours, and afterwards the surgeon will close the incision line with sutures, which will be removed about ten to fourteen days later.

Immediately after the operation, a surgeon will speak to the family to discuss the surgery, and the donor will go to the Post-Anesthetic Care Unit (Recovery Room – 2nd floor) for a few hours. Once the donor is awake and in stable condition, he or she will be transferred to the Transplant Unit (4th floor) or the Surgical Ward (8th floor) and can have visitors at that time.



Recovery after Transplant

Most donors remain in hospital between six and ten days. During that time, many patients elect to manage their pain with a pump that allows them some control in when the medication is delivered. This patient-controlled analgesia (PCA) pump can be used in combination with anti-nausea medication to ensure your comfort. You will be given pain medication on a regular basis and may need this medication for two or three weeks.

The day after your surgery, you will be getting out of bed, participating in a physiotherapy program and will gradually become more active and regain your strength. You will have a tube in your nose that goes into your stomach to prevent vomiting. You will also have a drain in your abdomen for as little as five days or possibly for as long as two weeks. This will allow excess fluid to escape from around your liver. A urine catheter is inserted during the surgery and stays in place until you can get up to the bathroom. Blood tests will be done every day while you are in hospital to monitor your liver function.

It is very beneficial for donors to have a friend or family member with them while they are recovering in London. Although you will be able to walk and care for yourself, you will need help with meal preparation and some activities while you regain your strength.

Follow-up care

After you are discharged from hospital, you are asked to stay in London for two weeks to ensure that your incision is healing well and that your liver function has returned to normal. You will continue to have blood drawn until your liver tests are normal. You will also need to have an ultrasound at least twice to make sure that your recovery is going well. A letter will be sent to your family doctor so that they are aware of surgery and can arrange for any further care, if necessary.

You should not drive a car for at least four to six weeks after the surgery because of the effects of pain medication and the fatigue that is normal after the operation. Living donors usually can return to work three to four months after their surgery.

The liver tissue that has been removed will grow back (regenerate) within a few months and no long-term problems are anticipated.



Contacting the Transplant Team

If you have any questions about liver donation or would like to be assessed for donation, please contact the Recipient Coordinator who is working with your family member or friend. The assessment will not begin until the person interested in donating contacts the Coordinator directly.

To contact the Recipient Coordinator, please call or e-mail:

Sandy Williams – phone 519-663-3933 E-mail address – sandy.williams@lhsc.on.ca

Grant Fisher - phone 519-663-3760 E-mail address - grant.fisher@lhsc.on.ca

To reach the Social Worker, please contact:

Kelly Thomas - 519-685-8500 ext. 32484 E-mail address - kelly.thomas@lhsc.on.ca

Multi-Organ Transplant Program's website:

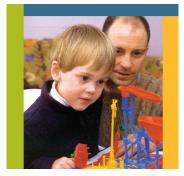
www.lhsc.on.ca/transplant











Living Liver Donation