

# Vancouver Coastal Health

## Live Liver Donation

### A Potential Donor's Guide



*Promoting wellness. Ensuring care.*

# Live Liver Donation A Donor's Guide

Live Donor Liver Transplants	3
Who Can Donate?	3
Advantages	4
Risks	5
Assessment Process	6
Donor Assessment Stages	7-9
The Decision	9
Important Considerations	10
<i>Pre-donation</i>	10
<i>Options</i>	11
<i>Post-donation</i>	11
Surgical Aspects of Living Donation	12
The Surgery	13
Post Operative	14
Frequently Asked Questions	15-18
References	19

For more information contact the Living Liver Donor Coordinator

# Live Donor Liver Transplantation

Usually, livers for transplantation come from donors who have died. Some may have registered their wishes with the Organ Donor Registry, if not their family may have given permission. Unfortunately, there are not enough deceased donor organs available for today's growing list of people who are waiting for a transplant. Many patients waiting for liver transplants become too sick to undergo transplant surgery, or die while on the waiting list.

Success with live kidney transplantation stimulated the development of live donor liver transplantation. The first successful live donor liver transplant was performed in the United States in 1989 from a mother to her child, who had irreversible liver damage. Since that time, thousands of children and adults have received live donor liver transplants.

In a live donor liver transplant, a portion of the liver is surgically removed from a live donor and transplanted into a recipient immediately after the recipient's liver has been entirely removed.

Live donor liver transplantation is possible because the liver (unlike any other organ in the body) has the ability to regenerate or grow. Both halves of the liver used for transplantation regenerate to the size of a normal liver within a period of 4-8 weeks. Today, many transplant centres are performing these life saving surgeries.

## Who Can Donate?

Selecting the right donor for a live donor liver transplant requires experience, skill and technical expertise on the part of the many doctors, nurses and other health care professionals who make up the Live Donor Team.

Potential live liver donors are carefully evaluated. The health and safety of the donor is the most important concern during the evaluation. Only donors in good health are considered.

### ***A potential donor should:***

- Be either a relative, spouse or friend
- Have a compatible blood type
- Be in good overall health and physical condition
- Be older than 19 years of age and younger than 55 years of age
- Have a near normal body mass index (not obese)

### ***A donor must be free from:***

- History of Hepatitis B or C
- HIV infection
- Alcohol dependence/abuse
- Substance abuse
- Major mental illness unresponsive to treatment
- A recent history of cancer

**If you have any questions regarding eligibility please contact the Live Liver Clinical Coordinator at: 604-875-5182 or toll free at 1-855-875-5182**

# Advantages of Live Liver Donation

Live liver donation provides people waiting for a liver transplant 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 several years. Some patients will die while waiting for a deceased donor organ. Should a relative or loved one meet the criteria for live liver donation, the wait time and risk of death while on the waiting list can be substantially reduced.

***Healthy donor organ:***

Live donors tend to be young, healthy adults who have undergone a thorough medical evaluation. As a result, the liver from a live donor is more certain to be normal than a liver from a deceased donor.

***Surgery can be scheduled electively:***

With live donor liver transplantation, it is possible for the recipient to have surgery earlier while he/she is in better overall condition. This increases the chances for an uncomplicated recovery. In addition, with a live transplant, the time that the donor organ is kept on ice after retrieval is minimized. This improves the chance that the organ will function well.

***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.

**Please note, even after the live donor transplant is scheduled, the recipient will remain on the active transplant list until he/she is actually transplanted. If a deceased donor liver becomes available for the recipient, the living liver transplant would be cancelled.**

***Questions / Notes:***

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# Potential Risks of Live Liver Donation

The Live Donor Team will describe in detail the risks involved in living liver surgery.

For the live 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 to the donor with live liver donation is minimal, the risks specific to the 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 colour 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: worldwide risk in donors is between 1 in 200 and 1 in 400
- The recipient may be at slightly higher risk of bile leak complications from a live donor liver transplant compared to a deceased liver transplant.

Live donor liver 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 of the surgery (most of this growth occurs within weeks of the surgery).

