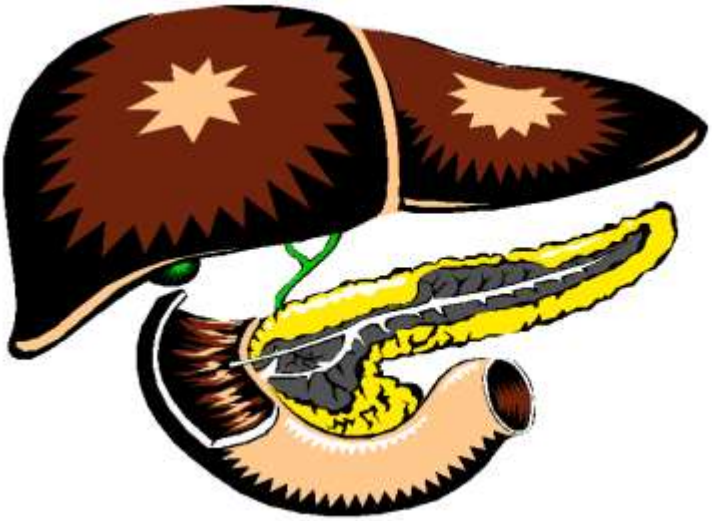
UHN Multi-Organ Transplant

LIVING DONOR **LIVER** TRANSPLANTATION: **Donor Manual**



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Introduction

This manual is written for people who want to learn about living liver donation. It includes information on the rationale for living donation, the assessment process, the operation, post-operative care, and the alternatives, benefits and special risks of this surgery.

Over 700 living liver donations at the Toronto General Hospital have been performed since 1990. There have been no donor deaths, nor have any donors experienced a disabling long-term complication. Detailed information about our program is provided below.

It takes great courage and commitment to save a life through living liver donation. It is only possible however for approximately 1/3 people who apply to become donors for reasons that will be discussed in this manual. Please read this information carefully and completely. If you decide to pursue living liver donation, please complete the Donor Health History Form and submit it to the Living Donor Liver Office, along with proof of your blood type (E.g. a copy of bloodwork done through your family physician or a blood donor card). The Donor Health History Form can be found on our website, www.UHNtransplant.ca.

Abbreviations

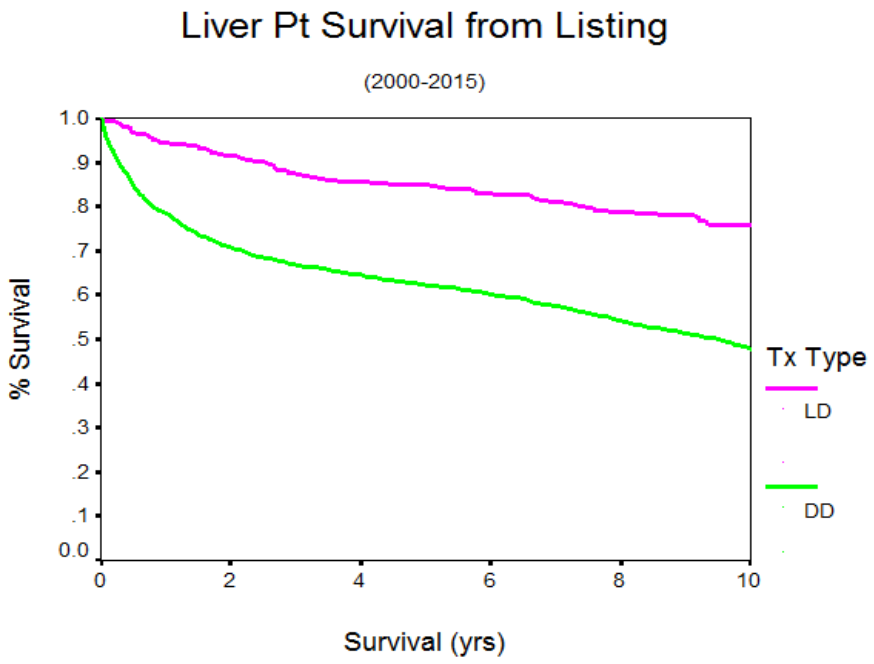
Deceased donor	DD
Living donor	LD
Living donor liver transplantation	LDLT

Benefits and Risks for the Transplant Recipient

Deceased donation is the standard of care for liver transplantation in Ontario and Canada. The benefits and risks of living donation compared with deceased donation from the recipient's perspective are discussed below.

