

Pre-Liver Transplant Manual

Pre Liver Manual



Toronto
Liver Transplant
Program

*This manual is dedicated to our donors, our patients, and
their families*

Acknowledgements

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Table of Contents

Discharge Planning Consent Form	5
Alcohol Abstinence Agreement	7
Welcome to the Transplant Program	10
Our Philosophy of Care	
Our Expectations of You	
Your Transplant Team	
Why You Need a Liver Transplant	13
Signs & Symptoms of Liver Disease	
Am I Eligible for a Liver Transplant?	
Advantages & Disadvantages of Liver Transplant	
Transplant Risks	16
Infection Risks with Transplant	
Disease Recurrence After Transplant	
Liver Transplant for Hepatocellular Carcinoma (Hepatoma)	
	21
The Transplant Assessment Process	
Transplant Work-up	
Living Donor Liver Transplant	
Living Donor Assessment	
Center for Living Donor Donation	
Drug Coverage, Financial Information, Legal & Advance Care Planning	26
Costs of Transplant Medications/Drug Coverage	
Trillium Drug Program	
Seniors Medication Coverage	
Financial Information	
Legal Information for Patients/ Advance Care Planning	
Pre and Post-Transplant Support Requirements	
After the Assessment Process	35
While you are Waiting	
Your Place on the List	
Clinic Appointments	
Maintaining Contact	
The Deceased Donor Process	
Dealing with Stress	
Reminders While you are Waiting	
	43
The Call for Transplant	
Getting the Call	
False Alarms	
When A Liver Becomes Available	
Coming to Hospital	
What to Bring to Hospital	

Your Hospital Stay	48
Your Transplant Surgery	
Care after Transplant	
Possible Complications after Liver Transplant Surgery	
Clinical Trials	
UHN Discharge Policy	
Guidelines on the Transplant Unit	
Your Recovery after Transplant	
Discharge Checklist	

myUHN/Patient Portal	58
What is myUHN	
Sending Messages to your Care Team	

Appendices

Resource List	59
Getting to Toronto General Hospital	61
Map of Toronto General Hospital - Ground Floor	62
Vaccines in Solid Organ Transplant Recipients	63
Important Contact Numbers	64

WARNING:

If you are approached or contacted by someone who offers to move you up the list in exchange for money, please call the transplant program immediately.
416-340-5163
This person is **NOT** a member of the transplant team.

What they are suggesting is illegal.

In accordance with the Ontario *Human Tissue Gift Act*,
The Toronto General Hospital & the Soham & Shaila Ajmera Family Transplant Center do not support or accept payment of any kind from patients, organizations or any party for organs for transplantation.

It is against the law to buy, sell or otherwise deal in, directly or indirectly, any tissue for transplant, or any body part or parts of the body for therapeutic purposes, medical education or scientific research.

**If at any time you are approached by a person to purchase or sell an organ for transplantation, please immediately contact:
Patient Relations at (416) 340-4907.**

DISCHARGE PLANNING CONSENT FORM
Soham and Shaila Ajmera Family Transplant Centre
University Health Network
University of Toronto

Introduction

You are being considered for solid organ transplantation. Discharge planning is a critical part of the recovery process after transplantation. Before listing candidates, our program requires that you and your designated caregiver(s) 1) obtain adequate drug coverage, as outlined below; 2) if necessary, arrange accommodation for you and/or your caregiver(s) for 2-3 months following transplantation; 3) agree to work with our team to expedite your discharge, whether to home or to a secondary health facility, as discussed below; 4) be prepared to transport yourself/your caregiver(s) to and from the hospital for follow-up care. **Please note that in uncomplicated cases, we aim to discharge our liver transplant patients from the hospital in the first 1 to 2 weeks after the operation, and that it is possible that your hospital stay may be even shorter.**

Consent:

The discharge planning process at the Soham & Shaila Ajmera Family Transplant Center and University Health Network has been explained to me. We have been given the information package regarding discharge policies at University Health Network and any questions have been answered to our satisfaction. By signing this form as patient and designated caregiver(s), we hereby confirm:

1. Before the transplant, we have been approved for all possible drug coverage programs that have been recommended by the multi-disciplinary team. (i.e. Trillium Drug Program, Ontario Works, Ontario Disability Support Program, or Seniors Benefits) **ACCEPTANCE TO ONE OR MORE OF THESE PROGRAMS IS MANDATORY FOR LISTING.** Coverage must be maintained while you are on the transplant waiting list. Adherence to this requirement will be monitored while you are on the transplant waiting list. Failure to ensure adequate coverage will impact your listing status.
2. Before the transplant, if deemed necessary by the multi-disciplinary transplant team, we will arrange for our accommodation close to Toronto for the immediate six to eight week period following discharge from hospital after transplantation.
3. After the transplant, we will work with the multi-disciplinary healthcare team to expedite recommended discharges from University Health Network;
4. After the transplant, in the event that the care giving team recommends discharge to a secondary health care facility (i.e. rehabilitation, chronic care,

nursing home, etc) as opposed to home, we will accept the first available opening from a list of facilities developed by the team and hospital.

5. After the transplant, we will be prepared to transport ourselves to and from the hospital for follow-up care for at least six to eight weeks after transplantation.

_____	_____	_____
Patient's name	Signature	Date
_____	_____	_____
Designated Caregiver	Signature	Date
_____	_____	_____
Name of Person Obtaining Consent	Signature	Date

Was the participant assisted during the consent process? YES NO

If YES, please check the relevant box and complete the signature space below:

The person signing below acted as a translator for the participant during the consent process and attests that the information as set out in this form was accurately translated and has had any questions answered.

_____	_____	_____
Print Name of Translator	Signature	Date
_____	_____	
Relationship to Participant	Language	

The consent form was read to the participant. The person signing below attests that the information as set out in this form was accurately explained to, and has had any questions answered.

_____	_____	_____
Print Name of Witness	Signature	Date

Relationship to Participant		

**Soham and Shaila Ajmera Family Transplant Centre
Alcohol Abstinence Agreement
University Health Network
University of Toronto**

It is important for you to know that your liver disease has been caused by, or has been getting worse because you were drinking alcohol in the past.

With this, it is the practice of the Liver Transplant Team at the University Health Network (and of other liver transplant centers across Canada) **to evaluate for liver transplantation only to those patients who have stopped drinking for at least 6 months and agree to completely abstain from drinking alcohol before and after liver transplantation.**

To be considered for a liver transplant at UHN, you may be required to:

1. Receive support and counseling to help you remain abstinent from alcohol
2. Provide evidence that you have attended these sessions,
3. Agree to give random blood or urine samples (or both) to test for the presence of alcohol in your system

If you cannot commit to these requirements, you will not be listed for liver transplantation, or you may be removed from the transplant waiting list if you are found to be continuing to drink alcohol.

This agreement is intended to help you make a **personal commitment** to stop drinking alcohol before and after your liver transplant.

Please read the agreement carefully and, talk to your Transplant coordinator or Transplant doctor about any questions or concerns you may have before you sign this form

Alcohol Abstinence Agreement

Liver transplant alcohol abstinence agreement:

I, _____, understand that the practice of the Toronto General Hospital Liver Transplant Program forbids me from drinking alcohol before and after liver transplantation. I also understand that I will only be considered a candidate for transplant if I have stopped drinking for at least six months and agree to remain abstinent from alcohol.

- I agree to receive individual counseling to help me stop drinking alcohol and, to provide evidence that I have received, or am receiving counseling as requested
- I agree to be an active participant in any alcohol abuse support group that my transplant team believes would be best for me
- I understand that if I do not participate in a support group or individual counseling session, this may affect my candidacy for transplant

Permission for samples to test for alcohol use:

I give permission for Toronto General Hospital to take blood or urine samples, or both, from me for the purpose of screening for alcohol use.

- I understand that a positive test will mean that I have used alcohol.
- I also understand that a positive test will mean that I will be removed from the liver transplant waiting list.

Transplant candidate commitment to stop:

By signing this, I agree with and, understand all of the information about the UHN liver transplant program alcohol abstinence expectations, as well as the consequences for me if I cannot stop drinking alcohol, or consume alcohol while waiting for transplant.

Patient's name	Signature	Date
Designated Caregiver	Signature	Date
Name of Person Obtaining Consent	Signature	Date

Transplant Team use only:

Was the participant assisted during the consent process? YES NO

If YES, please check the relevant box and complete the signature space below:

Language Interpretation

The person signing below acted as an interpreter for the participant during the consent process and attests that the information as set out in this form was accurately interpreted and that the participant has had all his or her questions answered.

Print Name of Translator Signature Date

Relationship to Participant Language

Literacy Assistance

The consent form was read to the participant. The person signing below attests that the information as set out in this form was accurately explained to the participant, and that the participant has had all his or her questions answered.

Print Name of Witness Signature Date

Relationship to Participant

Welcome to the Soham and Shaila Ajmera Family Transplant Centre & Your Liver Transplant Team

The Soham & Shaila Ajmera Family Transplant Center at Toronto General Hospital is Canada's largest transplant centre and performs a broad range of transplants. Our program performs over 150 liver transplants each year, with results that are equal to or better than those of any program in the world. The hospital is proud to support the largest living donor liver transplant program in North America. We have a long history of pioneering efforts in the clinical and scientific foundations of transplantation.

The liver transplant program offers both living donor and deceased donor liver transplantation for patients with end stage liver failure. Among the advantages of live donor liver transplantation are shorter waiting times and improved survival from the time of listing, but both live donor and deceased donor liver transplantation are good options for the treatment of end stage liver disease.

It is important that you join us in our teaching programs and share this manual with your support persons and family. Transplantation is a team effort, we are your team and you are the most important member.