## ***Questions / Notes:***

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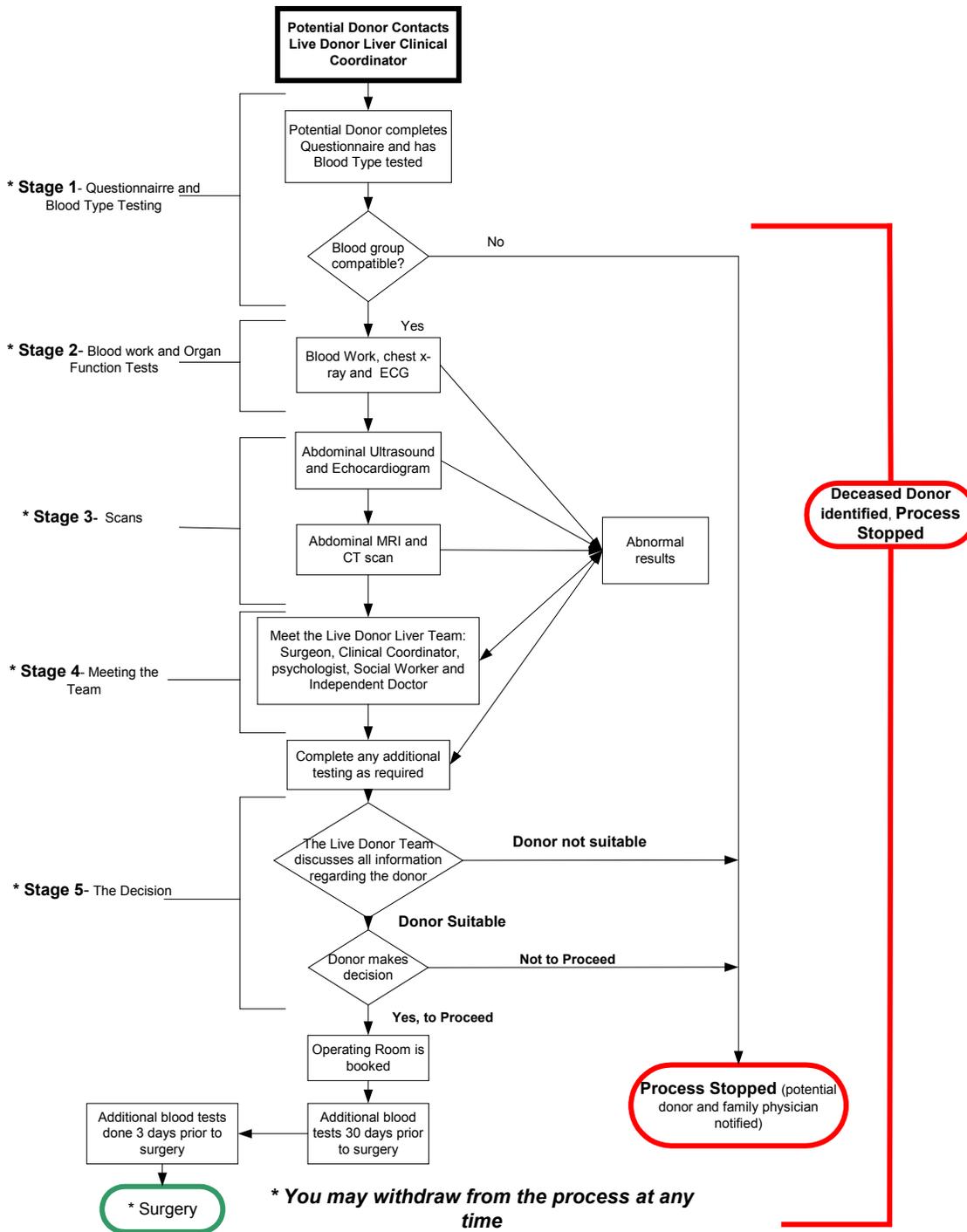
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# Assessment Process

## Live Donor Liver Transplant Assessment Process



# Stages of Donor Assessment

The purpose of the donor assessment is to ensure that the donor and recipient are compatible and to ensure that donation is safe for the donor. This is done by carrying out various blood and urine tests, x-rays and clinical assessments by transplant nurses, social workers and doctors.

If you or someone you know is interested in donating a portion of their liver, initial screening will be carried out over the phone or in person. A potential donor must be at least 19 years of age, and under 55 years old.