There are not enough deceased donor organs to meet the needs of listed liver recipients. In Toronto, at any point in time, there are approximately 200 people waiting for liver transplantation. The waiting time for deceased donor (DD) liver transplantation ranges from days to months to years, depending on the health status of the recipient. Each year 30-60 patients referred to our program for a liver transplant die during their work-up or while waiting for a deceased donor organ.

Living donor liver transplantation (LDLT) reduces the risk of health deterioration and death for patients who need a liver transplant. In Toronto, survival from the time of list is much better for those who undergo living donor liver transplantation compared with those who wait for a deceased donor organ as shown in the figure below.



A LDLT can also be performed before the recipient's health severely deteriorates, and may allow for a faster recovery.

LDLT also provides the recipient with a high quality organ whereas approximately 35% of deceased donor organs may be less than ideal due to advanced donor age, mild to moderate liver abnormalities, incomplete knowledge of the donor's health history and the use of extended criteria, exceptional release and donation after cardiac death (DCD).

LDLT allows recipients to bypass the risks of waiting for a deceased donor graft. After transplantation, the long term outcomes with live donor liver grafts and deceased donor liver grafts are similar.

Principles Guiding the Assessment for Living Liver Donation

- Donor assessments do not usually start until the recipient has been deemed eligible to receive a living donor transplant. The intended recipient must agree to living donation.
- If the potential recipient is also deemed suitable for a deceased donor organ, he/she will remain on the deceased donor waiting list while the living donor work-up is in progress. When a donor is cleared and a surgery date is booked, the recipient is placed on "hold" on the deceased donor waiting list.
- Becoming a donor is an option for healthy people, age 16 to 60 years. Living donation must be a voluntary choice without external pressure, coercion, or material gain. The donor's primary goal should be to help the recipient. Donors must be able to provide informed consent, have a healthy liver, and have no major health (psychological, social, or physical) issues.

- **Donor safety is our first priority**. **We will not rush or compromise the donor assessment process even if the recipient is very sick.**
- Potential donors have a responsibility to honestly and fully report any and all health concerns, issues, and/or behaviors that might affect their candidacy or pose health risks to a potential organ recipient. All information obtained during the assessment is strictly confidential and will not be discussed with anyone other than the donor. If the screening questionnaire reveals major health issues, we may ask the donor to provide consent to obtain reports from their doctor before starting the work-up. It is the donor's responsibility to inform the donor team of any prescription, non-prescription, homeopathic or herbal remedies as these may interfere with liver function.
- The duration of work-up is determined by availability of resources, the donor's schedule, the complexity of the donor's health issues, and the time needed to ensure informed consent. It may take days, weeks, or sometimes months to complete all of the necessary tests.
- The possibility of donation will not be offered if the medical and/or surgical team believes that the potential for physical, emotional, or social harm outweighs the benefits. The final decision to perform the living donor transplant rests with the donor's healthcare team. If we decide that living donation is inappropriate, we will offer referrals to other programs for another opinion.
- The Ontario government pays for the costs of the donor investigations, surgery, hospital stay, and post-discharge care as it does for other forms of health care. Donors who pay into Employment Insurance may be eligible for Employment Insurance Sick Benefits to help with the loss of income while recovering. Some travel, dining, and accommodation costs may also be paid through the living donor reimbursement program (PRELOD), funded through the Ministry of Health and Long-Term Care and aimed at minimizing the costs incurred by living donor. Detailed information is available on the Trillium Gift of Life Network website (http://www.giftoflife.on.ca/).
- If a potential donor comes from a province other than Ontario, the recipient's OHIP will cover the costs of the donor's medical care at UHN including the evaluation, potential surgery, and post-donation care. On a case-by-case basis, we may arrange for some testing before surgery to be done locally to the donor. Post-donation follow-up care may also be arranged locally as appropriate.
- Our program will consider out-of-country donors on a case-by-case basis. We do not accept donors from countries in circumstances when high quality on-going medical follow-up cannot be guaranteed or when it is difficult to obtain supporting data to confirm that beneficence (doing good) and / or altruism (helping someone else without material gain) are the primary motivations of the donor.
- If you wish to speak with someone who has undergone the living liver donor process, please let the office know and we will arrange an opportunity to speak with one of the past donors.

Questions for Potential Living Liver Donors to Consider

We have developed questions to ask yourself as you consider living donation. Please consider discussing any or all of these issues with members of the Donor Advocate Team as you go through the assessment process.

