

Living Liver Donation Information Package

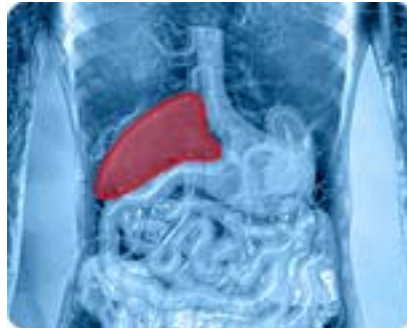
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What Does The Liver Do?

The liver carries out many functions and damage to it can affect every major organ in the body. Liver impairment can affect the body's ability to absorb life-enhancing vitamins and nutrients, prevent waste products from being effectively eliminated and reduces the production of proteins. When the liver is damaged, energy levels plummet, the blood loses its ability to clot, concentration becomes poor and heart and lung function deteriorate.



Although the liver often can recover from injury, extensive disease throughout the entire organ sometimes makes this impossible. When 80-90% of liver function is lost, a liver transplant is the only treatment option. Liver failure can happen suddenly or slowly, over many years.

There are many types of disease which preclude the liver from healing itself and which progress to end-stage liver disease. Basically, these diseases can be grouped into four categories:

- Diseases which directly affect liver cells, such as viral hepatitis, Wilson's disease and hemochromatosis;
- Diseases which produce changes in the structure of the liver; examples include cirrhosis and polycystic liver disease;
- Diseases which affect the blood supply to the liver, including portal hypertension and congenital fibrotic disease; and
- Diseases that interfere with the blood supply from the liver, such as Budd Chiari syndrome.

For more information on liver disease visit the Canadian Liver Foundation's website at: www.liver.ca

About Living Liver Donation

Living donor liver transplantation, made possible by the unique ability of the liver to regenerate within 6-8 weeks, is a life saving procedure.

Success with living kidney donation, coupled with the chronic shortage of organs and long waiting times for pediatric patients with end-stage liver disease, stimulated the development of living donor liver transplantation. In 1989, the first living donor liver transplant was performed in the U.S. between a mother and her child, who had irreversible liver damage. Since that time, thousands of children and adults have received living donor liver transplants, with outcomes comparable to deceased donation.

Preliminary results with adult-to-adult living donor liver transplantation, in which either a full right side or full left side of the liver from a healthy adult is transplanted into another adult, are also very encouraging. It is important to note that only these people with irreversible liver failure, in who all other medical or surgical treatments have failed, qualify as candidates for a liver transplant. The prevalence of the hepatitis C virus, which can lead to irreversible liver damage, along with the chronic shortage of deceased donors has resulted in long wait times for those in need of a transplant.

Advantages of Living Liver Donation

Living liver organ donation provides those waiting for liver transplantation with many advantages over deceased organ donation. These include:

Shortened waiting times:

The length of time it takes for an organ to become available is significantly reduced when the organ comes from a living donor versus a deceased donor. Depending on their condition, diagnosis, status, blood type and size, patients can be on the waiting list for months or even years. Many patients will die while waiting for a deceased donor organ. Should a relative or loved one meet the criteria for living liver donation, the wait time and risk of death while on the waiting list can be reduced.

Healthier donor organ:

Living donors tend to be young, healthy adults who have undergone a thorough medical evaluation. As a result, the liver from a living donor is usually healthier than a liver from a deceased donor.

Surgery can be scheduled electively:

With living donor liver transplantation, it is possible for the recipient to have surgery earlier. This increases the chances for a quicker recovery. In addition, the time between recovering the liver and transplanting it is minimized to minutes instead of hours as with a deceased donation transplant, something that is critical to the preservation of the donor organ.

A feeling of satisfaction:

For a living donor, knowing that he or she has made a contribution to the improved health of another individual is a very positive psychological experience.

Who Can Donate?

Selecting the right donor for a living donor liver transplant requires experience, skill and technical expertise on the part of the many doctors, nurses and other healthcare professionals who make up the liver transplant team. As a result, adult living donor liver transplantation is considered one of the most challenging procedures in modern medicine.