Our Philosophy of Care

- We believe that our work is possible because of the generosity of organ donors. Our work must honour these remarkable gifts from donors and their families.
- We believe that respect, dignity, integrity and empathy drive care and support relationships. We expect courtesy and consideration in every interaction.
- We believe that the goal of the Liver Transplant Program is to work in partnership with individuals, families, and the community to promote optimal health and quality of life for patients through all phases of transplantation.
- We believe that transplantation is a very specialized area in health care. To succeed, we need the knowledge skill and ability of our multi-disciplinary team.
- We believe that all members of the health care team make an important and valuable contribution to the plan of care. Each member of the team is a dedicated professional who continually maintains a current knowledge base and consistently strives to advance the science and art of transplantation.
- We believe that all people are unique, with their own needs, goals, and abilities.
- We believe that people achieve their optimal state of the health in collaboration with the health care team.
- We believe that information and education provide patients with knowledge to exercise their rights and responsibilities to make informed decisions about their health care.
- We believe that the best possible care is based on patient needs, available resources, and ethical principles.

- We believe that all services must be provided in a safe environment that supports health goals and enables care to be delivered with comfort and efficiency.

Our Expectations of You

Throughout your transplant experience in the Liver Transplant Program at The Toronto General Hospital you have the responsibility to:

- Work in partnership with the health care team to ensure the best possible treatment, rehabilitation, discharge planning, and follow-up care
- Provide accurate information and to share any concerns with all members of the health care team
- Inform the team if you do not understand or cannot follow the health care instructions
- Respect that the needs of other patients and families may be more urgent than your own needs
- Treat staff, other patients and their families in a considerate, courteous, confidential, and cooperative manner
- Understand the Toronto General Hospital's role as a teaching and research hospital and to partner with health care professionals in training
- Smoking cessation is strongly encouraged for all of our patients

Your Transplant Team

Throughout your transplant journey, we will teach you how to care of your organ and your health and support you through this process.

Your transplant team includes:

- | | |
|-------------------------------------|---------------------------|
| ➤ Doctors (Physicians and Surgeons) | ➤ Nurses |
| ➤ Social Workers | ➤ Transplant Coordinators |
| ➤ Nurse Practitioners | ➤ Spiritual Care Workers |
| ➤ Physio/ Occupational Therapists | ➤ Psychiatrists |
| ➤ Dietitians | ➤ Pharmacists |
| ➤ Other health care professionals | ➤ <i>You</i> |

Some of the health care professionals that you will come in contact with are:

Hepatologist

A Hepatologist is a doctor who is highly skilled in the diagnosis and treatment of liver disease. This doctor, together with your family doctor, will care for you before and after your transplant.

Liver Transplant Surgeon

The Liver Transplant Surgeon is involved in patient evaluation and selection. The surgeon performs the transplant operation, and is involved in your post-operative recovery in hospital.

Transplant Coordinator

The Transplant Coordinator is a registered nurse or nurse practitioner who coordinates the transplant evaluation process, provides transplant education and provides follow-up care before and after the transplant. The coordinators work together with your transplant hepatologist to assess and support your progress.

Medical Secretary

The Medical Secretary is an administrative assistant who works closely along with the transplant coordinator during the transplantation assessment, prior to and after transplantation. The Medical Secretary can relay concerns to the transplant team but is not qualified to give medical advice.

Social Worker

A Social Worker meets with all transplant patients and their families to review your individual situation and family supports. They will work with you and your support people to plan for your transplant.

Psychiatrist or Psychiatric Nurse

Our psychiatrists and psychiatric nurses specialize in helping patients and their families cope with chronic illness and its effects, as well as any acute psychiatric problems that might arise after transplantation. They may meet you during your transplant evaluation.

Physiotherapist

The physiotherapist will work with you after your transplant to help you gain and maintain optimum strength and flexibility.

Health Care Providers outside of the Transplant Team

Your family doctor and/or liver specialist (i.e.: the family doctor or gastroenterologist who referred you to our program for transplant evaluation) are still your primary source of healthcare. It is important for you to have regular check-ups in addition to your visits with the transplant team. The transplant team will work with your family doctor or liver specialist to provide care before and after your transplant.

Transplant patients with diabetes also need to see a diabetic specialist (Endocrinologist) regularly before and after transplantation.

Why You Need a Liver Transplant

Your doctor has suggested that you may need a liver transplant. To understand why, it is important to know how the liver works. The liver is the largest solid organ in your body. The liver has many functions, all are important to support life and health.

The liver:

- builds special proteins to prevent bleeding
- filters blood and helps fight infection
- makes bile to break down fats from food
- builds sugar, stores sugar, and releases sugar for energy
- stores vitamins and minerals
- helps to break down proteins in the food you eat
- sends hormones to other organs in the body

When disease damages your liver, it does not function normally.

Many diseases may lead to liver failure:

- Viral Hepatitis: Hepatitis B or C
- Alcoholic Hepatitis
- Non-Alcoholic Steatohepatitis [NASH]
- Primary Biliary Cirrhosis [PBC]
- Primary Sclerosing Cholangitis [PSC]
- Alpha-1-antitrypsin deficiency
- Drug-induced Hepatitis
- Budd Chiari Syndrome
- Congenital Fibrotic Disease
- Cryptogenic Cirrhosis
- Hemochromatosis
- Polycystic Liver Disease
- Wilson's Disease

In addition to liver failure, liver cancer may develop as a result of many of these diseases.

There are also cases of sudden liver failure with unknown causes called acute or subacute fulminant liver failure.

Signs & Symptoms of Liver Disease

A diseased liver cannot carry out its normal functions. People with liver disease or liver failure may experience:

- Ascites (fluid in the abdomen)
- Fatigue
- Confusion
- Change in sleep patterns
- Itching
- Easy bruising
- Nausea and vomiting
- Muscle cramping
- Swollen ankles
- Dark urine
- Fever and infections
- Pain over the liver
- Internal bleeding
- Jaundice (yellow color of the skin or the white part of the eyes)
- “Spider veins” (broken blood vessels on the face, arms & chest)
- Change in appearance of bowel movements (pale stools, black stools or, fatty stools)

Please note that not everyone will experience all of these symptoms.

After being damaged, the liver may be able to grow new cells. However, if the damage is too extensive for repair, then you will need a new liver.

If your doctor is recommending that you consider having a liver transplant, it means that there is little to no chance your liver will recover, or that you have developed a complication of liver disease that can best be managed with transplantation (e.g. liver cancer). We will help you understand the benefits and risks of having a transplant. This will give you the information to make an informed decision. **The decision to proceed is up to you.** We will support your choice whether you choose to go forward with liver transplantation or not.

Am I Eligible for a Liver Transplant?

Each patient is assessed individually for their suitability for transplant. Basic requirements for liver transplant are:

1. Your transplant assessment shows that you:
 - a. Have liver failure (or a complication of liver disease) that will not improve without transplantation
 - b. Are able to safely tolerate anesthesia and surgery.
2. You want to have a transplant, you understand and accept the responsibilities, and have the resources required before and after the transplant.

Our goal is to make your transplant as safe and as successful as possible. Our commitment to you includes involving you in your care decisions, helping you to understand your treatments, and checking with you regularly to ensure that your treatment plan is working.

We will need your commitment too. **Having a transplant will change your life significantly.** Before you make this choice, you need to be prepared to make many changes. After your transplant, you must follow the treatment plan carefully to have a successful transplant. This includes being part of your healthcare team, learning about your treatments, taking your medications, and attending your clinic appointments.

Advantages & Disadvantages of Liver Transplant

Advantages:

- You have more energy
- Your diet is less restricted
- You do not have fluid restrictions
- Your hemoglobin increases.
- Your memory will improve and you will have clearer thinking
- Overall, your health is improved

Disadvantages:

- You will need transplant medication (immunosuppressants and others) for the rest of your life to prevent rejection.
- You will need follow-up transplant care for the rest of your life.
- You may have side effects from your medications
- You will be at greater risk for infection after the transplant
- You will be at greater risk for certain types of cancer

Infection Risks with Transplantation

The risk of infection related to transplantation needs to be considered when choosing whether or not to proceed with liver transplantation. We hope this helps transplant candidates make an informed decision about transplant surgery. Please speak to your doctor or transplant coordinator if you have **any** questions about the information that follows below.

Infections are an unavoidable risk of transplantation. They are the most common complication after transplantation, occurring in about 1/3 of patients. The risks of developing an infection must be balanced against the benefits of a transplant.

Transplant patients are at greater risk for infection because the anti-rejection drugs given after transplant affect their immune systems. Bacteria, viruses, fungi, or other organisms can cause infections. Most infections can be successfully treated, but some are difficult to treat and can cause disability or death.

We try to minimize the risk and impact of infections in part by

- 1) routine testing of the donor and of blood products;
- 2) giving anti-infective medications at the time of surgery and sometimes afterwards; and
- 3) monitoring and testing recipients.

Our knowledge of the infection risk with transplantation continues to grow. Over time, we will continue to learn about new infections that are currently unknown. Wound infections, abscesses, pneumonia, and urine infections are potential complications of any surgery. Some, but not all, of the infection risks associated with transplantation are discussed below.

Multi-drug Resistant Bacteria

Some patients in hospital have developed bacterial infections that are resistant to standard antibiotics. Some specialized antibiotics may be effective in this situation. We try to reduce the risk of multi-drug resistant bacterial infections in our transplant unit by only giving antibiotics when absolutely necessary.

Viral Hepatitis (Hepatitis B, C)

Donors are tested for the presence of hepatitis B and C virus infections. As with other viral infections, testing is accurate but not 100% effective in avoiding disease transmission. Organs from donors who have been exposed to the hepatitis B or C virus are sometimes knowingly given to recipients who have also been previously exposed to, are already infected this virus or have developed immunity.