Motivation

- Have I been totally open with myself about why I want to donate part of my body to the recipient?
- Am I making this decision of my own free will because I believe it is the right choice for both the intended recipient and me?
- Am I considering this surgery because I feel pressured or influenced by others?
- Am I expecting anything in return for my donation? (e.g., Gratitude? Publicity? Other kinds of attention? A better relationship with the recipient?)
- Is my family/personal/professional life relatively stable and secure?
- If not, are there things that I can do now to improve the situation?
- Is there anything I can do now that will improve my recovery? (e.g. lose weight, exercise more, stop smoking).
- Has anyone among my close friends and family shown disapproval or criticized me for wanting to make this donation?
- Will I be able to handle these reactions when I am feeling weak and/or emotionally fragile?

Potential Pain and Discomfort

- Do I feel adequately prepared to deal with the pain and discomfort associated with this surgery?
- Will I be able to communicate my needs – both physical and emotional – to hospital staff and/or my family?
- Can I manage the recovery period without running into problems? (e.g. boredom, anxiety, nervousness)

Financial Concerns

- Am I financially prepared to be away from work for a period of time?
- At what point will I become concerned about my lack of income?
- Do I have an adequate back-up plan in case I need to be off work longer than expected?
- Am I prepared for the possibility that my insurability or employment status may be affected by live donation? (For example, a new condition might be identified during the work-up process or the surgery or a complication could affect your ability to obtain insurance or employment).

Post-Donation Concerns

- Do I have expectations about what this experience will be like for me? Are they realistic?
- Have I thought about how I would feel if the recipient fails to “take care” of the portion of liver I donated?
- Have I thought about how I would feel if the recipient has serious complications or does not survive the transplant?

Family Concerns (Other concerns)

- Have I spoken to my family about how they will cope if I should have serious, unexpected complications?
- Do I have a plan in place for my children and/or dependents if I should have an unexpected outcome?
- Does my healthcare proxy or substitute decision-maker know my treatment preferences if my condition should deteriorate so that I need advanced medical technology to survive?
- Does my family know who my healthcare proxy agent or substitute decision-maker is?
- Do they understand that I have chosen that person to make medical decisions for me if I should become unable to communicate with the medical team?

The Living Donor Assessment Process[1]

Overview of the Phases of the Assessment Process *(Italics indicate tests and consultations on an as-needed basis*
Phase I: Screening Questionnaire - Health history - Blood type compatibility (Must be blood type compatible to proceed to Stage II)
Phase II: Initial Visit - First appointment with a donor team doctor and donor coordinator - Serology (test for infections) - ECG (test for the electrical activity of the heart) - Chest X-ray (image of the lungs) - *Consultation for weight loss if Body Mass Index (BMI) > 30*
Phase III: Initial Diagnostic Tests - MRI (visualize bile ducts) - CT (visualize vascular anatomy and size of liver) - *Echo (if over age 50, if ECG is abnormal, or if pre-existing cardiac history)* - *Exercise Stress Test (if over age 50, if ECG is abnormal, or if pre-existing cardiac history)* - *Pulmonary Function Test (if current or previous smoker, or if history of asthma)* -
Phase IV: Initial Consultations - Psychiatry Assessment - Social Work (support and financial planning, drug coverage) - Surgical Risk Consultation (review of surgical procedure and risks, consent for donation surgery) - Independent Medical Consult (3rd party opinion to determine suitability) - *Other consults as needed (i.e. hematology, cardiology, etc.)* - *Liver biopsy as needed (i.e. fatty liver; abnormal liver enzymes, etc.)*
Phase V: Preparation for Surgery - Pre-Operative Education with donor coordinator - Pre-Admission Consultation (Anaesthesia and preparation for admission for surgery) - Schedule surgery date

In compliance with national standards, the Medical Director and Donor Coordinator will guide the assessment. You will also see a general internal medicine consultant who works independently of the donation and transplantation programs and who is available to protect your interests if you have any concerns.

The evaluation process educates donors about the medical, psychosocial and financial implications of donation; determines your suitability (an acceptable medical risk); ensures free (autonomous) informed consent; discusses results of the work-up; provides emotional support and follow-up; and ensures continuity of care throughout the entire donation process.

The assessment process requires donors to plan on attending about 12 different appointments for the tests and consultations. To minimize visits, we try to schedule as many tests as we can in one day. However, completing the assessment process may take up to four hospital visits or more. Donors travelling a long distance to Toronto (out-of-province or out-of-country) should plan a minimum of two trips to Toronto.