Potential living liver donors are carefully evaluated. Only those individuals who can donate a portion of liver that will likely function immediately are selected. Since the health and safety of the donor is of paramount concern during the evaluation, only those donors for whom a risk of death is less than 0.5% are considered.

A potential donor must:

- Be in good overall health and physical condition
- Be older than 18 years of age and younger than 60 years of age
- Have a liver that is the right size for the recipient
- Have a blood type compatible with the recipient
- Have a near normal body weight (body mass index less than 35)

A potential donor must be free from:

- HIV infection
- Known viral hepatitis
- Active alcoholism with frequent and heavy alcohol intake
- Psychiatric illness
- A history of cancer
- Heart and lung disease requiring medication
- Diabetes
- A history of previous liver surgery

The Evaluation Process

In most cases, the amount of time required to fully assess a potential living liver donor's health status and compatibility with the recipient is 4-8 weeks. In special circumstances however, such as rapid deterioration of the health of the recipient, this process may take place in as little as 48 hours.

Blood Type Matching

The first step in the evaluation process is to determine whether or not the living donor has a blood type that is compatible with the recipient. There are four blood types. The following blood types are compatible:

Donor	Recipient
O	O, A, B, AB
A, O	A
B, O	B
AB, O, A, B	AB

Note: The Rh factor may be positive or negative.

Liver Function Testing

If the potential donor's blood type is compatible, further blood tests are carried out to make sure the potential donor's liver is functioning well. In addition, thyroid and kidney function are evaluated. Blood tests are also used to screen for exposure to transmissible viruses such as hepatitis and HIV, to assess immune system function, to look for evidence of cancer, and for other potential causes of liver failure.

Overall Health Assessment

A complete physical examination with a liver specialist or "hepatologist" is used to assess a potential donor's overall health status as well as family medical history. A chest X-ray and EKG may be ordered as well as a hepatic angiogram that involves injecting a dye through a vein in the groin to test arterial blood flow and determine whether or not the anatomy of the blood vessels around the liver will permit surgeons to safely remove a segment of it. A liver biopsy may also be performed to further determine the health of the potential donor organ.

Imaging Studies: Computerized Tomography, Abdominal Ultrasound, and Magnetic Resonance Imaging

These non-invasive imaging studies are conducted to rule out abnormalities of the liver and other abdominal organs.

Mental and Emotional Health Assessment

A social worker and a psychiatrist working with the liver transplant team to determine the potential donor's feelings and concerns carry out this consultation.

Additional Testing

In some cases, other tests may be required to determine heart and lung function. These might include pulmonary function testing, an echocardiogram or an exercise stress test.

Risks Involved

The transplant team will describe the general risks, benefits, special risks, and alternatives to living donation and also provide a detailed summary of their specific experience and results.

Left lateral segment liver donation (adults to children) is less risky than right lobe donation because a smaller volume of liver tissue is removed (30% versus 60-70%).

For the living liver donor, there are some risks involved, as there would be with any surgery requiring general anesthesia. These include:

- Heart complications
- Stroke
- Blood clot formation in the legs or lungs
- Bleeding or infection

While the risk of severe complications with living liver donation is minimal, risks specific to this procedure include:

- Small bile leaks from the remaining portion of the liver
- Incisional hernia
- Gastrointestinal upset such as constipation, indigestion, nausea or diarrhea
- A temporary yellow color to the eyes and skin (jaundice)
- Temporary numbness in the arm
- Psychological trauma should the transplant fail
- Failure of the remaining portion of the liver
- Death (0.2-0.5% risk)

Living liver donor surgery is still relatively new so there may be long-term risks that are not yet known. However, studies indicate that a donor's liver mass returns to near normal within 12 months after surgery (most of this growth occurs within weeks of surgery).

Making the Decision

The decision about whether or not to become a living liver donor is a complex one and it is important that you discuss it with the transplant team, a living donation coordinator, as well as with the recipient and the families involved.

The transplant team determines whether or not you are mentally, emotionally and physically fit to become a donor but ultimately, the final decision rests with you. The good news is that the evaluation process takes place in stages, leaving time between appointments for a donor to discuss any questions or concerns as they arise.

