

Pathways to Liver Transplantation: Common Questions & Answers

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Waiting for Transplantation

How many people are on the liver transplant wait list, and has the number been reduced due to the opioid crisis?

In Ontario, there are approximately 280 patients waiting for a deceased liver transplant. At Toronto General, the number of patients waiting for a liver transplant has nearly doubled in the last few years. This is due to the increasing prevalence of liver disease and liver cancer, along with recognition that liver transplantation is the best form of treatment for liver cancer. The opioid crisis has not had a dramatic impact on the wait list.

When is best time to get a liver transplant?

In order to answer this question, we generally compare life expectancy with and without a transplant. If there is a benefit, we will recommend a transplant to a patient, keeping in mind that transplantation improves quality of life, but also has risks.

How many people die while waiting for a transplant?

Four (4) out of 10 people on the transplant waiting list will die or be removed from the list while waiting for an organ. At UHN, this is about 30-60 people each year.

Why is there an age cut off to receive a transplant?

The reason for the age limit of 70 for the recipient is because after that age there is a greater chance for complications. Older patients tend to not be able to recover as easily or as quickly from surgery as younger patients. While 70 is the cut off, we assess each case individually and have done some transplants in 71 and 72 year olds who were in excellent health other than their liver disease.

Can recipients consent to receiving higher risk organs such as livers infected with Hepatitis C or Hepatitis B?

Yes. In the past 2 years North America and Europe have been using Hepatitis C positive donors. There is a greater need for organs than supply, so we often receive offers for “extended criteria” organs, which are organs that are considered higher risk due to the way the donor died – maybe through drug overdose, so we worry about Hepatitis C and HIV. If we choose to use an extended criteria organ, we will advise the patient that it is a higher risk organ, and that they can choose if they wish to accept it. We are currently trying to consent patients as they go on the wait list if they are interested in receiving an extended criteria organ should one come available. We will test the patient for Hepatitis C after transplant because if we transplant a liver that is positive for Hepatitis C, the recipient will get Hepatitis C. However the drugs available to treat Hepatitis C are very good and 95% of patients who take them are cured.

In Canada we do not transplant Hepatitis B livers as we currently do not have a way to control this disease. We transplant Hepatitis C livers because the drugs available to treat Hepatitis C are very good and we can keep the disease under control. This is not the case with Hepatitis B.

How often do recipients need to repeat testing while waiting for a transplant?

Repeat testing depends on the type of test and a patient's underlying liver disease. We require tests to be completed while the patient is waiting for transplant. Imaging is required every 3-6 months, cardiac testing is usually done once a year unless there are changes in the patient's health while waiting, or something happens while waiting (such as hospitalization) which may require further investigation. In addition, patients are expected to attend clinic appointments with the transplant team every 3-6 months.

If you have an autoimmune disorder and you get a transplant can the disease come back in the new liver?

Yes, sometimes autoimmune disorders do come back in the new liver. There is still a lot we don't know about autoimmune disorders or why this happens.

Is it possible to pass an autoimmune disorder on to your children that would make them ineligible to be a living donor?

Yes it is possible, as there are some indicators that a genetic component may be connected to autoimmune disorders.

If a recipient continues to lose weight and muscle mass while waiting for a transplant, is there a point where they would be deemed unsuitable for transplant?

Weight and muscle mass do play a role in the patient's overall health, however, if a BMI is less than 17 or greater than 45, it may be decided that transplant is not safe. We determine transplant suitability by looking at the global picture – all aspects of the patient and not just one area. It is important to note that patients will continue to lose weight and muscle mass until they receive a transplant, and there is a possibility that a patient may become so sick that a good outcome from transplant is unlikely.

Should recipients waiting for a transplant take protein supplements?

We recommend that patients eat 1.5 grams of protein per kilogram of weight each day. Protein is needed to maintain muscle mass, which is often lost while patients wait for transplant. We do not recommend a patient eat a steak every night, but suggest non-meat proteins as these are easier for the body to break down. We recognize how difficult this may be for patients, as liver failure causes a decreased appetite and feeling of fullness. We also suggest that patients have protein drinks such as Boost or Ensure if they are finding it difficult to eat solid foods.

(Na) MELD Score

Do you need a Sodium (Na) MELD Score of 15 or higher to access your program?

A Sodium MELD (Model for End-stage Liver Disease) score of 15 is generally accepted as an indication of when the benefits of a transplant exceed the risks. Sometimes we will see patients with

a lower (Na) MELD score if the score does not reflect how sick they really are. There is no absolute number below which we will refuse to see a patient for consultation if there is a reasonable expectation that they may benefit.

Is there a minimum (Na) MELD score required to receive a living donor transplant?