We will support you during the work-up process and donors must also advocate for themselves. Remember, if there is a complication after donation, it is the donor who will be most affected. **If at any point in the assessment process you, your family members, or your friends have <u>any</u> reservations about donation, this information must be shared with the donor team.**

If more than one potential donor volunteers, we will contact the most suitable donor to start assessment unless the all intended donors meet and collectively instruct us otherwise. Other donors will be placed "on hold" and will only be contacted if the donor in assessment is deemed unsuitable.

Before undergoing an evaluation, donors should consider the possibility that previously undiagnosed medical conditions may be uncovered during this medical assessment. A new diagnosis could affect your suitability as a donor, your ability to obtain insurance or employment and/or cause emotional distress.

Before starting a work-up, we ask potential donors to confirm that they will be available to undergo the donor surgery within the next 3 months provided that **1)** no contraindications are found and **2)** they still want to proceed after learning more about the procedure.

Both blood type and donor history must be provided prior to proceeding with the donor evaluation. Candidates for liver donation must be in excellent physical and emotional health. A history of cancer and/or an active infection are contraindications to organ donation. The donor must have normal liver function. The liver must have a pattern of blood supply and a distribution of bile ducts that are suitable for transplantation. Donors should have family or friends that can provide support before, during and after the surgery. Donors are required to have a family physician.

Smoking and the birth control pill are avoidable risk factors for blood clots after surgery, therefore, we ask donors to stop smoking prior to donation. We also ask women using any form of hormonal birth control or replacement therapy to stop this medication and use two alternative forms of contraception before donation. Alcohol and marijuana (and any other

recreational or illicit drug use) must be avoided completely for 4 weeks before surgery and for at least 8 weeks after the surgery.

Whilst awaiting potential organ donation, donors have a responsibility to avoid all behaviors that would put them at risk for acquiring infections (HIV, HCV, syphilis, etc.) that could be transmitted to the recipient. We specifically recommend: 1) abstaining from any high risk behaviours (unprotected sex; intravenous drugs, tattoos, piercings, etc.); 2) taking steps to avoid disease transmission through sexual contact (condoms); and 3) avoiding being bitten by mosquitoes, which could transmit the West Nile virus infection, by wearing long sleeve shirts and pants and using mosquito repellant.

An electrocardiogram and a chest x-ray are obtained to confirm normal heart and lung function. If these studies are normal then CT (Computerized Tomography) and MRI (Magnetic Resonance Imaging) scans are arranged at Toronto General Hospital. A team of surgeons then review these tests to ensure that the liver is healthy and that the anatomy is suitable for transplant surgery. In some cases further studies are required, such as a liver biopsy.

If the screening blood work and scans are satisfactory, the potential donor is offered a tentative target surgery date based on their availability. Once a target date is defined, the potential donor will complete a number of consultations with healthcare specialists. These include assessments by the psychiatry team, an independent medical doctor who does not work directly with the transplant team and one or more of the donor surgeons. A medical assessment is obtained to determine the medical risks associated with liver donation for each individual.

Sometimes the assessment will identify the need for additional testing to be done. A condition may be identified that makes the health risks too high for the donor. The work-up is stopped and the donor is then notified first. The recipient and their team are then informed that this donor in assessment is medically unsuitable. The results of the tests performed during the work-up are sent to the family doctor who is requested to follow up these tests. If a reversible contraindication is corrected (e.g. fatty liver) the work-up can be restarted.

Donors meet with a surgeon at least twice during the assessment period. Both visits provide an opportunity to review the surgery, benefits, risks, and alternatives before signing the surgical consent form. The surgeon who obtains consent may not be the one who performs the operation. A different surgeon than the one who performs the operation may provide post-operative care.

Only 20 - 30% of those who indicate an interest in liver donation actually undergo this surgery. Some of the more common reasons for not proceeding to surgery include unsuitable blood vessel structure, abnormal blood tests and medical problems not previously identified or known. At any stage the potential donor or the healthcare team may decide that it is inappropriate to proceed with liver donation. **Protecting the confidentiality of the donor, recipients are <u>not</u> given information on the reason why a donor is unsuitable.**

If a potential donor does not attend a required test, the test will be re-booked and the donor informed by telephone or e-mail. This will occur twice. If the donor fails to come for the same test three times, a letter will be sent requesting that the donor call the coordinator to re-book. If we do not hear from the donor within two weeks of sending this letter, the donor team will

assume that the donor does not wish to proceed with the work-up and the file will be closed. The recipient team will then be informed that the donor is not suitable at this time and that a work-up on an alternate donor can begin.