If at any time you decide that donating is not for you, you should inform your contact on the transplant team right away. Even after a potential donor is accepted for living liver organ donation and surgery is scheduled, he or she has the option of opting out as a living donor at any time right up until the day of surgery.

Making the decision to become a living liver transplant donor is difficult and must be considered very carefully. However, living liver transplant donors say the experience was one of the most rewarding they have ever had.

Surgery

During the donor's surgery, which typically requires 8-10 hours to complete, a segment of the donor liver is removed through an incision that is either straight up and down or in the shape of an inverted 'T'. In most cases, the gallbladder is also removed.

Two surgical teams perform the donor and recipient operations simultaneously, with the donor surgery beginning 2-3 hours before the recipient surgery. The donor liver is carefully divided into the right and left lobe, making sure there is no damage to the remaining section. Often, the right lobe of the liver, which is slightly larger than the left lobe and comprises about 60% of the total volume of the liver, is the portion that is transplanted. Once separated, it is transplanted immediately into the recipient. This quick delivery of the liver graft ensures that the amount of time it is without circulating blood is minimized. This in turn increases the chances that the liver graft will function optimally right after transplantation. The donor's incision is then closed with either self-absorbing sutures or staples, which are later removed during a follow-up visit.

Following surgery, most living liver transplant donors spend their first night in the surgical intensive care unit where they are closely monitored. The next day, they can be transferred to a general surgical floor with specialized nursing staff. There, donors are encouraged to get out of bed and sit in a chair the day following surgery. Walking the hospital corridor is also encouraged as soon as possible to prevent the formation of blood clots.

Most donors are in the hospital for 5-10 days and experience pain and discomfort for about 4 – 6 weeks after surgery, particularly during the first week. A living liver transplant donor needs time to rest and recover from surgery and it is recommended that 8-10 weeks be allowed for this before returning to work. Light duty is also recommended for the first two weeks after surgery and strenuous activity and heavy lifting should be avoided for about 6-8 weeks. The donor may drive within 3-4 weeks. After 1-2 weeks, the donor goes back to the surgeon for a follow-up visit and lab work will be required at one month, three months, six months and then twelve months following surgery. After this, lab tests (blood and urine) will be required annually for the rest of the donor's life.

What to Expect After Living Liver Donation

Barring any post-operative complications, the living liver donor can expect to return to a completely normal life within 2-3 months of surgery and to remain healthy for the rest of his or her natural life. Since the procedure of living donor liver transplantation is fairly new, statistics on the long-term follow-up of donors who have undergone this surgery are not yet available.

The procedure is major surgery, so monitoring in the immediate post-operative period is very important. Ten days after surgery, a checkup is scheduled and staples are removed. There may be another check-up one month after surgery and then a final checkup at about three months during which a physical exam is conducted by a hepatologist, basic blood tests done and an ultrasound to check liver anatomy. After this, an annual physical exam by the primary care physician is recommended for all living liver donors.

Frequently Asked Questions About Living Liver Donation

What are the advantages of a living donor liver transplant?

Living liver organ donation provides those waiting for liver transplantation with many advantages over deceased organ donation. These include:

Less waiting

The length of time it takes for an organ to become available is significantly reduced when the organ comes from a living donor versus a deceased donor. Depending on their condition, diagnosis, status, blood type and size, patients can be on the waiting listing for months or even years. If a relative or loved one meets the criteria for living donation, the wait time can be reduced.

Healthier donor organ

Living donors tend to be healthy adults who undergo a thorough medical evaluation. As a result, the liver from a living donor may be healthier than an organ from a deceased donor.

Surgery can be scheduled electively

With living donor liver transplantation, it is possible for the recipient to have surgery earlier. This decreases the risk of complications during the early post-transplant period and increases the chances for a better result overall. It also decreases the chance of the recipient becoming too sick and too weak to qualify for surgery. In addition, the time between recovering the liver and transplanting it is minimized to minutes instead of hours, something that is critical to the preservation of the donor organ.

A feeling of satisfaction

For a living donor, knowing that he or she has made a contribution to the improved health of another individual is a very positive psychological experience.