Common reasons for potential donors to be turned down at the outset include a history of previous abdominal surgeries, high blood pressure or diabetes. Testing is performed in stages to help rule out incompatible donors as soon as possible. Once a potential donor starts the assessment process, information shared between the donor and the transplant centre is confidential.

Test results will be given to the donor and sent to their family doctors. The information will be discussed with the recipient and other family members only if permission to do so is given by the donor. The donor can withdraw from the program at any time.

The assessment is carried out in the following order:

1. Questionnaire and Blood Type Testing
2. Blood work and Organ Function Tests
3. Scans
4. Meeting the Team
5. The Decision

If a potential donor decides to initiate testing, arrangements will be made by the Clinical Coordinator. The blood tests can be done at a laboratory close to the home or work place. Some of the initial radiological testing may be done close to your home. The final CT scan and MRI will normally be completed at Vancouver General Hospital. If the potential donor lives in a different province or country than the recipient, the Coordinator will sometimes make arrangements for the tests to be done near the donor's residence.

## ***Stage 1: Questionnaire and Blood Type Testing***

After a potential donor has identified themselves to the Live Donor Clinical Coordinator, a brief telephone interview will occur, and then an information package will be sent to the potential donor, including an information booklet, a medical and social history questionnaire, and a blood test requisition.

The Donor blood type is:	The Recipient Type must be:
O	O, A, B, AB
A, O	A
B, O	B
AB, O, A, B	AB

## Donor Assessment Stages, continued

### ***Stage 2: Blood work and Organ Function Tests***

If you are a potential donor, and if your blood type is compatible, and if the details on the questionnaire show you are suitable, the Clinical Coordinator will arrange for testing of your liver, kidney, heart and lung function. Blood tests will be used to screen for exposure to transmissible viruses such as hepatitis and HIV, to assess immune system function, and to look for evidence of cancer.

In addition to bloodwork, an electrocardiogram (ECG) and chest x-ray will be ordered.

We request that a complete medical and physical examination be completed with your family doctor and the results forwarded to the Pre-Transplant Assessment Clinic.

Copies of tests and evaluations will be sent to your family doctor.

### ***Stage 3: Scans***

Once the reports from blood work, chest x-ray, electrocardiogram (ECG), echocardiogram, and ultrasound are received the Live Donor Team will review the results. If there are no abnormalities, a CT scan (to measure the size of your liver), and an MRI of your abdomen (to evaluate the bile ducts), will be ordered by the Clinical Coordinator.

### ***Stage 4: Meeting the Team***

When the Live Donor Team has received and reviewed all the results, an appointment will be made for you to be assessed.

The Live Donor Team consists of:

- Clinical Coordinators
- Surgeons
- Psychologist
- Social Worker
- Independent Doctor.
- A Chaplain is also available to see you.

The Mental and Emotional Health Assessment carried out by the social worker and psychologist is an important piece of the evaluation process. This assessment evaluates the relationship between the donor and recipient, and ensures that the donor is psychologically ready to proceed to surgery. The amount of social support available to the donor throughout the process will be also assessed.

After this assessment, it may be deemed necessary for further specific testing (e.g. pulmonary function studies, angiogram, etc) to be completed.

## Donor Assessment Stages, continued

### ***Stage 5: The Decision***

Once all tests have been completed, based on assessments of your medical and emotional status, a decision is made regarding the suitability of the donor. This decision will be communicated to the donor by one of the team members.

All information concerning the donor is kept in strict confidence and will not be given to the potential recipient or any third parties.

## Making the Decision

The decision about whether or not to become a live liver donor is a complex one and it is important that you discuss it with the Live Donor Team, a Clinical Coordinator, as well as with the recipient and the families involved.

The Live Donor Team determines whether or not you are mentally, emotionally and physically fit to be a donor, but ultimately, the final decision rests with you. The good news is the evaluation process takes place in stages, leaving time between appointments for a donor to discuss any questions or concerns that may arise. If at any time you decide that donation is not for you, you should inform your contact on the transplant team immediately.

Even after a potential donor is accepted for live liver donation and surgery is scheduled, he or she has the option of **opting out** of the operation at **any time**, even up until the day of surgery.