Potential donors must communicate directly with the team regarding questions and concerns. We do not communicate with third parties or give information to anyone (family members, friends, recipients, etc.) other than the potential donor.

There is a risk of transmitting infections via organ donation. Blood samples are obtained from the donor to confirm normal organ function and test for the presence of several viral diseases including but not limited to Hepatitis B and C, HIV and Syphilis. **Please note that some viruses are reportable by law to the Public Health Department. You may be contacted by Public Health if you have a positive test for these viruses.** Potential donors should immediately report any fever, flu-like illness or neurological symptoms. If a donor has an active infection they cannot donate part of their liver because they could transmit this illness to the recipient. To minimize the risk of disease transmission we obtain blood tests to check for infections at the start of the donor assessment and again a few days before the surgery date.

You can withdraw from the assessment process at any time. The recipient will not be told the reason, only that the donor is deemed unsuitable.

Urgent Donor Assessments

Urgent donor assessments are not the standard of care. Urgent work-ups are generally undertaken in exceptional circumstances – usually for adults with acute liver failure or children with rapidly deteriorating liver function where death is expected to occur within hours to a few days.

There are no shortcuts regardless of the pace of deterioration of the intended recipient. The pace of the work-up is determined by **a)** available hospital resources; **b)** the time that the donor assessment team believes is required to ensure informed consent is obtained; and **c)** the time required to complete a thorough work-up.

Potential donors must understand and accept that the risks of donation may be slightly greater in urgent circumstances (for example, there might be a higher risk of pneumonia or blood clots if the donor does not have time to stop smoking or to stop the birth control pill).

Donor surgery is performed during the daytime when the donor surgeons are well rested and when all of the highest standards needed to perform this surgery and provide safe follow-up are available.

If the probability of recipient survival is less than 50%, the option of living donation for rapidly deteriorating recipients will not be offered.

Anonymous Donation

An **anonymous non-directed living donor** is a person who would like to donate their liver but does not have an existing recipient. An **anonymous directed donor** is a person who wishes to donate without their intended recipient knowing who they are.

In case of anonymous, non-directed donors, donors are asked to agree to maintain their anonymity according to the program guidelines. This requirement serves to protect both the privacy and interests of the donor and those of the recipient and family. Our program does not facilitate a meeting between the donor and the recipient in the event of anonymous non-directed donation. The team will facilitate an exchange of written communication in the form of a card or letter, if both donor and recipient are in agreement. Screening includes the removal of any identifying information.

When donation is not directed, we will consider anatomic issues, relative recipient risks of right or left lobe donation, medical need of potential recipients, and probability of recipient benefit when allocating the liver. Directed anonymous donation will be considered on a case-by-case basis. The program refuses to accept a directed donation that discriminates against potential recipients based on the recipient's race, ethnic group, skin color, or religion.

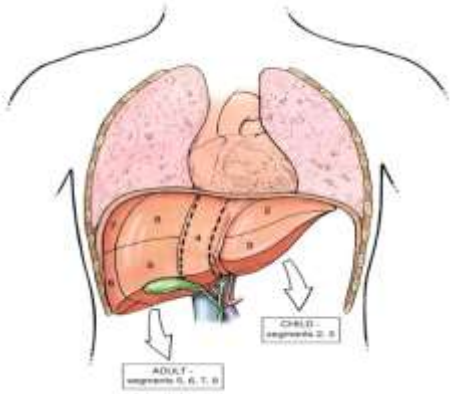
Living Donor Surgery: Standard Procedures and What to Expect

The target surgery date is always tentative and is subject to change in approximately 40% of cases. Reasons for changes include: **1)** the potential donor could confidentially opt out of donation at any time; **2)** the liver transplant program may decide that other living donor cases need priority for medical reasons; or 3) resource limitations (availability of hospital beds and nurses primarily). We will re-schedule the surgery as soon as possible if a donor surgery is cancelled or delayed.

In approximately 5% of living donor cases, we cancel scheduled surgery with only 1 or 2 days of notice when a final team review of both the donor and recipient charts identifies contraindications. A last-minute cancellation is disappointing and frustrating for both the donor and recipient. Our primary focus when offering living donor transplantation is the safety of our patients. This can be a stressful event and our team can provide support during this difficult time.