How much of the donor's liver is removed?

About 30% of the liver is removed for an adult to child donation and about 60-70% for adult to adult donation. The liver can be divided into two distinct lobes which can function independently of each other. The right lobe, which is slightly larger than the left, comprises about 60-70% of the total liver volume and is the lobe most often removed for transplant purposes. The left lobe, which is slightly smaller than the right, comprises about 30-40% of the total liver volume. When the recipient is a small child, a piece of the donor's left lobe called the left lateral segment is usually removed.

How much time passes between removing the piece of liver from the donor and transplanting it into the recipient?

Both the donor and the recipient undergo surgery simultaneously (although the donor's procedure begins about three hours earlier than the recipient's) so that the donor organ can be transplanted immediately into the recipient. This minimizes the length of time that the liver is without circulating blood, ensuring a healthier, better functioning donor organ for transplant.

Can I be a living liver donor?

Potential living liver donors are carefully evaluated. Only those individuals who can donate a portion of liver that will function immediately are selected. Since the health and safety of the donor is of paramount concern during the evaluation, only those donors for whom a risk of death is less than 1% are considered.

A potential donor must:

- Be in good overall health and physical condition
- Be older than 18 years of age and younger than 60 years of age
- Have a liver that is the right size for the recipient
- Have a blood type compatible with the recipient
- Be a blood relative or have a close emotional bond with the recipient.

A potential donor must be free from:

- HIV infection
- Known viral hepatitis
- Active alcoholism with frequent and heavy alcohol intake
- Psychiatric illness
- A history of cancer
- Heart and lung disease requiring medication
- Diabetes

Do I need to be related to the recipient?

No. You do not need to be a blood relative of the recipient in order to qualify as a potential donor. A spouse or a friend is often a living donor.

If I am related to the recipient, will he or she have less rejection?

Studies indicate that the risk of rejection between a donor and a recipient who are related is no less than for non-related donors and recipients. What's more, the amount of anti-rejection medication needed doesn't seem to be affected by the relationship between the donor and recipient. On the other hand, if the donor and recipient are identical twins it could be expected to have a very positive impact on the success of transplantation and possibly a reduction in the risk of complications following surgery.

What is the evaluation process all about?

The evaluation process ensures that the donor's liver is healthy and of adequate size to meet the needs of the recipient. It is also conducted to make sure that a potential donor is free from any medical or psychiatric illness which could make the procedure more risky or difficult as well as any diseases which could be transmitted to the recipient. Finally, the evaluation process ensures that the donor is making the decision freely, without pressure or coercion.

Will my recipient be removed from the transplant waiting list if I am evaluated?

No. The recipient remains on the waiting list during potential living donor evaluation. Should the potential donor not be able to donate, the recipient still has the same priority status on the waiting list.

How quickly will I know if I can be a living liver donor?

The evaluation time varies. Completely healthy donors may be notified as soon as several weeks after all the various tests, evaluations and consultations have been completed. The evaluation may take longer if issues are identified during the work-up.

Who makes the final decision as to whether or not I can be a living liver donor?

The decision about whether or not any particular donor qualifies is made collectively by the transplant team, which is made up of physicians, surgeons, nurse coordinators, social workers and others. The donor's safety is put ahead of every other factor in making this decision.

If I am cleared to be a living liver donor, who decides when to do the transplant?

This is a joint decision made by the transplant team, the donor and the recipient, based on the recipient's time of best health and the donor's schedule.

What are the possible complications of a living liver donor operation?

For the living donor, there are some risks involved as there would be with any surgery requiring general anesthesia. These include:

- Heart complications
- Stroke
- Blood clot formation in the legs or lungs
- Bleeding or infection

While the risk of severe complications is minimal with living liver donation, risks specific to this procedure include:

- Small bile leaks from the remaining portion of the liver
- Incisional hernia
- Gastrointestinal upset such as constipation, indigestion, nausea or diarrhea
- A temporary yellow color to the eyes and skin (jaundice)
- A temporary numbness in the arm
- Psychological trauma should the transplant fail
- Failure of the remaining portion of the liver
- Death (0.2 – 0.5% risk)

Will I require a blood transfusion during my surgery?