**The BC Transplant does not support organ donation where there may be material or financial incentives influencing the individual's decision to donate.**

# Donor Considerations

The decision whether to donate a part of your liver to a family member or friend is a very personal one. There is no right or wrong choice. In some cases, it is difficult for a recipient to ask someone to donate or to accept the offer of a portion of a liver from a potential donor. On the other hand, a potential recipient or others may place pressure on the donor to proceed with the testing. The Live Donor Team is available to assist in any way if the donor or recipient experience frustrations or difficulties while making the decision or during the assessment period. The decision has to be the one that is best for the donor and the Live Donor Team is committed to supporting the donor throughout the decision making process.

The transplant is never final until the donor liver is physically visualized by the surgeons. Although there are numerous tests completed on the donor, the actual anatomy and health of the donor liver can not be fully realized until the liver is seen by the surgeons. During the donor surgery, if there is a concern, the surgery will not proceed. The recipient will remain on the deceased donor active waiting list.

A consideration for women of childbearing years is that the donor surgery cannot occur if you are pregnant. Oral contraceptives must be discontinued 3 months prior to surgery, therefore alternative birth control methods are required.

## *Pre-Donation Considerations*

A liver transplant is often the best treatment option for someone living with end stage liver disease. A successful transplant will restore the patient's health and vitality and allow the recipient to return to a more normal life. However, the success rate for this operation is not 100% and there is a risk that the recipient may die after the transplant. There is also a slightly higher risk of bile leaks complications for a recipient of a living donor transplant compared to a deceased liver transplant. It is important as a potential donor to be aware of these possible outcomes.

There are also financial costs to be considered. The British Columbia Medical Services Plan (MSP) covers the medical costs of the living donor assessment such as lab work, team consultations, and the surgery itself, even if the potential donor lives outside the province of BC. If a potential donor lives outside of Canada, some of the assessment can be completed prior to coming to Canada, and arrangements can usually be made to reimburse the donor or the assessment centre for the costs of the tests.

Other costs that may need to be considered are the non-medical costs such as travel and loss of income involved in the assessment and donation. Will the potential donor be able to take 6 to 12 weeks away from work following surgery with the support of their employer? Will there be financial stability during this time?

You may be eligible for the **Living Organ Donor Expense Reimbursement Program**, designed to help reimburse donors of expenses incurred from the donation process. Your Transplant social worker can provide more information.

## ***Options***

The Travel Assistance Program (TAPS) offers free travel on BC Ferries and discounted air travel when authorized by a doctor. These forms can be obtained through family physicians or the Transplant social worker.

If the donor has an Extended Benefits plan through work, they will qualify for the Sick Benefits as described by the plan for any similar illness or surgery. The fact that this may be a voluntary medical procedure does not disqualify the donor from receiving benefits. Similarly, if contributions have been made to the National Employment Insurance program and the donor meets the number of qualifying hours of work in the past year, they should be eligible to receive up to 15 weeks of benefits. Employment Insurance benefits may be up to 55% of the maximum insured weekly earnings.

Obtaining relief from loan or mortgage payments during the recovery period will depend on whether the donor has loan insurance and/or on the discretion of the banking institution. A letter from the Transplant Team, describing the procedure and supporting the donor's request, may make a difference.

The support of family and friends will assist in preparing for surgery and recovery. Social support can help reduce healing time and will contribute to an overall sense that the decision to be a donor is the right one. A liver donation is considered an acute illness and therefore homemaking support is not available through the Provincial Long Term Care Program. If the donor's financial situation allows this, some people choose to hire a homemaker temporarily during the recovery period. There are some meal and grocery delivery programs available. Your Transplant social worker can provide more information.

The Clinical Coordinator is available during the working week to answer questions and concerns ( 1-855-875-5182). In addition, the Clinical Coordinator can facilitate conversations between past Live Liver Donors and people who are considering this option.

## ***Post-Donation Considerations***

The period leading up to donation may be very intense. There will be medical tests, appointments, and frequent contact with the Live Donor Team. There may be practical affairs to arrange such as leave from work, short-term disability applications to be completed, and perhaps child-care arrangements to be made. The donor usually spends a lot of time talking about the donation with friends and family, and a sense of apprehension is normal.