Cytomegalovirus (CMV)

CMV can cause flu-like symptoms, pneumonia, hepatitis, and other illness. Most people have already been exposed to this virus and have some degree of immunity. Since CMV is very common in the general population, you may receive an organ from a donor that is positive for CMV. Transplant recipients who are at high risk of developing CMV infection will be given medications to reduce the risks of CMV infection. Reasonably effective treatment is available if a CMV infection develops or recurs post-transplantation.

Epstein - Barr virus (EBV)

EBV also causes flu-like symptoms. Rarely, it can cause a disease similar to a lymphoma (a type of blood cancer). Fortunately, most people have been exposed to EBV and have partial immunity.

West-Nile Virus

Most patients with this infection have no symptoms or minor symptoms. Sometimes the infection can produce permanent brain or nerve damage. This virus is transmitted by insect bites, but also through blood transfusions or organ transplantation. It is a fairly new problem in Ontario. We do not yet know the likelihood of contracting this infection but a very small number of our transplant recipients have become infected. Although some have recovered, others have become disabled or have died. Currently, blood and organs from donors with symptoms suspicious for recent West-Nile infection are excluded.

AIDS (Human Immune Deficiency Virus)

All donors are tested for HIV. The testing is very accurate but again not 100% reliable for preventing HIV transmission with blood organ donation. There is a brief period of time during the beginning of an HIV infection when the virus testing could be negative but the donor could still be infectious.

COVID 19

The risks of being infected with COVID-19 and having complications are higher in transplant recipients. Patients who are currently being considered for transplant or on the transplant waitlist are required to be fully vaccinated against COVID-19 (2 doses). If you have received the COVID-19 vaccine already, **please send your proof of vaccination by mail or fax**. If you have not yet gotten the vaccine, we urge you **to make an appointment to be vaccinated as soon as possible**. Not receiving the COVID vaccine could affect your eligibility for transplantation.

Unknown Infections

Transplant recipients may be at risk of acquiring previously unknown infections due to their weakened immune system. It is possible such an infection may be acquired from the donor. Every effort is made to ensure that donors with symptoms suspicious for any type of known or unknown infection are excluded.

Disease Recurrence After Transplantation

Some liver diseases that were present before transplant, and caused the need for transplant in the first place, may recur in the new liver graft.

Hepatitis B

There are highly effective and well tolerated medications available to control hepatitis B virus (HBV) replication prior to transplant. These medications need to be continued after transplantation long-term. In addition, patients transplanted for HBV related liver disease will receive injections of antibodies against the hepatitis B virus at regular intervals during the first year after transplantation. The combination of these measures is highly effective and can prevent HBV recurrence in the graft in almost all cases.

Hepatitis C

During transplantation for hepatitis C virus (HCV) related liver disease, the graft is always re-infected by HCV. There is no way to prevent this HCV re-infection, and recurrent hepatitis C in the graft occurs universally. In general, HCV infection after liver transplantation runs a more aggressive course than in the non-transplant setting. Thus, 10-30% of patients develop graft cirrhosis within 5 years after transplantation. As in the non-transplant setting, cirrhosis may lead to complications and death. Current antiviral therapy for hepatitis C is less effective after transplantation, has numerous side effects and can trigger acute and chronic rejection of the graft. Treatment is therefore only started if there is evidence of progressive hepatitis C in the graft. To detect this, liver biopsies are performed not only when required by blood work indicating a problem with the graft, but per protocol in regular intervals after transplantation.

Non-Alcoholic Steatohepatitis

Non-alcoholic fatty liver disease (NASH) can recur in the graft after transplantation. This is the case in at least 20-30% of patients. Optimal control of the risk factors for NASH, including diabetes and body weight, are important preventative measures. Beyond control of risk factors, there is no drug therapy available that is of proven efficacy and safety. It is rare, but not impossible, that recurrent NASH leads again to end-stage liver disease in the graft.

Autoimmune Liver Diseases

Autoimmune liver disease such as **autoimmune hepatitis (AIH)**, **primary biliary cirrhosis (PBC)** and **primary sclerosing cholangitis (PSC)** may recur in the graft in about 10-30% of patients. Recurrent AIH, PBC and PSC are typically controlled by medications. It is rare, but not impossible, that recurrent autoimmune liver diseases lead again to end-stage liver disease in the graft.

Hereditary Liver Diseases

Hemochromatosis is not cured with liver transplantation and excess iron may accumulate with time in the new liver. It is advisable to regularly monitor total body iron stores with determination of serum ferritin and to re-start phlebotomies as required to keep them within normal limits.

The defect leading to excess copper accumulation is cured with liver transplantation and **Wilson's disease** does not recur in the graft after transplantation. However, damage that may have been caused prior to liver transplantation by excess copper accumulation in other organs such as the brain is not reversible with liver transplantation.

The new liver does not carry the genetic defect causing **Alpha-1-Antitrypsin Deficiency** and this disease does not recur in the graft. However, damage that may have been caused by alpha-1-antitrypsin-deficiency to other organs such as the lungs, is not cured by liver transplantation.

Liver Transplantation for Hepatocellular Carcinoma (HCC/Hepatoma)

Introduction

Hepatocellular Carcinoma (HCC or “Hepatoma”) is a malignancy that starts in the liver, usually in the setting of pre-existing liver disease, such as Hepatitis B or cirrhosis from hepatitis C, alcohol, NASH or Hemochromatosis. Very small, solitary tumours may be effectively treated with ablation (i.e. placing a needle through the skin into the tumour and destroying it by heating it with hi-frequency radio-waves). Many other tumours may be effectively treated surgically by removing them within a section of the liver (i.e. a liver resection).

Indications for transplantation

Liver transplantation has been shown to be effective treatment for small, early Hepatocellular carcinoma that is confined to the liver. A cancer-free survival of 70-80% is predicted following transplantation for tumours that fulfill specific criteria as defined by Trillium Gift of Life. A variety of extended criteria have been proposed by different transplant centres. In Toronto, tumours that exceed the specified criteria may be considered for transplant if they are confined to the liver (i.e. no metastases), without invasion into veins (i.e. no venous tumour thrombus), no constitutional symptoms, and a biopsy that indicates that it is microscopically favourable (i.e. not “poorly differentiated”).

Patients who are listed with HCC that is > 2cm in diameter and/or multifocal disease are eligible for a slightly higher priority on the liver transplant waiting list.

Treatment while waiting for transplantation (Bridging therapy)

Since liver transplantation for HCC is a hope/desire and not inevitable because of the organ shortage, we recommend that the HCC be treated as if the patient were not listed for transplant, using the other best-available therapies. The purpose of this “Bridging Therapy” is to control the tumour(s) during the waiting time, and specifically to prevent the patient from being taken off the waiting list because of spread or progression of the HCC. The bridging therapies that are used are:

1. **Ablation** – placing a needle through the skin into the tumour and destroying it by heating it with hi-frequency radio-waves (RFA = radio-frequency ablation). This is an out-patient procedure.
2. **TACE** – Through the Artery Chemotherapy with Embolization – chemotherapy is delivered via the artery directly into the tumour(s). This requires 2-3 days of hospitalization
3. **Radiotherapy** – highly focused irradiation that spares most of the liver. This is usually administered for 10 days as an out-patient.
4. **Radioembolization (Y90)** - Radioembolization is a minimally invasive procedure that combines embolization and radiation therapy to treat liver cancer. Tiny glass

or resin beads filled with the radioactive isotope yttrium Y-90 are placed inside the blood vessels that feed a tumor.

Unfortunately, for many patients, there is no effective bridge therapy available because of the toxicity of the treatment and the risks associated with their advanced liver disease. Moreover, despite bridge therapy, up to 25% of patients drop off the waiting list because of tumour progression.

Monitoring while waiting

During the waiting time, HCC patients must have their tumour(s) monitored to ensure that when they are called in for a transplant, the tumour is under control, and they are still “transplantable”. Monitoring by a Transplant Surgeon consists of CT or MRI scans of the chest and abdomen and blood tests every 3 months for patients whose tumours fulfil criteria. For some patients, consults may be done virtually, however the standard of care includes in person appointments.

New or recurrent tumours are treated, when possible, with RFA, TACE, radiotherapy or radioembolization as described above. If the tumour progresses and metastasizes outside the liver or invades a major vein, transplantation no longer remains an option; the patient is removed from the transplant waiting list; and alternate treatment for the progressive HCC is offered.

Monitoring after Liver Transplant

Because the immunosuppression required to prevent rejection following transplantation increases the risk of recurrence of HCC, the doses of these medications are kept as low as possible. The risk of tumour recurrence following transplantation depends on the pre-transplant stage of the tumour and ranges between 10% for early, favourable tumours to 30-40% for more advanced tumours. Surveillance for recurrent HCC following transplant is provided by regular CT or MRI scans of the chest and abdomen and blood tests.

If the HCC recurs following transplant, then depending on the extent and location of the recurrence, the treatment options of surgical resection, RFA, TACE and/or radiotherapy are available.

Diagnosis of Liver Cancer – Canadian cancer Society: <https://cancer.ca/en/cancer-information/cancer-types/liver/diagnosis>

The Transplant Assessment Process

The transplant assessment process helps to determine if you are a transplant candidate. An important part of this assessment is to try to ensure that you can tolerate the physical and emotional stress of the operation and the post-operative recovery. During your initial assessment for liver transplant, you will meet with many of the health care team members who will help decide if transplantation is the right option for you.

Sometimes your assessment will uncover a problem that makes transplantation a poor option for you. It could also identify a problem that needs to be corrected before you become a candidate for a liver transplant.