Although it is not routine during this type of surgery, sometimes it is necessary. In the event that this may be required, you will be asked to donate two units of your own blood 2-4 weeks before surgery.

Should I stop smoking before my surgery?

Even a light smoker should stop smoking before surgery. Heavy smokers are not eligible for living liver donation because of the additional risks that smoking creates.

Should I not drink alcohol?

If you are going to be a living liver donor, stop drinking alcohol. If you have a history of alcohol use, it is important that you share this information with someone on the transplant team. Although alcohol use may not preclude you from being a living liver donor, it could mean that you need to undergo a liver biopsy to make sure your liver has not sustained any damage.

Should I stop taking my medication before the evaluation or the surgery?

Do not stop taking any prescription medication unless your physician tells you to do so. That being said, you should avoid aspirin or non-steroidal medications such as Advil or Motrin for seven days prior to a liver biopsy or surgery. These medications affect the blood's clotting ability and increase the risk of bleeding complications. Women who are taking birth control pills or hormone replacement therapy will be advised to stop because of the increased risk of blood clot formation after surgery.

How long will I be off work?

At the very least, you will need 4-6 weeks to recover from surgery. Depending on the amount of pain and fatigue which you experience post-operatively – and everyone is different – you may need 8-12 weeks for a full recovery.

Will I have much pain after surgery?

For this kind of surgery, yes. Even with pain medication, you can expect to be in significant discomfort for at least a week or even two weeks.

Once the transplant is scheduled, will it definitely happen?

There are a number of things that can happen to delay or cancel a scheduled liver transplant procedure. First, the recipient's condition could deteriorate, making him or her a poor candidate for surgery. Second, the recipient could develop an infection or some other condition that would have to be treated before the surgery could be re-scheduled. On rare occasions, the sudden availability of a deceased organ may cause the living donor liver transplant to be canceled. Since a deceased organ donor transplant must take place within a very short time, it would have priority over the scheduled living liver transplant.

How long will I be in surgery?

About 8 - 10 hours.

Will I need to come back to the hospital for check-ups?

Yes, at ten days, one month, three months and then at one year. After this, you will be examined annually by your primary care physician.

Will I need to take any medication after I donate a part of my liver?

No, not unless you develop a wound infection. Otherwise, you would only require pain medication for a short period of time.

When will my sutures or staples be removed?

About 10 days after surgery.

How long before my liver grows back to normal size?

Most of the liver regenerates within the first two weeks after surgery and is back to near normal size by about three months.

Would I be able to donate my liver again in the future to someone else?

No. You can only be a living liver donor once.

Will I have a normal life after surgery?

Barring any post-operative complications, the living liver donor can expect to return to a completely normal life within three months of surgery and to remain healthy for the rest of his or her natural life. Since the procedure of living donor liver transplantation is fairly new statistics on the long-term follow-up of donors who have undergone this surgery are not yet available.

What are the emotional effects of living donation on the donor?

A living donor usually feels a sense of accomplishment but donors must be prepared for the possibility of recipient death. If this were to happen, it is natural to feel very sad and disappointed but most living donors also have the peace of mind that they did everything possible to help someone they care about.

For more information contact the Trillium Gift of Life Living Donation Advisor at 416-363-4001 or 1-800-263-2833.

GLOSSARY OF TERMS

Abdominal ultrasound: A non-invasive test that uses high-frequency sound waves to create a picture of the internal organs of the abdomen including the liver, gallbladder, spleen and pancreas. The blood vessels to some of these organs can also be evaluated using this test.

Source: *Medline Plus Medical Encyclopedia*

<http://www.nlm.nih.gov/medlineplus/ency/article/003777.htm#Definition>

Budd Chiari Syndrome: A rare disorder characterized by narrowing and obstruction (occlusion) of the veins of the liver (hepatic veins). In most cases, the exact cause of Budd-Chiari syndrome is unknown.

Source: *WebMD* http://my.webmd.com/hw/health_guide_atoz/nord583.asp

Cirrhosis: A disease in which scar tissue replaces normal, healthy tissue in the liver, blocking the flow of blood through the organ and preventing it from working as it should.