Many donors report feeling a sense of relief after the surgery is completed. Watching the recipient recover with restored liver function may give the donor a sense of satisfaction. Donors often feel a very strong conviction that they made the right decision, and express a desire to speak with other potential donors.

Occasionally, donors report experiencing a sense of let-down or disappointment, particularly if the transplant is not entirely successful. This is a normal response. The letdown that some donors experience usually does not last long and disappears as they regain their strength and their recovery progresses. Discussing their feelings with family, friends, and the live donor coordinator may also help.

# Surgical Aspects of Live Liver Donation

## ***Approval***

Once the donor has been approved, the surgeon will arrange a date for the operation with the hospital.

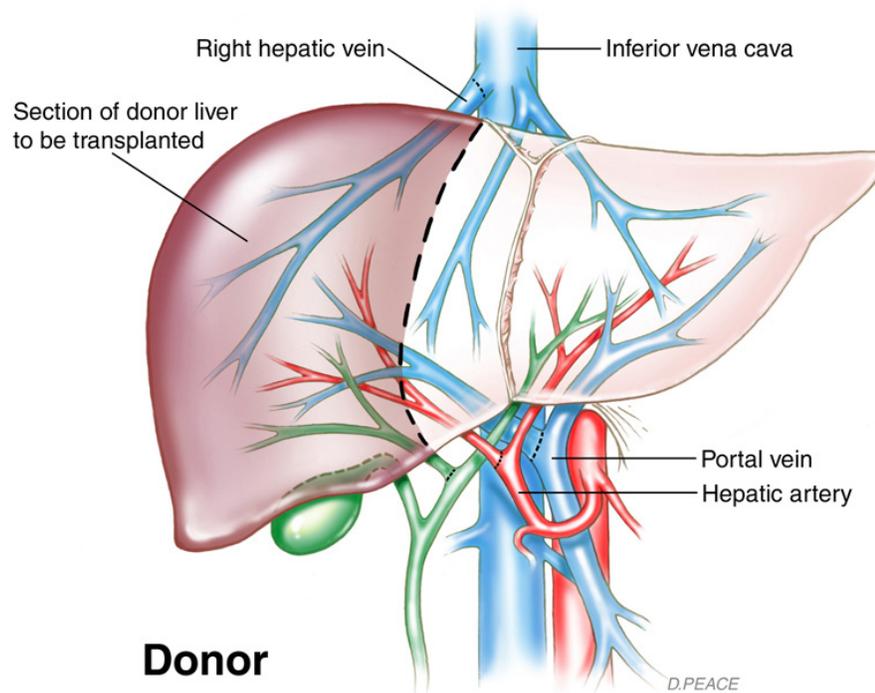
## ***Pre-Admission or Pre-Assessment Clinic***

An appointment will be arranged with the Pre-Admission Clinic at the hospital where the surgery will be performed. The main purpose of this appointment is to prepare for the day of surgery and the donor's hospital stay. A nurse will go over any questions the donor may have and an anesthetist will discuss the day of surgery and pain control following the operation.

## ***The Surgical Team***

The actual operation is performed with the help of a number of individuals. An anesthetist who will stay with the donor from the time they come in the operating theatre until the time they wake up and are stable in the recovery room. The anesthetist is responsible for administering the general anesthetic as well as monitoring vital signs and maintaining normal heart and lung function during the operation. The anesthetist will also be involved in the post-operative pain management.

A team of nurses will assist with the operation and stay with the patient from the time they come into the operating room until they are stable in the recovery room.





# Post Operative

Following the surgery, donors recover from anesthesia in the post anesthetic recovery room before moving to a surgical ward. 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.

## ***Post- Operative Pain Control***

Pain is a 'complication' of surgery that is unavoidable but it is also something that can be well controlled with appropriate painkillers. Immediately after surgery there are two ways of controlling pain. One way is called epidural analgesia and this involves placement of a small flexible plastic catheter in the upper back close to the spinal nerves. Placement of the catheter is done in the operating room while the donor is still awake (using local anesthetic). Narcotics are infused through the catheter and this blocks the pain signals coming from the incision. The catheter is usually left in place for three to five days. The narcotics do not block normal sensation or muscle function so patients can walk around with the epidural catheter still in place.