We want to ensure that our patients will benefit from a transplant. We try to make decisions about transplantation independent of whether or not the patient has a live donor. Patients with a live donor tend to have a lower (Na) MELD score because their liver disease is not as advanced. These patients also enjoy greater benefits from transplant because they are less sick when they go into the operating room.

Are there additional exception points for cholangitis, hospitalization, etc.?

Exception points are awarded in cases where the (Na) MELD score does not reflect how sick patients are. The exception point system is elaborate and includes a number of indicators. Most patients awarded exception points have cancer, however, there are number of other conditions such as recurrent infections arising from the biliary tree and lung disease attributable to liver disease, among others. We spend a lot of time talking to patients about exception points because it's important that they know where they sit on the deceased organ wait list.

Can the (Na) MELD score reverse?

Yes, some patients may be removed from the waitlist as a result of a falling (Na) MELD score. For example, patients with Hepatitis C who are successfully treated, may lose their indication for transplant. Sometimes an individual with alcoholic liver disease will continue to have improved liver function even one or two years after they stop drinking. In such cases, they may no longer require a transplant. Transplanting early is better than transplanting late. Patients are encouraged to remain physically active while waiting for a transplant.

Cancer

Does cancer increase one's (Na) MELD score?

Patients with cancer are prioritized on the deceased organ waitlist and this means these patients are more likely to get a transplant. The (Na) MELD score was adopted by Transplant Programs and the Trillium Gift of Life Network. It is used by our program and many others to assess which patients would benefit from a transplant, and to determine to whom the next organ should be allocated when someone is waiting for a deceased organ offer.

What are exception points for cancer patients?

In order to be placed at the top of the waitlist, patients need to have a high (Na) MELD score, and as a result are often very sick. We typically see offers for deceased organs when a patient's (Na) MELD score is between 28 and 31. This places cancer patients at a disadvantage because their (Na) MELD score does not accurately reflect how sick they are. If we are to rely on (Na) MELD score only, cancer patients could wait for a long time to reach the top of the list. Cancer patients receive 3 exception

points every 3 months, which is added to their (Na) MELD score. The exception points allow cancer patients to be competitive with patients who have other liver diseases and provides them with a better chance of receiving a transplant from a deceased donor.

What proportion of patients with liver cancer do not have underlying liver disease?

In our program, these patients are quite rare - less than 1% of patients are transplanted. This excludes patients who have cancer elsewhere in the body, which has spread to the liver. Primary liver cancer almost always arises as a result of underlying liver disease.

Does it matter if liver cancer patients receive a full graft or partial graft?

Patients who are transplanted for liver cancer have their whole liver removed. The damaged or diseased liver is replaced with a partial graft from a living donor or a full graft from deceased donor. The type of graft does not affect the risk of cancer recurrence.

Post-Transplant

When is the risk of organ rejection highest?

The risk for rejection is highest right after transplant and decreases as time goes on, therefore every recipient is put on immunosuppressant drugs post-transplant. Recipients usually receive steroids plus one or two antirejection medications. Additional antirejection medications may be required for some recipients, particularly those who are at greater risk for rejection – usually younger patients or recipients who were transplanted for an autoimmune disorder. We taper the antirejection medications as soon as possible to minimize the side effects of immunosuppression while maintaining the function of the transplanted liver.

Do liver transplant recipients require fewer immunosuppressant drugs than other organ transplant recipients? Is it possible for a recipient to stop taking immunosuppressing drugs?

Yes, typically liver transplant patients often require fewer anti-rejection medications than those who have received other organ transplants. The liver has the potential ability to develop tolerance and in a small percentage of cases, may eventually recognize the new liver as its own. We do not have a good predictor to tell if a recipient will become tolerant and there is too much risk to stop the medication to find out. We are currently trying to develop predictors to find out who is more likely to become tolerant by identifying genetic markers. Although the risk of rejection does decrease over time, patients should anticipate the need to take immunosuppression medications for life.

Is there anything the recipient should be aware of after they receive a transplant such as a special diet?

After transplant most recipients take steroids, which are slowly tapered and usually stopped by 12 weeks post-transplant. Steroids increase a person's appetite, so we tell patients that this is a time to replenish your body, which has been essentially starving before transplant. With that said we do not want to recreate the issues that may have led to transplant such as fatty liver and have to re-

transplant in 5-10 years for the same reason. We do offer dietician services and an exercise program to help people get motivated to restart eating. Grapefruit is known to interfere with a common class of anti-rejection medications and patients are advised to avoid grapefruit and products containing grapefruit.

Is the 20-year life expectancy based on a single liver transplant?

Generally, we anticipate a liver transplant to last for life. However, it is possible to re-transplant the liver. Approximately 5-10% of patients over the long-term will need a second transplant.