Source: *National Digestive Diseases information clearinghouse (NDDIC)*

<http://digestive.niddk.nih.gov/ddiseases/pubs/cirrhosis/>

Hemochromatosis: A disorder of iron metabolism partially characterized by excessive absorption of ingested iron, particularly in the liver, pancreas, and skin. Cirrhosis of the liver, diabetes (bronze diabetes), bronze pigmentation of the skin, and eventually, heart failure may occur. Hemochromatosis can also result from administration of large amounts of iron orally, by injection, or in forms of blood transfusion therapy.

Source: *The Canadian Haemochromatosis Society* www.cdnhemochromatosis.ca/

Hepatic: Pertaining to the liver

Hepatologist: Medical specialist trained in diseases of the liver.

Incisional hernia: Protrusion of an organ or tissue through an incision that has not healed completely.

Source: *lifespan/Rhode Island Hospital and The Miriam Hospital.*

http://www.lifespan.org/mininvasive/revised/patient/Incis_hernia/about.htm

Jaundice: A temporary yellow color of the eyes and skin.

Liver graft: The portion of the liver used for transplantation, usually the right lobe.

Liver function: Ability of the largest organ of the body to remove or neutralize poisons from the blood; produce immune agents to control infection; remove germs and bacteria from the blood; make proteins that regulate blood clotting; and produce bile to help absorb fats and fat-soluble vitamins.

Living donor liver transplantation: A surgical procedure in which a portion of the donor's healthy liver is removed for transplantation into a recipient in need. A family

member, usually a parent, sibling or adult child or someone emotionally close such as a spouse, may volunteer to donate a portion of their healthy liver. This procedure is made possible by the liver's unique ability to regenerate. After transplantation, the partial livers of both the donor and recipient will grow and remodel to form complete organs. *Source: Columbia University Department of Surgery, New York, NY*
http://hora.cpmc.columbia.edu/dept/liverMD/tx_donor.html

Lobe: One of two distinct sections that make up the liver and which can function independently of each other. The right lobe, which is slightly larger than the left, makes up about 60% of the total liver volume and is the lobe most often removed for transplant purposes. The left lobe, which is slightly smaller than the right, comprises about 40% of the total liver volume.

Magnetic Resonance Imaging (MRI): A non-invasive procedure which uses powerful magnets and radio waves to construct pictures of the abdomen and its organs, allowing surgeons to map them in detail prior to surgery.

Source: Medline Plus

<http://www.nlm.nih.gov/medlineplus/ency/article/003796.htm#Definition>

Polycystic Liver Disease (PLD): An inherited disorder characterized by many cysts in the liver. Abdominal discomfort from swelling of the liver may occur however most affected individuals do not have any symptoms. In some cases, PLD appears to occur randomly with no apparent cause (sporadic). Other cases are thought to be inherited as an autosomal dominant genetic trait.

Source: WebMD

http://my.webmd.com/hw/health_guide_atoz/nord665.asp?lastselectedguid={5FE84E90-BC77-4056-A91C-9531713CA348}#

Viral hepatitis C: a disease of the liver caused by the hepatitis C virus (HCV). You may be at risk for hepatitis C and should contact your medical care provider for a blood test if you:

- Were notified that you received blood from a donor who later tested positive for hepatitis C;
- Have ever injected illegal drugs, even if you experimented a few times many years ago;
- Received a blood transfusion or solid organ transplant before July, 1992; and
- Were a recipient of clotting factor(s) made before 1987.

Source: U.S. National Center for Infectious Diseases

<http://www.cdc.gov/ncidod/diseases/hepatitis/c/>

Wilson's Disease: an inherited disorder in which excessive amounts of copper accumulate in the body. Although the accumulation of copper begins at birth, symptoms of the disorder appear between the ages of 6 and 40. Liver disease is the primary consequence for approximately 40 percent of patients.

Source: National Institute of Neurological Disorders and Stroke

http://www.ninds.nih.gov/health_and_medical/disorders/wilsons_doc.htm