The second option for pain control is called patient-controlled analgesia (PCA). This involves the use of an intravenous narcotic (usually morphine), which is infused at a steady rate. There is a control button the donor can push to give them an extra dose of narcotic whenever the pain increases. There is a limit to how frequently the button will work so it is impossible to administer a large dose accidentally.

The choice of pain control is largely up to the patient although some people with prior back surgery or back problems may not be good candidates for the epidural catheter. The intravenous narcotics do have some side effects such as nausea, drowsiness and itchy skin. There is minimal risk of narcotic addiction developing in the few days that the drugs are administered. The epidural catheter uses much less narcotic since it is administered directly to the spinal nerves so the drug side effects are greatly decreased.

Most donors are in the hospital for 7-10 days and experience pain and discomfort for about 4-6 weeks after surgery, particularly in the first week. Approximately 10 days after surgery, a checkup is scheduled and the staples are removed.

A living liver donor needs time to rest and recover from surgery and it is recommended that 6-8 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 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 3 months, 6 months and then 12 months after surgery. There will also be routine follow-up ultrasounds of the liver and blood tests at the discretion of the liver transplant team.

# Frequently Asked Questions

## ***Who can be a live donor?***

The donor could either be a relative, spouse, or friend.

The blood type of the donor must be compatible with the recipient's.

The donor should be in good physical and mental health.

The donor should be between 19-55 years old.

The decision to be a donor should be made after careful understanding of the procedures, and consideration of the risks and complications involved.

## ***What would immediately disqualify me as a donor?***

History of Hepatitis B or C

HIV infection

Alcohol dependence/abuse

Substance abuse

Major mental illness unresponsive to treatment

A recent history of cancer

A significant medical condition

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

The risk of rejection in a live donor liver transplant is low. The same risk of rejection exists when the donor is related or non-related.

## ***What are the advantages to live donor liver transplant?***

The main advantage is the shortened waiting time for the recipient. Depending on their condition, diagnosis, status, blood type and size, patients can be on the waiting list for months or even years. Some patients may develop complications and even die while waiting for a deceased donor organ.

## ***Will the recipient be removed from the active transplant waiting list if I'm evaluated?***

NO. The recipient will remain on the active list until he/she is actually transplanted. Should a deceased liver become available for the recipient, no further testing of the living donor will take place, and scheduled surgery would be cancelled.

## ***What is the evaluation process all about?***

The evaluation process is to determine if the donor's liver is the right size for the recipient and is healthy. The evaluation also ensures that a potential donor is free from any transmittable diseases or psychiatric illness.

## ***What are the possible complications of the donor's operation?***

As with any surgery involving general anesthesia, there are possible complications of the anesthesia itself, including heart complications, stroke and blood clot formation in the legs or lungs.

There is also a risk that the remaining portion of your liver will fail and you will need an urgent liver transplant yourself. While these complications are very rare, the risks exist, and we will discuss them with you in more detail during the evaluation.

## FAQ's Continued

The most common complications of this surgery are small bile leaks from the remaining portion of your liver, wound infections, and hernias. Gastrointestinal upsets such as constipation, indigestion, nausea or diarrhea are common; however, usually resolve after a couple of weeks.

### **How quickly will I know if I can be a live liver donor?**

The evaluation time varies. Completely healthy donors may be notified as soon as 6-8 weeks. If issues are identified, the evaluation may take longer.

### ***Should I stop smoking before my surgery?***

Even a light smoker should stop smoking before surgery. A heavy smoker may not be considered a suitable donor due to increased health risks.

### ***Should I stop drinking alcohol?***

If you are going to be a liver donor, it is best that you stop drinking alcohol. If you have a history of alcohol use, it is very important that you tell our team.

### ***Should I stop taking my medications?***

You should only stop prescription medications under the advice of a physician. You should not use aspirin or non-steroidal medications such as Advil or Motrin for 7 days prior to surgery. This type of medication may increase your risk of bleeding. You may use Tylenol if needed. Women taking birth control pills or hormone replacement therapy will be advised to stop taking them because of the increased risk of blood clots during recovery from surgery.