Your assessment includes extensive medical tests and interviews with members of the transplant team. We try to make sure that you do not have any other conditions or health problems that would put you at too high a risk for a liver transplant. **It is important to stress that a liver transplant is a very major operation with significant risks at the best of time.**

The Transplant Work-Up

Several tests are routinely done during assessment. These include:

1. **Blood work** (to help us understand your liver disease and liver function)
2. **Chest X-ray** (to look at your lungs, diaphragm, and heart size)
3. **ECG** (Electrocardiogram) (an electrical picture of your heart)
4. **Echocardiogram** (an ultrasound of your heart)
5. **Dobutamine or Persantine Stress test** (to determine how your heart performs)
6. **Pulmonary Function Studies** (to measure how your lungs perform)
7. **Abdominal Ultrasound, Blood Vessel Ultrasound and/or CAT Scan** (to look at the size and shape of your liver, and to provide a 'map' of the liver's blood supply)
8. **Urine Tests** (to provide information about your kidneys)
9. **Gastroscopy/Colonoscopy** (to look for bleeding risk, and other disease)

Consultation Interviews

As part of the assessment process, interviews will be arranged with several members of the transplant team. They may include:

- Hepatologist
- Anesthesiologist
- Social Worker
- Psychiatrist or Psychiatric Nurse
- Nephrologist
- Cardiologist
- Respiriologist
- Transplant Surgeon

Additional Considerations for Diabetic Patients

If you have diabetes, additional testing may be required. This may include:

- ✓ an Ophthalmology consult to check for any eye damage
- ✓ 24-hour urine to check kidney function

Living Donor Liver Transplant

Over 1200 living donor liver transplants have been performed at Toronto General Hospital since 1996. Living donor liver transplants are as successful as deceased donor liver transplants and significantly reduce the risk of health deterioration and death for patients who would otherwise wait on the list for the next available deceased donor organ. Depending on their blood type, patients waiting for a deceased donor liver transplant may wait years for an organ, while a living donor liver transplant usually can be arranged within 2 to 3 months.

Benefits of Living Donor Liver Transplant

- the recipient receives a high quality organ with excellent graft function
- decreased recipient waiting time for liver transplant
- the capacity for the team to plan the transplant before the recipient's health deteriorates further
- reduced risk of death while waiting for transplant
- high success rates for donor and recipient
- the donor can restore good health to a close friend or family member.

Disadvantages of Living Donor Liver Transplantation

- a higher rate of bile duct complications following transplantation (especially narrowing of the bile duct outlet)
- placing an otherwise healthy individual (the donor) at risk

Living liver donors can be a friend or relative in good health, with a compatible blood type. If there is someone you know who is interested in learning about living donation, ask them to call or visit the website for more information.

Living Liver Donation Office at 416-340-4800 ext. 6581

https://www.uhn.ca/Transplant/Living_Donor_Program

Living Donor Assessment

Potential donors have a thorough evaluation by the health care team. They undergo a series of blood tests, x-rays, CAT scans, MRI and consultations with specialists to provide information about the procedure.

- Donors must be in excellent physical and emotional health.
- Donors cannot have any history of cancer, or any active infection at the time of donation.
- Donors must have normal liver function.
- The blood vessels to the liver and bile ducts in the liver must be suitable for transplantation.
- Donors should have family and friends who can provide support before, during and after surgery.

Principles Guiding Living Donor Selection

- ✓ Living donor must be between the ages of 18 and 60 years
- ✓ Living donation must be voluntary and benevolent
- ✓ Donor safety is the priority during assessment & donation
- ✓ Any newly found donor health issues will be addressed in consultation with the donor's family doctor
- ✓ It is the donor's responsibility to communicate if there are any concerns or issues that need to be addressed regarding the assessment
- ✓ OHIP pays for the entire costs of the operation & hospital care
- ✓ Costs for time lost from work, travel, etc are not compensated by the hospital or OHIP. (Some costs may be reimbursed by the government. Speak to your donor coordinator for more details)

Matching donor and recipient

To match a liver with a recipient, the donor must have a compatible blood type. The table below shows who can give you a liver by blood type.

If your Blood Type is	You can RECEIVE a liver from blood type:	You can DONATE to a patient with blood type:
O	O	O, A, B, AB
A	A, O	A, AB
B	B, O	B, AB
AB	O, A, B, AB	AB

******In approximately 5% of live donor cases we have needed to cancel scheduled surgery within 1 or 2 days prior. This is due to additional findings and concerns that arise from a final team review of both the donor and recipient charts. This last minute cancellation can be disappointing and frustrating for both the donor and recipient. Our primary focus when offering live donor transplantation is the safety of our patients. Due to the intense nature of donor and recipient assessments, as well as ongoing surveillance, new findings may develop and result in the team deciding that it is no longer safe to proceed with surgery.******

Considerations for Living Donor Liver Transplantation Recipients

- ✓ Recipient must be suitable for living donor graft
- ✓ Recipient agrees to living donor transplant
- ✓ Recipients agree that the program can provide donors with information regarding the cause of the recipient's liver disease, the potential for success and chance for disease recurrence

Risks Associated with Living Donor Liver Transplantation

The survival rates for the recipient at 1 year are similar between living and deceased donor livers. At 1 year, about 80 – 90% of liver transplant patients are still alive.

The risks for the recipient include:

- a slightly higher risk of surgical complications where the bile duct joins (anastomoses) compared to deceased donation.
- hepatic artery thrombosis (clotting of your hepatic artery) is a rate of about 2% with living donation compared to 1% with deceased donation.

The risks to the donor include:

- The same risks as with other major surgeries – these will be discussed in detail during the assessment process

We are usually able to take care of any complications without more surgery and without affecting your liver function in the long term. Our program has never had a donor death or long term complication with this procedure.

*Comparing these risks and benefits to the recipient,
the physicians and surgeons in the Liver Transplant Program
strongly believe that living donation
is the best choice.*

Living Liver Donation Office at 416-340-4800 ext. 6581

https://www.uhn.ca/Transplant/Living_Donor_Program

The Centre for Living Organ Donation

The Centre for Living Organ Donation was created in 2018 to improve access to living organ donation for people who need a life-saving kidney or liver transplant, and those who want to give a transformative gift of life. For those in need of a kidney or liver transplant, living donation may offer a shorter pathway to better health - providing faster access to a transplant and quicker recovery.

One of the world's first, the Centre for Living Organ Donation raises awareness, provides care, promotes research and offers hope to thousands of Canadians who are waiting for a kidney or liver transplant - and everyone who wants to be part of their future.

If you would like to learn more about living organ donation, our Outreach Coordinator leads regularly scheduled education sessions. Topics include:

- Living donation Q & A sessions for patients eligible for liver transplant (families and support persons are welcome).
- Webinars for those considering living liver donation.
- Living Donor Champion Education for those who would like to support a friend or family member in need of a liver.
- PRELOD Information sessions for living donors and candidates who need hands-on assistance to complete provincial reimbursement forms for out-of-pocket expenses.

All sessions are free of charge. To register, please visit <http://bit.ly/LivingOrganDonation>.

Our outreach coordinator is also available to answer questions and do presentations.

For more information, please contact us:

The Centre for Living Organ Donation
UHN Transplant Program
Tel: 416-340-5400 | Email: livingorgandonation@uhn.ca
www.livingorgandonation.ca



The Costs of Transplant Medications

YOU MUST HAVE A PAYMENT PLAN IN PLACE PRIOR TO TRANSPLANT!!

- When you are discharged from the hospital after your transplant, you must be ready to pay for your medications.
- The Inpatient Transplant Unit will not provide you with extra medications to take home.
- Transplant medications may cost as much as \$4,000 per month.
- Ways you can pay for your medications:
 - Private insurance
 - Trillium Drug Program
 - Ontario Drug Benefit (Ontario Disability Support Program, age 65+)

[Note: discuss out of province coverage with your medical team.]

Toronto General Hospital does not have a drug assistance plan for Transplant patients.

Drug Coverage – Private Insurance

Here are some questions that you can ask your insurance provider to understand more about your private coverage. You can also request a medication list from your social worker or transplant coordinator to submit for review.

- Who is the provider of your private drug coverage (i.e. Sunlife, Manulife, etc.)?
- What is the percentage of medication costs covered by your private insurance?
- Is payment of medications automatic or do you have to pay up-front and get reimbursed later?
- Are there any yearly maximums for drug coverage?
- Are there any lifetime maximums for drug coverage?

**If your insurance requires you to pay upfront, how will you pay?*

Regardless of private insurance, the transplant program strongly recommends that you enrol with the Trillium Drug Program as a supplement or back-up to your private coverage to prevent any delays in providing treatment.

The Trillium Drug Program

Who can apply?

You can apply to the Trillium Drug Program if you meet both of these criteria:

1. You reside in Ontario and have a valid Ontario Health Insurance (OHIP) Card
2. You are under age 65

Many transplant medications are expensive and uncommon. These medications can cost hundreds or thousands of dollars each month. Even the best insurance programs may not completely cover the costs of these medications. The Trillium Drug Program, funded by the Ontario Government, is available to all Ontario residents to help pay for such medications.

There is no cost to register with Trillium. The application takes only a few minutes to complete. Being registered with Trillium does not interfere with your private drug coverage. Patients with private coverage can still use this program. You can apply to Trillium for assistance with medications costs that are not covered or only partially covered by your private insurance. You can get applications at the pharmacy, online, or through our social workers.

How does the program work?

People who use the program are required to pay an annual deductible (approximately 4% of your household net income). Trillium's program year runs from August 1st to July 31st. You can join partway through a program year and sometimes you can back date your enrolment.

The program year is divided into four quarters (starting August 1st, November 1st, February 1st, and May 1st), so you don't have to pay your whole deductible at once. In each quarter, you will only pay one quarter of your household's total deductible before Trillium will pay for the rest.

For example, a household with two adults and one child with a total net income of \$40,000 will have a yearly deductible of about \$1,300.00. In each quarter, this household will have to pay \$325.00 out-of-pocket towards prescription costs before Trillium will pay for the rest.

The program only covers prescription medications that are listed on the Ontario Drug Benefits (ODB) list of covered medications, which does not include all of the medications your doctor may prescribe.

How do I apply?

Application forms and program guides are available online or at most pharmacies.