The team asks that donors to complete their air travel at least two days before the surgery if a donor needs to travel by airplane. Sitting in an airplane for a prolonged time increases the risk of blood clots during and after the surgery.

Donors are admitted to hospital at 6:00 AM on the morning of surgery. No food or fluids are allowed after midnight the night before your surgery. After arriving you will change into a hospital gown and be measured for compression socks. An intravenous will be inserted into your arm. Your blood pressure and temperature will be checked. An Anesthetist will come to speak with you regarding pain management and you will then be transferred to the Operating Room. You will receive preventative antibiotics and a blood thinner to prevent blood clots. After you are asleep (anesthetized), various tubes will be inserted to drain the contents of your stomach and bladder, to provide intravenous fluids and to monitor your blood pressure.



Right lobe donation involves removing segments 5, 6, 7, and 8.

Left lateral segment donation involves removing segments 2 and 3.

Left lobe donation involves removing segments 2, 3, and 4.

The liver grows back to its normal size in about 6 – 10 weeks.

Artist: Stephen Maider. © Copyright 2003. Property of UHN. This graphic cannot be reproduced or used for other purpose without permission.

Surgery begins with a careful examination of the internal structures including an intra-operative ultrasound and an x-ray of the bile duct. After removal of the gallbladder, the surgeons expose the blood supply and bile ducts to the part of the liver that will be removed. Sometimes at this point, despite satisfactory preoperative tests, we find a pattern of blood vessels or bile ducts that would make the transplant unusually risky for the donor or the recipient. In this situation we do not proceed with the donor surgery and the incision is closed. This happens in about 3-5% of donor surgeries. Once donor anatomy is confirmed to be suitable the recipient surgery will start.

To view the living liver donor and recipient surgeries in more visual detail, please visit http://pie.med.utoronto.ca/tvasurg_pe/TVASurg_PE_content/transplant_rightDonor.html.

The operation lasts 6-8 hours. Following surgery the donor goes to the recovery room for 2-3 hours and then is taken to the transplant stepdown unit. A team that includes surgeons, medical physicians (liver specialists), nurses, pain specialists, and nurse practitioners care for liver donors. . Toronto General Hospital is a teaching facility and your healthcare team includes nurses and physicians who are training.

We strive to minimize post-operative pain through management with patient-controlled analgesia pump (PCA) and sometimes through a transversus abdominus plane (TAP) anesthesia regional anesthesia block. This is similar in concept to the epidural often used to control pain with childbirth. After 2-4 days, these devices are removed and oral pain relievers such as Percocet are prescribed.

Most donors are discharged from hospital about 5-7 days after the operation. Tubes inserted during the surgery (intravenous and arterial lines, nasogastric tube, bladder catheter) are gradually removed over the first few days. Most patients are able to start eating and drinking about the 3rd to 5th post-operative day. Liver function blood tests are monitored during your hospital stay and after leaving hospital. An ultrasound is also done before discharge.

To minimize the risk of blood clots, donors are prescribed a blood thinner after surgery, which requires a daily injection during your hospital stay and for 5 weeks after discharge from hospital. Blood thinners carry a small risk of bleeding and stroke but the benefits are believed to outweigh these rare risks. 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: **1)** avoid air travel or prolonged car trips for 2-4 weeks postoperatively; and **2)** when traveling for the first 2-8 weeks after donor surgery to take time to walk every hour for approximately 15 minutes to promote blood flow in your legs (see Post-Discharge Instructions, page 15).

The remaining liver segment grows and resumes normal function within a few weeks after donation. Most complications are apparent soon after surgery but some complications can develop following discharge from hospital. 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 Department. Signs and symptoms to look out for will be reviewed during your discharge teaching.

It is common to experience a "let-down" or mild depression at the 4-6 week period while recovering from surgery. This usually resolves quickly but support is available if this occurs. 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.

Surgical Risks and Potential Complications [2, 3]

Liver donation is associated with significant risks no matter how carefully the donor surgery is performed. It is vital that persons considering donation have a good understanding of the nature of this surgery, the benefits, the risks, and the alternatives. Risks are discussed frequently during assessment and are carefully reviewed during visits with the surgeons. Feel free to ask for additional information. Some of the risks of living donation are outlined below.

Liver donation is challenging surgery. Donor deaths and/or severe complications can occur even when the very best care is provided. The risk of death is estimated to be 0.15% with left lobe donation and 0.30% with right lobe donation. To provide perspective, it is worth noting that the risk of death is higher after living donation than the risk of death after routine heart bypass surgery.