Living Donation

Is there an advantage to receiving a living organ transplant?

Living donation carries a survival advantage because it reduces the amount of time waiting for a transplant and eliminates deaths on the wait list. Patients with living donors have better outcomes overall.

When should I start my search for a living donor?

Once you are determined to be eligible for a transplant you should start looking for a living donor. We generally wait until patients have been approved for a transplant to start assessing potential living donors.

Do blood groups matter when it comes to finding a living donor?

Yes, blood groups do matter. Ideally, a living donor should have the same blood type as their intended recipient. If the blood groups are not compatible, the pair can avail of the paired exchange program where they will be matched with another incompatible pair. Both donors will donate a portion of their liver to the other pair's recipient. For some patients, ABO-incompatible living liver transplantation may also be an option.

Is organ size related to a person's physical size?

Somewhat. The volume of liver that is being removed must be large enough to sustain the recipient, while minimizing risk to the living donor. Volume not being compatible is one of the most common reasons why a living donor does not move forward in the assessment process. To get exact measures of the liver, the donor will undergo a CT scan. Usually it is easier to accommodate a liver from a larger person going to a smaller person, but do not rule out being a live donor based on your body size compared to your intended recipient.

Why do living donors with fatty liver get rejected from being living donors? Is it possible to give a recipient a fatty liver and have the recipient lose weight, diet, exercise to make the fatty liver go away?

No, we would not transplant a fatty liver for two reasons. One is donor safety. It would not be safe for us to remove 70% of a donor's liver to give to a recipient and leave the donor with 30% of a liver

that is fatty. This could cause complications for the donor and the liver may not be able to fully regenerate. The other reason we do not transplant fatty livers is because the fat is embedded in the makeup of the liver and would not be easily reversed through diet and exercise. UHN does have a program in place to support individuals who need to lose weight in order to be considered for living organ donation.

Is there an option for people thinking of living donation to meet someone who has been through it?

Yes. Many of our living donors have volunteered to share their experience with others. If this is something you are interested in, please contact your social worker or Living Donor Coordinator.

How are the risks of living donation communicated?

The risks of living donation are summarized in the living donor manual and reviewed in education sessions and materials provided throughout the process. The surgeon generally discusses the surgical risks with each prospective donor. Other risks are discussed with various members of the team during the assessment process. We tell living donors that recovery from surgery takes time. Once we start testing, results may indicate an underlying medical issue that was previously unknown, and this may impact the ability of the donor to obtain insurance.

Have any living donors died in your program?

No, we have done over 800 living liver transplants in the last 20 years and no living donors have died in our program.

Is the donor surgery covered if the living donor is from another country and the recipient is a TGH patient?

Yes, the cost for the living donor's surgery as well as the hospital stay is covered under the recipient's health plan. In Ontario this would be OHIP. If the living donor is donating to an Ontario resident, they are eligible to apply to the PRELOD program to help cover out of pocket expenses, (e.g., accommodation and time away from work) even if they live in another country. Living donors should be aware that medications they are required to take after surgery are not covered and they will need to pay for these out of pocket or through their private insurance. The assessment process for out of country donors may take longer than local donors due to travel needing to be arranged for testing.

If someone wanted to find a living donor what should they do?

It is often difficult for the recipient to broach a conversation about living organ donation. It is helpful to have a close friend or family member have this discussion on your behalf. You may want to say that your doctors have told you that live donation is the preferred route because you are likely to be transplanted more quickly and recover more quickly. We suggest that you start with close friends and immediate family and widen the circle to work groups, social groups, neighborhoods and

potentially more widely. As you widen the circle and tell more people, there is a loss of privacy, so it is important that you are comfortable with others knowing about your health status.

Living Donor Assessment

How long does it take from when a medical history is submitted to living organ donation?

When you submit an application, we will respond within 2 business days to confirm we have received the application and then begin the assessment. If you are not contacted immediately, it may mean that there is another living donor in assessment for that recipient. Generally, when a donor starts the assessment it takes about 4-6 weeks for the assessment to be completed. Surgery is scheduled based on the availability of the donor and the recipient's health as well as availability of hospital resources.

Has the age cut-off for liver donation changed?

In Ontario, the minimum age to donate was changed to 16 as a result of legislative changes. All donors, particularly younger donors, must fully understand the potential risks of donation and provide informed consent. The cut off at age of 60 was agreed on by our program because an older liver regenerates more slowly and this poses a risk for both the donor and the recipient. After the age of 60, you also don't recover from surgery quite as well or as quickly.

What is paired liver donation?