<https://www.ontario.ca/page/get-help-high-prescription-drug-costs>

(Google search term: “Trillium Drug Program”)

Please review the Guide to Understanding the Trillium Drug Program.

What if I have more questions?

Contact Trillium directly at:

By Phone:

Hours: Monday to Friday, 9am to 5pm (excluding holidays):

- 416-642-3038 (in Toronto calling area)
- 1-800-575-5386 (toll-free)
- 1-800-387-5559 (TTY)

By Email:

trillium@ontariodrugbenefit.ca

Seniors' Medication Coverage (65+)

Once you turn 65 years old, all Ontario residents are automatically eligible for Ontario Drug Benefits (ODB).

Under the ODB program, you pay a yearly set amount of up to \$100 towards your drugs, called a deductible. You pay off your deductible by buying prescription drugs covered under the ODB. Once you pay the yearly deductible, you will pay up to the maximum ODB dispensing fee of \$6.11 for each prescription drug. This fee is called a “co-payment.” Seniors can apply for help with these costs through the Seniors Co-Payment Program (SCP) by completing the form found on the website below. Under this program, your co-payment will be \$2 or less and you pay no yearly deductible.

To learn more, visit: <https://www.ontario.ca/page/get-coverage-prescription-drugs>

(Google search term: “Ontario Seniors’ Benefits”)

Financial Information

Having a transplant can have an impact on your finances. Use the following information as a guide to see if there are opportunities for financial support.

Transplant patients may be eligible for financial help from sources such as:

- Employment Benefits (through your workplace)
- Employment Insurance (sickness benefits or family caregiver benefits)
- Canada Pension Plan - Disability OR Post-Retirement Disability Benefit
- Ontario Works (OW)
- Ontario Disability Support Program (ODSP)

Employment Benefits

Depending on your employer and the amount of time you are off sick, you may have **short or long-term disability (STD or LTD)** benefits. Your employer will be able to tell you more about this.

Employment Insurance (EI)

- A. Sickness Benefits (patient)
- B. Family Caregiver Benefits (caregiver)
- C. Compassionate Care Benefits (caregiver)

If you have contributed to EI, EI sickness benefit gives you up to 15 weeks of income. If your support person has contributed to EI, they may be eligible for Family Caregiver Benefits and/or Compassionate Care Benefits. Contact your local EI office for more information about qualifying.

<https://www.canada.ca/en/services/benefits/ei.html>

(Google search term: "Employment Insurance Canada")

Canada Pension Plan - Disability (CPP-D)

Canada Pension Plan- Post-Retirement Disability Benefit

If you have paid into CPP, you can apply for CPP-D benefits OR CPP post-retirement disability benefit (if you are between ages 60 to 65 and you already receive a monthly CPP retirement pension).

CPP-D approves your application based on the medical information that they receive from your doctor. Drug benefits are not included. Fill out an application as soon as possible. It can take several months to process.

<https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-disability-benefit.html>

(Google search term: "Canada Pension Plan Disability")

Ontario Works (OW)/Ontario Disability Support Program (ODSP)

OW and ODSP are two financial assistance programs for individuals with low income and limited assets. If eligible, OW can provide immediate financial support, whereas ODSP may take time and requires medical documentation.

For more detailed eligibility criteria, please visit the website below or contact your local OW/ODSP office.

<https://www.ontario.ca/page/social-assistance>

(Google search term: “Ontario Works” or “Ontario Disability Support Program)

Other Financial Considerations

There may be some additional out-of-pocket expenses for you to consider:

Parking

UHN provides discounted parking passes in five, ten, and thirty-day increments. This discount provides parking at 50% of the daily maximum rate.

<https://www.uhn.ca/corporate/Directions/Pages/parking.aspx>

(Google search term: “Parking at UHN”)

Para-Transit Services

Certain municipalities offer para-transit services as an accessible transit option for person with disabilities. To learn more about what your municipality may offer, call 211, visit www.211ontario.ca OR Google search the term “para-transit” and your city.

Travel

Getting to the hospital for transplant and follow-up appointments is your responsibility. Funding supports for travel are limited to the following:

Northern Health Travel Grant

For patients living in northern Ontario, the Northern Health Travel Grant provides some financial assistance for travel to medical appointments. As a patient, you must pay the cost of travel and then apply for reimbursement.

You will need to have your local doctor fill out their section of the travel grant form, and then bring this form to your TGH specialist to fill out their section.

<https://www.health.gov.on.ca/en/public/publications/ohip/northern.aspx>

(Google search term: “Northern Health Travel Grant”)

Social Assistance (Ontario Works/Ontario Disability Support Program)

Social assistance (OW/ODSP) may help you with travel costs for your medical appointments. Travel should be discussed in advance with your OW/ODSP caseworker.

Hope Air

Hope Air may offer fares at a reduced rate for patients who live outside Toronto. This is **NOT** an air ambulance service. You will need to book 2 weeks in advance of your appointment.

<https://hopeair.ca/>

(Google search term: “Hope Air”)

Accommodations

Following transplant, some patients may be required to stay in Toronto, and others may choose to do so, for a short period of time. Your medical team will tell you if you need to stay close to the hospital for any period of time. Support people cannot stay overnight in the hospital with patients. Social assistance programs may cover accommodation expenses, but pre-approval is required. If you do not receive social assistance, accommodation costs will be an out-of-pocket expense, as there are currently no funding options available. Some hotels offer a patient discount rate - ask about this when you book your room. Speak to your social worker for an accommodation list.

Other Costs

There may be other unexpected costs related to your transplant that cannot be predicted, at this time.

Tax Tips

You may be able to claim medical expenses on your income taxes related to your illness and/or transplant.

<https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/deductions-credits-expenses/lines-33099-33199-eligible-medical-expenses-you-claim-on-your-tax-return.html>

(Google search term: “Canada Revenue Medical Expenses”)

Disability Tax Credit

You may be eligible for the Disability Tax Credit related to your illness and/or transplant.

<https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html>

(Google search term: “Canada Revenue Disability Tax Credit”)

Legal Information for Patients

Advance Care Planning / Power of Attorney

Advance Care Planning is also known as advance directives and living wills.

There may be a time in the future when you are unable to make decisions about your medical care and treatment. This situation may be temporary or permanent; it could happen suddenly or gradually. If you were unable to make decisions for yourself, there are two important things we need to know:

1. What are your specific wishes regarding your healthcare?
2. Who would you want to make decisions for you?

It is important to answer these questions now, while you are capable of making decisions. This helps to ensure that **your** wishes will guide your care.

Advance care planning helps to clarify how you wish to be cared for and gives someone you trust the authority to act on your wishes. This person is also known as a Substitute Decision Maker or a Power of Attorney (see below). This is the only person we would ask to make decisions, in the event that you are unable to do so.

Please talk about your care wishes with your family and anyone else who might make decisions for you in the future. We are always happy to answer any questions you have about advance care planning.

<https://advancecareplanningontario.ca>

(Google search term: “Advance Care Planning Ontario”)

There are two types of Powers of Attorney:

- Power of Attorney for Personal Care
- Power of Attorney for Finances

<https://www.ontario.ca/page/make-power-attorney>

(Google search term: “Power of Attorney Ontario”)

Powers of Attorney are powerful documents and should be considered carefully. It is important for you to learn more about them to understand how your decisions applies to your situation.

Pre- and Post-transplant Support Requirements

Our program requires each patient to have adequate support before and after transplant surgery to ensure an optimal outcome.

Pre-transplant: Support requirements are based on patients' needs. Some examples of the role of support people pre-transplant include helping you take medications as prescribed, attending appointments with you for support and information gathering purposes, as well as helping you to make plans for post-transplant recovery. Also, support people can help you obtain medical care if/when needed by checking in on you and supporting your ongoing changes in health. You must have and maintain adequate housing in order to be considered for transplantation.

You need to have a plan on how you will get to Toronto General Hospital when called for transplant.

Post-transplant: Patients are generally hospitalized for 7 to 10 days. We cannot delay discharge from hospital due to inadequate support, lack of transportation home or inadequate housing; therefore patients without adequate plans in place at time of social work assessment will not be listed for transplant.

Home Care and formal community supports are not an acceptable alternative as the only source of support, as availability of this type of support is not guaranteed. Referrals for home care are a) based on a patient's individual health needs at the time of discharge from hospital and is requested by medical team at Toronto General Hospital (not by patients); b) not provided for 24-hours at a time; and c) not reliably timed to ensure supervision of medications, etc.

The following relates to **AFTER your transplant surgery:**

Clinic Visits (Location: Toronto General Hospital, 12PMB)

- Scheduled: 1x/week for 6-8 weeks once you are discharged from hospital
- Unscheduled: as needed based on your medical condition/blood work

Blood work

- 2x/week for 6-8 weeks
 - 1-2x/week - close to home at LifeLabs
 - 1x/week - at Toronto General Hospital (ONLY if you are here for an appointment)

Support

- A day or two before you are discharged from hospital, you and a support person will need to attend discharge teaching. During this session, you will learn about your medications and post-surgery care.
- You will need a support person to accompany you home from the hospital.

- You will need someone at home with you for at least two weeks during the day to help with medications, meals, appointment scheduling, and overall supervision during recovery (needs to be flexible in case more support is needed).
- You will need someone to come with you for clinic visits (*see above*), as changes to medications and information sharing occurs.

You may choose to hire a support person to help you during this time. Any out-of-pocket costs associated with private home support will be your responsibility. There is NO government assistance for this type of service.

Drug Coverage

- You need to ensure you have adequate and guaranteed drug coverage.

Transportation

(You will NOT be able to drive for 3 months following your transplant)

- You will need someone to drive you home when you are ready to be discharged from Toronto General Hospital.
- You will need someone to drive you to the hospital for clinic visits.
- You will need someone to drive you to get your blood work done.