The surgery is performed through a large upper abdominal incision that results in mild, permanent weakness in the abdominal wall and a small patch of numbness beneath the incision just above the umbilicus (navel).

At Toronto General Hospital, about 20% of liver donors will experience a complication. Most of these complications are mild and temporary; however some can be very serious and life-threatening. Some, but not all, of the risks of liver donation surgery include:

- An adverse reaction to anesthesia
- A decision to stop the donor surgery based on intra-operative findings (about 4% of cases)
- Stroke
- Heart attack
- Blood clots in the legs or lung
- Fluid around the lung (pleural effusion)
- Fluid retention (edema)
- Mild or severe infections
- Infection or other adverse effects of a blood transfusion (required in about 5% of cases)
- Re-operation (about 5% of cases, usually due to bleeding)
- Bile leakage
- Bile duct damage requiring repair
- Injury to adjacent organs such as the spleen, stomach, or intestine
- An injury to the remaining liver segment's blood vessels resulting in liver failure
- Severe depression
- Unsightly scar
- Retractor injuries causing temporary or permanent nerve damage
- Persistent incisional pain

Several donors in the United States and Japan have required liver transplantation to treat liver failure that has developed after donating part of their liver.

If complications occur, they could impair the donor's ability to obtain health or life insurance as well as affecting the donor's lifestyle and/or ability to maintain or obtain employment. Potential donors should consult an insurance agent and/or speak to their employer about the surgery itself, which even without complications, might impact on their insurability or job security. Staff from the donor program will be pleased to provide any information that is required.

No matter how carefully the transplant is performed, there is the potential that the liver recipient will die during or after the transplant surgery. If this happens, donors will know that they have done everything possible to help a loved one. Nonetheless, potential donors should consider carefully how you might respond to the stress of dealing with the recipient's death. In the highly unlikely event that your liver segment has been removed and your intended recipient develops a complication that makes transplantation impossible, (a so-called "orphan" graft) we will try to transplant your liver segment into another recipient. This problem has only happened a few times in the world and it has never happened in Toronto so far. Unforeseen problems may be identified as we continue to gain further experience with this operation.

Results of Living Liver Donation at the UHN [2, 3]

Outcomes of donor surgery: Over 700 donor liver procedures have been performed at the UHN with no deaths and no persistent major long-term ill effects. In published analyses of our outcomes, the median operative time was 390 minutes, estimated blood loss was 500 ml and there were no intra-operative complications. As expected with major surgery, 20% of donors experienced reversible complications. 4.7% of donors have had unsuitable anatomy and the plan to remove the liver segment was abandoned.

The frequency of early post-operative donor complications was 14%. Early post-operative bleeding requiring re-operation occurred in (3%); these were among the only patients who required blood transfusions from someone else. Other morbidities include (1.8%) with bile leaks that required endoscopic treatment, (3.6%) with abscesses or fluid collection requiring insertion of a drainage tube in the radiology department (1.8%) with blood clots to the lung (pulmonary emboli) and (2.2%) of patients with wound incision hernias that required repair.

Outcomes of recipient operation (living donor liver transplantation): Patients receiving living donor liver transplants have done well. Survival after living donor liver transplantation has been similar to survival after deceased donor liver transplantation (~90% at one year). There has been a higher rate of bile duct complications in living donor recipients compared with deceased donor recipients (~20% versus ~5%) but most of these complications were managed with non-surgical management.

Discharge Instructions and Post-Donation Care

The information is provided below to promote a safe recovery and return to normal health.

Symptoms that require immediate medical attention:

- Fever greater than 38°C
- Yellow eyes or skin (Jaundice)
- Shortness of breath
- Uncontrolled pain

The living donor liver team is available to discuss any issues or concerns that you have. During business hours, please do not hesitate to call the office (416 340-4800 ex. 6581). After business hours or on weekends, call TGH locating (416-340-3155) and ask to speak with the liver transplant surgical fellow who is on-call.

Activity:

Do not lift anything heavy or perform strenuous exercise for the next 6 weeks after which you can gradually resume full activities. In the first 6 weeks while recovering from surgery, you can:

- Go for walks daily
- Light exercise
- Have normal sexual activity when it is comfortable

Return to Work:

You can return to work within 6-8 weeks if your work does not require heavy lifting or strenuous exertion, in which case return to work may be delayed for a total of 12 weeks.