### ***Is the surgery guaranteed to happen on the scheduled day?***

No. While every step is taken to ensure the surgery takes place at the scheduled date and time, a number of situations could arise that could mean the date is changed. The recipient's condition might deteriorate or he/she may be ill with an infection. Also, due to emergencies beyond anyone's control, the OR and/ICU may not be able to accommodate the surgery on the scheduled day.

### ***How long will the surgery take?***

The donor surgery usually begins early in the morning and may last between 8-10 hours. There is approximately a 2 hour change over time in the OR before the recipient's surgery begins. The recipient's surgery may take up to 6-12 hours.

### ***Will I require a blood transfusion during my surgery?***

Blood transfusions during this surgery may be necessary, as with any kind of operation, but are not usual with living liver surgery.

### ***Will I have pain after the surgery?***

It is normal to experience some pain or discomfort after surgery. We use a variety of methods to minimize post-operative pain including intravenous, epidural and oral medication.

## FAQ's Continued

### ***When can I start to drink and eat after my surgery?***

Usually you will start having sips of water in the recovery room. You will gradually be advanced and you will be eating a normal diet in 4 or 5 days.

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

Normally, you would only require pain medication for a short period of time.

### ***How long will I need to stay in the hospital?***

If there are no complications, the usual hospital stay is 7-10 days.

### ***How long will I be off work?***

The minimum amount of time you need to recover is 4-6 weeks. However, even if there are no complications, some donors require a few months before they feel ready to return to work.

### ***Will I have a normal life after surgery?***

We expect that you will return to a totally normal life within 3 months after your surgery, provided you do not experience any complications.

### ***When can I resume sexual intercourse?***

You may want to refrain from sexual intercourse for a couple of weeks until your incisions are well healed.

### ***How long after surgery should I wait to get pregnant?***

There is no definite answer, but we recommend that you do not become pregnant for at least 3-6 months.

### ***Will I be able to donate part of my liver again in the future to someone else?***

At this time we do not believe future donation will be possible.

### ***When will I be able to drive again?***

We advise you not to drive for at least the first 2-3 weeks after the surgery. You must be physically and mentally strong, with normal reflexes, and free from any abdominal pain or discomfort before you resume driving. You should also not be taking any narcotic pain medications such as Tylenol #3 or Oxycodone.

### ***When can I begin to exercise?***

As soon as you wake up from the anesthesia, you will begin "exercising". You will need to take deep breaths and cough to make sure you are getting air into all areas of your lungs. This will help prevent pneumonia. You will also begin to exercise the muscles of your legs by flexing and relaxing them periodically. You will be helped out of bed within 24 to 48 hours after your surgery and encouraged to walk around. By walking as soon after your surgery as possible, you will help to prevent complications such as blood clots, pneumonia and muscle wasting. You are also encouraged to continue a program of daily walking when

## FAQ's Continued

you go home but it is recommended that you wait 6 weeks before starting any major physical exercise regime. Remember the goal is to be back to normal health within 2–3 months.

### ***When can I lift weights, jog, swim, etc?***

You will need to avoid any heavy lifting (no weight greater than 15-20lbs, or about 2 grocery bags) for the first 6 weeks, until your abdomen has completely healed. After 6 weeks, if you are feeling well and have not experienced any complications, you may begin to return to your normal activities. Begin slowly and build up gradually. Be cautious with activities that strain abdominal muscles.

### ***Will I be able to drink alcohol?***

After your recovery is complete, your normal lifestyle may be resumed with no special considerations. However, if you drink alcohol it is recommended that this be consumed in moderation.

### ***How long after the surgery will it take before my liver functions normally again?***

Unless there are unforeseen complications, your liver will function immediately after the surgery. After 4 weeks, your liver will have grown back to almost its normal size.

### ***What type of follow-up care do I need?***

You may go home with a tube in your abdomen that will need to be removed within several weeks. You will receive letters from the Coordinator at Vancouver General Hospital requesting blood tests every 3 months for the first year, and then yearly for life. We also recommend a yearly ultrasound. This is to ensure that there are no delayed complications (such as bile duct narrowing) as a result of the surgery.

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### **Contact Information**

**If you have any questions please contact the Live Liver Clinical Coordinator**

**Pre-Transplant Assessment Services  
Gordon & Leslie Diamond Health Care Centre  
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Vancouver, BC V5Z 1M9  
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