You can choose to travel to Toronto General Hospital by car, taxi, train or plane, depending on where you live.

Accommodation

- Your medical team will tell you if you need to stay close to Toronto General Hospital for any period of time. If you have not been told to do so, you **DO NOT** need to relocate.
- Support people cannot stay in hospital with patients.

Financial support for travel and accommodation is only available for patients receiving Ontario Disability Support Plan (ODSP) or Non-Insured Health Benefits (NIHB). Pre-approval is required for all expenses. If you do not receive pre-approval, you may not receive reimbursement for expenses.

Northern Health Travel Grant (NHTG) is a possible option for Northern patients travelling more than 100km to Toronto General Hospital. Please review NHTG for eligibility:

<https://www.health.gov.on.ca/en/public/publications/ohip/northern.aspx>

(Google search term: “Northern Health Travel Grant”)

IF YOU DO NOT RECEIVE ODSP, NIHB or NHTG, ANY TRAVEL AND/OR ACCOMMODATION EXPENSE IS OUT-OF-POCKET AND NOT ELIGIBLE FOR REIMBURSEMENT.

A patient's inability to meet the above stated transplant requirements may deem them unsuitable to proceed with transplant. We expect all patients to provide verification of the ability to meet these requirements in the form of verbal discussion during assessment, support people's names and contact information, and proof of drug coverage, among other things.

Please ensure a support person attends your social work appointment with you.

After the Assessment Process

Once the tests and consults are finished, the transplant team will meet to review the results. If there are no contraindications and you are prepared to go forward, you will be placed on the waiting list for liver transplant. You will be informed by telephone and by letter that you are on the waiting list.

You must provide several contact phone numbers so we know how to contact you at all times.

A meeting will be scheduled for you with the liver transplant surgeon. He will review information with you and your family regarding the transplant surgery. Bring someone with you to help you understand what the surgeon says. The surgeon will tell you about the successes and risks of liver transplant as well as:

- Risk of death during transplant surgery
- Primary non-function of the liver
- Hepatic artery thrombosis
- Neurologic & other complications
- Severe infections
- Prolonged stay in Intensive Care Unit
- Need for re-operation
- The commitment of you and your family
- Introduction to clinical trials

There may also be a meeting scheduled with the transplant hepatologist to discuss the option of living donation. Living donation offers many advantages and is a vital consideration for all liver transplant candidates.

Waiting on the List

There are 3 goals for the waiting period for transplantation:

1. Maintain your health as you wait for transplant surgery
2. Identify and manage any new illnesses or conditions
3. Assess and treat (if possible) your signs and symptoms of liver failure

You will have regular clinic appointments for the Pre-Liver Transplant clinic while you are waiting for liver transplant. You must keep these appointments. They are important opportunities for the experts in the transplant program to monitor your health and ensure your suitability for transplant. At the clinic visit we may adjust your medications and order additional tests.

Assessment testing will be redone every 6 to 12 months to ensure no new problems have developed.

** It is especially important for tumour patients to have their required assessments done every 3 months to ensure the tumours have not become too large. **

Blood Work While Waiting for Liver Transplant

You will need ongoing bloodwork while you wait for liver transplant. Please have your blood drawn at a local **Life Lab** if possible. These labs are familiar with our routine tests and work with us to complete your tests quickly. They will not charge you for your blood tests. Some other labs may charge you.

To find the Life lab nearest you, call: 1(877) 849 - 3637 or 416-675-3637 or visit:
<https://locations.lifelabs.com/locationfinder>

Your Place on the Waiting List

The waiting list is generated based on several criteria. At any time there are hundreds of patients in Ontario waiting for a liver transplant.

Each patient on the list is given a status based on:

- the severity & type of illness of the transplant recipient
- blood work results

It is important to notify your transplant coordinator if you are hospitalized while waiting.

Your status may change as your health and urgency for transplant changes. This decision will be made by your transplant team.

Organs are allocated based on medical need, not on length of wait time.

Patients who have liver disease caused by Hepatitis B or C can receive an organ from a donor who has the same virus in their blood but still has a normal liver.

The race and sex of the donor and recipient do not matter. Donors must, however, be:

- approximately the same height & weight as the recipient
- free of heart disease and cancer
- free of infection and chest trauma

In Ontario livers are allocated according to:

- compatibility of blood types and liver size
- the severity & type of illness of the transplant recipient

Clinic Appointments

In Person Appointments

It is important for us to see you in person while you are waiting for transplant. You will meet with the transplant coordinator and the transplant physician at your visit. We will ensure that you remain a good transplant candidate and it is a good opportunity for you to ask questions. We strongly encourage you to bring a support person with you to all of your appointments.

MS Teams Visit

This is a video conference appointment with your UHN physician or healthcare provider. You DO NOT come to UHN for this appointment. This video conference will be on your own computer, tablet, or cell phone using Microsoft Teams. You will be sent an email with a link to install Microsoft Teams video conference software, instructions on how to use the software, and a link for attending your video conference. If you need to cancel or change the appointment or need help with using the software, please contact your physician's office or the clinic directly.

Visit https://www.uhn.ca/PatientsFamilies/Virtual_Care#MicrosoftTeamsVideoVisits for more information on how to join a virtual visit with your care team through myUHN.

Phone Visit

DO NOT come to UHN for this appointment. This is a phone appointment with your UHN doctor or health care provider. Your healthcare provider will contact you within 1 hour of the appointment time. Please have your phone ringer on and have your phone near you. Note that the caller ID may display as "No Caller ID" or "Unknown Number". If you need to cancel or change this appointment, please contact your doctor's office or clinic.

Maintaining Contact

When a liver becomes available, time is critical and we need to get in touch with you right away.

We must know how to contact you at all times. For this reason, you need to provide your assessment coordinator with all your contact information:

- Home phone number & address
- Work phone number (if applicable)
- Cell phone number
- A nearby friend or relative

Keep your contact information up to date at all times.

You must inform your transplant team immediately if:

- any of these contact numbers change
- you will be out of reach for a period of time (e.g. travel)
(be sure to leave a telephone number where you can be reached while you are away.)
- you are admitted to another hospital

If you are not prepared to come in at any time, you must contact your transplant coordinator to discuss.

If You Are Hospitalized While You Are Waiting

If you are admitted to hospital while you are waiting for transplant, please have a friend or family member contact your transplant coordinator to let them know. It is up to the doctor who has admitted you to call your transplant doctor to discuss your status. Your transplant coordinator is not able to change your status without your admitting doctor contacting the transplant program.

The easiest way to do this is to have your admitting doctor phone Toronto General Hospital Locating services, and request to speak with the liver transplant doctor on service.

Toronto General Hospital Locating Services (416) 340-3155

The Deceased Donor Process

If a living donor liver transplant is not an option for you, you must wait for an organ from a deceased donor.

Organ donation within Canada is based on the kindness and generosity of the donor family consenting to donate a loved one's organs and tissues, at the time of their death. The continued success of transplantation hinges on organ donation.

The waiting list is made up of people throughout Ontario who are waiting for a donor liver. **The Trillium Gift of Life Network (TGLN)** is the organization that takes care of the organ sharing and database system in Ontario. They support donor families and organize the organ donation process with transplant centers.

- Once a potential organ donor is identified, the next of kin is asked to consent for organ donation.
- The organ donor is tested to make sure the organs are suitable for transplant. Tests include blood tests, virus tests (such as HIV, Hepatitis B & C), x-rays and scans.
- After testing, organs are assigned to the most appropriate patient on the wait list.
- After the transplant program accepts the organ, the donor is taken to the operating room. A specialized team of surgeons then works carefully to remove the organs for donation.

The wait time for a donor liver varies from a few months to several years. This can be a very stressful and discouraging time for you.

Waiting for transplantation can be a difficult time. There are many resources available to help you deal with this stress. A good place to start is with the members of your transplant team.

Helping You Deal with Stress

Waiting for a transplant can be a stressful time because of the unpredictable nature of the waiting list. Your transplant team also does not know how long you will have to wait for a new liver. Feelings such as fear, impatience, and even anger are normal.

During your assessment you may meet some of the Psychosocial Team members. They are:

- Social Workers
- Psychiatric Nurses
- Medical Psychiatrists

Our team offers:

- Education and information before and after your transplant.
- Resource navigation.
- Counseling and emotional support resources, both for you and your support persons.

The Canadian Liver Foundation developed a peer support program for patients and family members who have been diagnosed with liver disease. Follow the link below for the Peer Support Network.

<https://www.liver.ca/support-programs-and-services/>

(Google search term: “Canadian liver foundation peer support”)

The following resource may help you discuss transplant with the children in your life.

The Inside Story: A Kid’s Guide to Kidney and Liver Transplants:
<http://www.bridges4kids.org/Disabilities/InsideStory.pdf>

(Google search term: “the inside story bridges4kids”)

Reminders While you are Waiting

Driving

If you have confusion due to your liver disease, you **must not** drive. Your doctor may decide to notify the Ministry of Transportation if there are concerns. Talk to your doctor if you have questions.

Vaccinations

Vaccinations are important for your health. We recommend:

- COVID 19 Vaccinations
- Flu shot every year.
- Pneumovax vaccine every 6 years, which protects you from a type of bacterial pneumonia.
- Hepatitis B vaccine, (except for patients who have previously been infected with Hepatitis B.)
- Hepatitis A vaccine
- Tetanus

Dental Procedures

Talk to your doctor or coordinator before any dental work. Such procedures may result in increased bleeding and an infection risk.

Alcohol

To stay on the wait list for a liver transplant, you must not drink alcohol. To monitor this, we may do random blood and urine alcohol checks. If your tests are positive for alcohol, we will remove you from the wait list.

Please review the Alcohol Abstinence Contract at the front of this Manual for additional information.