Diet:
Eat a normal healthy diet. Try to maintain ideal body weight by taking a low fat diet and eating foods with fiber such as fresh fruits and vegetables. Continue to abstain from alcohol for 8-12 weeks after surgery.

Travel:
We recommend that everyone remain in the Greater Toronto Area for the first week after discharge from hospital. Thereafter, you can travel within Canada. To minimize the risk of blood clots during travel it is critical to complete the full 6-week course of the blood thinner. During travel, it is important to drink fluids (avoid dehydration), extend and flex your legs at least 10 times every hour, and every 1 hour walk around and move your legs for at least 10-15 minutes.

We strongly recommend that you do not travel internationally for 6 weeks post-donation. If you ignore this advice and develop a complication that requires treatment in another country, you might incur very high treatment costs that will not be covered by OHIP.

Medications:
Tinzaparin must be injected daily to prevent blood clots. It is essential for your safety that you complete the full 6-week course of this treatment.

Percocet or Tylenol # 3 or extra strength Tylenol can be taken as prescribed for relief of incisional pain. If this does not control your pain, please contact the living donor office for further instructions. **Please do not exceed recommended dosing. If pain persists, please contact the living donor office and doctors.**

Follow-Up Tests and Appointments:
- **1 month post-surgery:** you will see your surgeon and do bloodwork.
- **3 months post-surger**y: you will see living donor physician, do bloodwork, and have an MRI to ensure liver regeneration and rule out any post-operative complications.
- **1 year post-surgery:** you will do bloodwork

We ask donors to see your family doctor for longer term screening for late complications. We recommend that liver function tests. ALT, AST, ALP and bilirubin levels are checked annually for 10 years. Additional appointments and tests will be scheduled as required.

Potential Expense Reimbursement: PRELOD Program

This is a Government of Ontario initiative that provides donors with some reimbursement for the costs incurred during the living donor evaluation process. There is limited coverage available for out of province/country donors IF the recipient is an Ontario resident with OHIP. This program does not reimburse the costs of medications. You must provide receipts for submission with the reimbursement claims forms (e.g. parking, food, hotel, travel costs, etc.). More information is available at the Trillium Gift of Life website: http://www.giftoflife.on.ca/en/transplant.htm

Social Media and Media Involvement in Living Liver Donation

As a patient waiting for transplant, you need to consider what, if anything, you would like conveyed regarding social and general media and to inform your loved ones about your choice. Once images and details of your care are posted on a social media site or on the general Internet, you have no control over the information and images.

From time to time, patients use the media and social media to appeal for a donor or for funds to support their transplant expenses. This is entirely up to you, your family and friends. **UHN cannot take part in fundraising or donor appeals for individual patients.** However, please be aware that any media coming into the hospital must first coordinate their request with UHN Public Affairs. UHN will never release confidential information to the media.

For more information or, if you have questions about the use of media and social media as transplant patients, please call Public Affairs & Communications at 416-340-4636.

The Next Steps

Individuals who want to be assessed for living liver donation should send the completed and signed **Donor Health History Form** (found at www.UHNtransplant.ca) along with documented **proof of your blood type** to the address, email or fax number below. The Living Liver Donor Office will contact you and coordinate your assessment. Please let us know if you have any questions.

Toronto General Hospital
Living Donor Liver Office
585 University Avenue
Peter Munk Building
11th Floor, 11C-G19
Toronto, ON M5G 2N2
Fax: (416) 340-4317
Email: livingdonorliver@uhn.ca
Phone: (416) 340-4800 ext.6581

References

1. Steel, J. Living donor advocacy: an evolving role within transplantation. New York: Springer; 2014.

2. Adcock, L., Macleod, C., Dubay, D., Grieg, P., Cattral, M., McGilvray, I., Lilly, L., Girgrah, N., Renner, E., Selzner, M., Selzner, N., Kashfi, A., Smith, R., Holtzman, S., Abbey, S., Grant, D., Levy, G., Therapondos, G. Adult living liver donors have excellent long-term medical outcomes: the University of Toronto liver transplant experience. American Journal of Transplantation. 2010, 10:364-371.

3. Guba M., Adcock, L., MacLeod, C., Cattral M.., Greig, P., Levy, G., Grant, D., Khalili, K., McGilvray, I. Intraoperative 'No Go' donor hepatectomies in living donor liver transplantation. American Journal of Transplantation. 2010; 10:612-618.