Paired liver donation is helpful in cases when a donor would like to donate but has a blood group that is incompatible. It allows two patients to swap living donors and receive an organ that is matched to their blood group and body size.

If I am not blood compatible to my intended recipient is there a match program?

Yes. Given the size of our program there is probably another pair who are in a similar situation. Not being a blood match does not eliminate you from being a living donor as there are opportunities to do paired liver exchange. Our first paired exchange was a year ago and it was a success. If you are interested in paired exchange, please submit your living donor application and team will look for opportunities for paired exchange. An ABO-incompatible liver transplant may also be an option.

Is there way to improve communication regarding where the living donor is in assessment phase? Not hearing anything creates anxiety for the recipient.

The number one priority for the living donor program is the safety and well-being of the donor. We do not inform the recipient about what is happening with the donor because it is a breach of privacy and privacy laws prevent us from disclosing the donor's information. We understand that not knowing what is going on can be stressful and cause anxiety for the recipient, however donor autonomy and privacy are our priority. Even telling the recipient that "there is a donor in assessment" could be a breach of privacy. If only one person has expressed interest in being living donor, then the recipient may be able to identify who that person is. Another issue with sharing information about the donor, is that the donor may not be ready to tell the recipient that they are going through the assessment and may want to wait until they know they have been approved.

Many donors do not tell the recipient about their assessment because they do not want to disappoint them or give them false hope if they do not get approved. Most often the donor and recipient have a close relationship and share information with each other. As a program we will not prevent this, but we are unable to facilitate the sharing of patient information.

Is there a number of living donors that are assessed before a match is found?

There is no specific number of donors that one should look for, as each case is different. On average for every six people who apply to be living donors, three are assessed (the others are ruled out based on age, health history etc.). Of the three people who we assess, only one is approved as a living donor. This is why it is so important for recipients to keep looking for a living donor, even if you know someone is going through the assessment. It is important to note that even if a potential donor is not a blood match to the intended recipient, they should still apply as there are other options for living donation such as paired exchange and ABO-incompatible liver transplant.

Post Donation

How long does it take the living donor to get back to their “old self” after transplant?

What is the recovery like?

Most living donors are “back to normal” within 5-6 weeks post-surgery, however it can take up to three months to recover fully. Donors usually report that the first month is the hardest and that they must take it easy and take time to recover. Many living donors are back to work within eight weeks post-surgery if they have desk type jobs. Some donors are off work for up to three months post-surgery if they work in jobs that are physically demanding.

What if your living donor is your spouse? Who will help/provide care if both of us are recovering from surgery?

Living donors need to be aware that the first month after surgery is often the most difficult. During the first week to two weeks post-surgery, the living donor needs help with everything – showering, meal prep etc. It is recommended that living donors have someone at home to provide assistance, as they can do very little for themselves. Even simple things like getting groceries is a challenge. By two weeks post-surgery the living donor should be able to get themselves up, walk and do little things. While the living donor is recovering at home, the recipient is still in hospital being cared for by hospital staff.

What medications do living donors need to take after they donate?

For the first six weeks after surgery the living donor must take blood thinners, iron pills and an antacid. The blood thinners are an injection that the living donor must give themselves daily, which may be difficult for some donors.

Is pregnancy an option after being a living donor?

Yes, pregnancy is possible after living organ donation. As far as we know, living donation has no impact on fertility.

What do living donors need to know before the surgery?

Living donors are healthy and may not realize how much help they will need with everyday activities like dressing and bathing during the post-surgery recovery period. It is important to build your support system prior to surgery so that you have lots of help after it.

Are living donors able to receive EI? Is it difficult to receive EI? EI could view the living donor as having intentionally made themselves sick and are therefore not eligible.

Yes, living donors qualify for EI, however it can be a struggle to get approved and it can take a while for approval to occur, resulting in a gap in income. EI advises that it can take 2 weeks to process a claim, however this is a minimum and many patients wait much longer before receiving benefits. It is suggested that the living donor apply for the PRELOD program, which can help with income recovery. There is also an EI clause that protects a donor's job while they are off work recovering from surgery.

Other

Where are things headed in terms of liver transplant? Do you see the possibility of improved technology? New surgeries? New innovations?

When liver transplants started, a surgery would take 15-20 hours. As things have advanced, we are now at a point where liver transplant surgery takes five hours and has become more routine. Our program is one of the busiest liver transplant centre in North America, which has given us the opportunity to gain more and more experience and get better and better at doing things. The hope is that with new innovations such as stem cells, there will not be a need for transplants in 25 years.

For answers to other common questions, or more information on living liver transplantation, please visit www.uhn.ca/transplant.

For the latest statistics on organ donation and waitlists in Ontario, please visit www.giftoflife.on.ca/en/publicreporting.htm.