Connex Ontario – Mental Health & Addiction Treatment Services

1-866-531-2600

Toll-free, confidential, anonymous, 24 hours

<https://www.connexontario.ca/en-ca/>

Smoking

Smoking cessation is an expectation of all of our patients. This expectation is based on the health risks associated with smoking, including early cardiovascular disease, cancer, emphysema and gastrointestinal tract disease. If you continue to smoke before your transplant, you may experience damage to your heart and lungs. This damage may make anaesthesia difficult to manage, as well as result in a slower recovery process after surgery.

The benefits of smoking cessation can be seen almost instantly:

- Within 20 minutes: Your blood pressure drops and your pulse returns to normal
- After 8 hours: The carbon monoxide level in your blood drops
- After 24 hours: Your risk of having a heart attack decreases
- After 48 hours: Your ability to smell and taste will improve
- After 72 hours: Your lung capacity increases and your breathing will become easier
- 2 – 3 weeks: Your circulation improves and walking is easier; lung function goes up by 20%
- 1 to 9 months: Fatigue and shortness of breath may decrease
- 1 year: You've cut your risk of heart disease in half!!

(Quit: You Have it in you. Smoke Free Ontario. Government of Ontario)

If you require assistance with smoking cessation, speak to your family doctor or refer to the resource list at the back of this manual.

Travelling / Out of town trips

If you are going on a trip, please speak to us before you make arrangements. We will help you decide if you are well enough to travel.

If you are going out of the range of your cell phone, please make sure that the transplant office has the telephone number where we can reach you. If you are traveling out of range and will not be available for transplant, please tell us. We will put you “on hold” on the transplant waiting list for the time that you are out of range.

It is your responsibility to notify the transplant office when you return in order to be re-activated on the waiting list.

Over-the-Counter medications

For pain, you may take Tylenol®. The maximum dose in 24 hours is four 500 mg tablets or six 325 mg tablets.

If you need pain medication for more than 2 days, please call your family doctor or transplant coordinator to discuss.

Do **not** take:

- over-the-counter medications
- aspirin (unless prescribed by your doctor) or non-steroidal anti-inflammatory drugs such as Advil or Ibuprofen. With liver disease, these types of medications may cause bleeding or kidney damage.
- Gravol®, Benadryl, cold medications, sleeping pills or anxiety reducing medications. These may cause drowsiness and confusion.

Emergency Situations

If you have an emergency, such as

- Bleeding from stomach or bowels
- Shortness of breath
- Chest pain

Call 911 or go to your nearest Emergency Department.

The Call for Transplant

When a liver from a deceased donor becomes available, we need to contact you right away.

Once you are chosen as the most suitable recipient, the transplant program's coordinator will work to reach you by calling your contact numbers in this order:

1. Home phone number
2. Alternate phone numbers that you provide

* Messages will be left where answering machines are available.

Time is critical when an organ becomes available. If the coordinator cannot reach you after 1 hour, another recipient must be selected.

The coordinator will leave a phone number for you to call back to further discuss the reason for the call.

If you are unable to reach the person who called you, contact the **Transplant Inpatient Unit at 416-340-5163**. Ask to speak to the Charge Nurse. Tell the nurse that you are waiting for a liver transplant and you received a call from the coordinator. The charge nurse will put you in touch with the coordinator.

Refusing to come in when called for transplant will mean that you are immediately placed 'on hold' and must contact your transplant coordinator to discuss your situation.

The call to come into hospital for transplant may come at any time of the day or night, even weekends or holidays. The coordinator will identify themselves and ask you a few questions. They will ask:

- How are you feeling?
- Do you have any fever or flu symptoms?
- Have you had any recent surgery, blood transfusions, infections or new medical information?
- Are you taking any antibiotics, or have you had any new medications prescribed?

If they have no concerns regarding your present condition they will ask you to come to hospital as soon as possible. An estimated arrival time will be discussed on a case-by-case basis. Instructions will be provided regarding your usual medications.

Given that there may be 4-20 hours before the anticipated surgery, the coordinator will give you direction as to when you can have your last food/drink. You will also be asked to bathe with soap & water prior to coming to the hospital. Do not apply lotions or creams.

Is the Donor Liver Suitable for Transplant?

Not every liver that comes available will be right for you. We use blood typing to match a liver with your blood type as well as other factors to be sure it is right for you.

Please Note:

Every effort is made to ensure that you receive a healthy organ. Even if all the tests are ok, there are still times when your transplant may not happen. Even though the initial testing may look good, the final approval must come from your surgeon after he or she has looked at the liver to be transplanted.

False Alarms

A false alarm happens when you are called in for your transplant and then at the last minute, your surgery is cancelled. This is one of the more upsetting things that can happen to you while you are on the transplant list. Keep in mind that false alarms can happen.

Your surgery can be cancelled for many reasons:

- We may have found a problem with the donor organ at the last minute
- One of your tests may have an unusual result so the operation cannot safely proceed
- In some cases, there may be an issue in matching an organ to a recipient
- Occasionally, another person on the waiting list may require the organ more urgently than you do

You and your family may feel shock, disappointment and sadness when this happens. Hopefully, you will be called again soon, for another possible organ transplant.

If you, or any members of your family are having difficulties coping with the false alarm experience, let your social worker know. They will be able to refer you to someone on the transplant team who can help you.

Becoming Too Sick For Transplant

Sometimes, in spite of doing all you can to stay healthy and in spite of all we do to keep you fit for transplant, you can become too sick to undergo transplant surgery. There are several possible reasons. These include:

- If you become bedridden
- If you develop serious infections and do not respond to antibiotics
- If you have a liver tumor and it becomes too big, or spreads outside of the liver

If you become too sick to have a transplant then we will work with your referring doctors and family doctor to plan your care. If you need to remain in hospital, you would be admitted to the one closest to your home.

When a Liver becomes Available

Once you are called in for a liver there is an urgent need to make sure you arrive at the hospital quickly and are ready for surgery.

We expect you to arrive at the hospital as soon as possible after getting the call for transplant. Estimated time of arrival will need to be discussed with the Recipient On-Call Coordinator.

Getting to the hospital when called for transplant

- It is your responsibility to arrive at the hospital when called
- Estimated time of arrival will need to be discussed with the Coordinator on call
- If you live outside the Toronto area, specific plans need to be made ahead of time
- If weather or traffic delay your trip to the hospital, call the Transplant Inpatient Unit to advise them of the situation **416-340-5163**

We want you to arrive safely to hospital.

If you are coming by car, please have someone to drive you.

If you do not have a car, you can take a taxi to hospital.

If you call an ambulance to get you to hospital, there is a fee for this service that the hospital **will not** pay for.

Depending on the time that you are called to the hospital, you will either go to the Admitting department or the Emergency department. The Coordinator who calls you will tell you which entrance to use.

Between 7 am to 11 pm Monday - Friday go to:

Admitting Department

Toronto General Hospital, 200 Elizabeth Street, Ground Floor, East (Eaton) Wing

Between 11 pm and 7 am Monday - Friday & Weekends go to:

Emergency Department, Toronto General Hospital, Elizabeth Street Entrance

Once you arrive at the hospital, you will be admitted to the transplant unit where the nurses will prepare you for surgery.

We will:

- Do bloodwork & a chest x-ray
- Ask for a urine sample
- Start an intravenous (IV)
- You will not be given anything to eat or drink

Please Note:

You may go through the process of getting the call, coming in and getting ready for surgery, and then have your surgery cancelled. This can be very disappointing, but it is for your protection.

We will not give you an organ that we do not believe is in good condition and may not work well for you.

What to Bring to Hospital

Bring these items with you to hospital:

1. Ontario Health Card (or provincial health card from another province).
2. An accurate list of all medications (names, doses, frequency) or bring the medications with you in their original packages.

After your surgery, you will go to the Intensive Care Unit. You do not need any of your personal belongings here, and we want to lessen the risk that such items are lost in hospital.

Personal belongings will not be needed until you are transferred back to the Transplant Unit. At this later time, your family may bring personal items to hospital, such as:

- 1) Your drug card (if you have one)
- 2) A credit card that you can use to pay for:
 - i. television and/or telephone,
 - ii. your medications at the time of discharge,
 - iii. your return trip home.
- 3) Toiletries: soap, shampoo, comb/brush, toothbrush, etc.
- 4) Dentures or glasses
- 5) Cell Phones, Laptops, Tablets

Do not bring:

1. Any valuables such as rings, watches, jewelry.
2. Large amounts of cash
3. Any large electrical equipment that needs to be plugged in (you may bring an electrical razor or hair dryer).

UHN Patient Personal Property & Valuables Policy

Patients are advised not to bring money or valuables into the Hospital. University Health Network (the Hospital) **does not** assume responsibility for patient money or valuables. Patients choosing to bring them into the Hospital do so **at their own risk and expense**. It is recognized that patients will have personal items such as clothing, medications, and personal support aids with them (e.g., eyeglasses, contact lenses, dentures, hearing aids, mobility aids and prostheses, etc.). However, the Hospital **will not** assume responsibility for these items if they are damaged

Your Transplant Surgery

Living Donor Liver

The Living Donor will be sent to the Operating Room early in the morning. A few hours later, we will have confirmation that the surgeon has examined the donor liver and is sure that the liver is safe to transplant, and the surgery is safe for the donor. We will then send you to the operating room to begin the transplant surgery.

We **never** put you to sleep in the operating room until your surgeon is satisfied that the liver is suitable for you.

Patients receiving a Living Donor Transplant first have their entire liver and gall bladder removed. Then a portion of liver from their donor is transplanted into the abdomen. This section of liver will grow new cells in about 6 to 8 weeks.

Deceased Donor Liver

In almost all cases, members of our surgical team will participate in the surgery to remove the liver from the deceased donor. Only after our surgeon examines the donor liver can we say for sure that the liver is safe to transplant. The liver will be transported to our hospital and we will send you to the operating room for the transplant surgery.

We **never** put you to sleep in the operating room until your surgeon is satisfied that the liver is suitable for you.

Your old liver and gall bladder will be removed first during the surgery to make room for the new liver. The new liver is then attached. This is a complicated process involving the attachment of arteries, veins and the bile duct. Every recipient and every donated liver has slightly different structures and the attachments will change somewhat because of this.

The Bile duct attachments are very challenging since they are very small and must be connected carefully to avoid leaks of bile into your abdomen. The connection between your bile duct and the donor duct will be done either by connecting:

- the ducts directly to each other, or
- the new duct to a loop of your bowel (roux loop).

Sometimes a small tube, called a stent, is placed in the duct to give it support. Usually this tube passes out of your body on its own in your stool, but sometimes it will need to be removed by your doctor. If needed, this is done a few weeks after surgery by gastroscopy.

When the surgery is complete, the muscle layers of your abdomen are stitched together and the skin is closed with staples. The staples will be removed in clinic 2-3 weeks after surgery.

Some patients may have drainage tubes placed in their abdomen to allow any extra fluid to drain for a few days after surgery. These tubes will be removed before you are discharged.

Whether you receive a living donor or deceased donor liver, the transplant surgery takes about 5 - 8 hours. You may receive blood products such as packed cells, plasma, or platelets during the operation. There is a small chance (10-15%) you will go on a bypass machine to keep your blood pressure stable during surgery. If this happens, you will have 2 small incisions in your left groin and in your left armpit.

Your family can wait in our waiting room until your surgery is over. This is located either on the 2nd or 3rd floor. The nurses will direct your family during your surgery. Your surgeon will talk to them once the operation is finished.

Care after your Transplant

Once you've had your surgery, you can expect to be in the hospital for about 1 - 2 weeks. You will stay in different inpatient units depending on the stage of your care.

Before surgery

You will be admitted to the Transplant Unit on 6 or 7 West PMB or 10 West PMB

After surgery - Care in MSICU

You will be in the Medical/Surgical Intensive Care Unit (MSICU) on 10 West - B after surgery, until your condition stabilizes and your blood pressure and breathing are well controlled, and you are off the ventilator. ICU nurses manage your health during this critical stage in your recovery.

Various equipment is used to monitor and support your health needs. Liver Transplant patients usually stay 2-3 days in MSICU as long as there are no complications and you are responding well after the transplant surgery. Visiting is limited in this area.

After the MSICU - Care in the ACU

We will transfer you to the Acute Care Unit (ACU) of the Transplant Unit which is located on 10 West - A.

Specially trained Transplant nurses will closely monitor your condition until you further improve and your recovery is progressing well. Some monitors will still

be used in the ACU. Patients usually spend another 2-3 days in this area. Visiting is also limited.

There is a designated patient rest period from 3 pm- 5 pm.
No visiting is allowed during this time.

After the ACU - Care on the Ward

You will complete your recovery back on the Transplant Unit. Our transplant nurses will help you continue to recover, gain strength, and learn how to manage with your organ transplant.

Accommodation on this unit may be in a private or semi-private room. Private rooms are first allocated to patients requiring isolation, then to patients with private insurance coverage or those who have arranged to pay the daily fee for a private room.

Possible complications in the first 1 to 2 weeks following Liver Transplant Surgery

While in hospital, you will be monitored carefully for a number of possible complications that can occur in the first 1-2 weeks following a liver transplant.

Complications related directly to the liver transplant operation include the following:

- 1) The liver transplant may fail to function immediately after the transplant – this is called primary non-function (PNF), and is extremely rare (<0.5%). This may require another transplant to be performed very urgently.
- 2) Blood clots may form in arteries or veins carrying blood to the new liver (vessel thrombosis). This is very rare (1%), but may severely damage the new liver if it cannot be corrected immediately by surgery or blood thinners. In some cases, another transplant may be required because of this.
- 3) Internal bleeding may occur and may require blood transfusion or surgery (<5% risk).
- 4) Leakage of bile may occur from the connection between the new liver's bile duct and your bile duct or bowel (10-20% risk). This may require surgery or placement of a drainage tube by the radiologist.
- 5) Narrowing or stricture of the bile duct after liver transplant may cause a problem with bile flow which may require surgery or placement of a stent by a radiologist or gastroenterologist (10-20% risk).
- 6) Acute rejection of the liver transplant may occur and can almost always be treated with medications to further suppress the immune system (15% risk).

Other complications that can occur to any patient having major surgery are also possible, including:

- 1) Cardiovascular problems such as heart attack, arrhythmia, or stroke
- 2) Kidney failure
- 3) Neurological problems such as seizures, tremors, or confusion
- 4) Respiratory problems such as pneumonia or pulmonary embolism
- 5) Infections of the surgical wound, IV sites, or urine

Most of these are rare, but depend on your condition prior to the transplant.

Clinical Trials

We are a leading hospital in transplant care and research. We participate in many clinical trials. Clinical trials are studies looking at new and current medications that we use to care for our transplant patients. Many of our transplant patients have participated in clinical trials.

Some of the clinical trials include looking at medications that:

- prevent rejection
- treat infection
- help prevent other illnesses; such as Hepatitis B.

Before we begin a clinical trial, there is a strict review process at the government level and an approval process at our Research Board of Ethics. Studies take place for all organ groups, newly transplanted patients, and patients who have had their transplant for several years.

During your transplant journey, we may ask you to participate in a clinical study. Participating is completely voluntary. If you are interested, we will ask you to sign a consent form to enroll in the study. This consent form will explain the study. The department will update you regularly on the progress of the study. A nurse who works specifically in research will meet with you when you come to your clinic visits. You can withdraw from a study at any time by telling your doctor or your study nurse.

If you would like to know more about the clinical trials that are taking place right now, please call the **Clinical Trials Department** at: **416-340-3125**.

Planning for Discharge – Please review the Discharge Contract at the front of this manual

Members of the liver team will see you each day and they will determine when you will be discharged home. You and your family will be advised a day in advance of your discharge date to ensure all preparations are in place.

The team may decide that spending a short time in rehabilitation may be valuable to improve your strength and independence. If the team decides that this is the best option for you, we will transfer you to St. John's Rehab Hospital in Toronto and continue to work closely with our partners there to monitor your condition. St. John's provides a specialized transplant rehabilitation program specifically for our patients.

Dear Patient/Family of the University Health Network:

We know that you have many things to think about during your stay at University Health Network (UHN). An important area we would like you to consider is your plan for when you leave the hospital. This brochure explains what you may need to plan for.

Leaving the Hospital

University Health Network is an acute care hospital. That means we treat short-term injuries and illnesses. Because demand for our services is growing, we need to discharge our patients after we treat them as efficiently as possible. This helps us free up beds for new patients.

How and when patients leave our hospital is explained in our "discharge" policy. This policy also looks at what is best for patients after they leave the hospital.

The Department of Social Work at UHN is here to help you plan for your discharge. If you have any questions about this brochure, speak to a social worker, or call the numbers listed in this brochure.

Returning Home

Your healthcare team will decide when you are going home. You will need to leave the hospital before 11a.m. on the day of your discharge. If possible, arrange to have someone take you home.

When you are discharged, you may be eligible for professional in-home services, which may or may not be free. Professional services include homemaking, friendly visiting, meals on wheels, nursing, and personal care.

For those patients who need care in another facility our goal is to help patients move through the health care system into facilities that are best equipped to meet their needs.

Rehabilitation (Therapy)

Your health care team may feel that you need special rehabilitation services

such as occupational therapy, physiotherapy or speech therapy. If so, we will assist you in sending applications to all facilities that offer the services you need.

Chronic Care (Ongoing Care)

If your health care team feels that you need complex medical care, we will assist you in sending applications to all facilities that offer the services you need.

Palliative Care

If your health care team feels that you require inpatient palliative care, we will assist you in sending applications to palliative care facilities that offer the services you need.

Long Term Care (Nursing Home):

If your health care team feels that you need care in a long-term care facility, your social worker will help you apply to the Community Care Access Centre (CCAC) for that service. You will be asked to choose 3 long-term care facilities. At least 2 of your choices must have short waiting lists.

A Chronic Care/Long Term Care Daily Fee

If you are waiting in this hospital for chronic or long term care and you are no longer receiving acute care at this hospital, you will be charged a daily fee. The fee is based on how much you can afford to pay. Under certain circumstances you may not have to pay this fee.

Completing Applications

After meeting with your social worker to begin the application process, you will have four days to submit your facility choices to him or her. Please note that you must accept the first available bed that is offered to you.

Retirement Home, Other Housing:

If your health care team feels that you need assisted living, your social worker will help you decide which facilities best suit your needs.

Convalescent Care

If your health care team feels that you require convalescent care in a long-term care facility, your social worker will help you apply to the Community Care Access Centre (CCAC) for that service. You will be advised of which long term care facilities offer convalescent care.

Questions?

If you have questions or concerns, please talk to the social worker, or call the number listed below.

Toronto General Hospital: (416)340-3616

Guidelines on the Transplant Unit

Visiting

- Visiting hours are generally from 9am to 9pm.
- All visitors must sign in at the reception desk
- Only **2** visitors are allowed in a patient's room at one time.
If there are more people who would like to visit at once, this must be done in the visitor's lounge or other part of the hospital.
- Children under 12 are **discouraged from visiting** patient rooms because of the risk of infection to the patient. *Please speak to the unit manager or charge nurse before bringing children to the unit.*
Any child visiting must be supervised by an adult. If children are disruptive or noisy, they cannot be allowed to disturb other patients, and visitors will be asked to leave the unit and visit with the patient elsewhere in the hospital.
- We encourage patients and families to get good sleep, and do not encourage families to spend the night due to privacy concerns and limited space. Discussion with management can happen to extend these hours if needed.
- Visitors for isolation patients must fully respect precautions in place to protect the patient, themselves, and others on the unit.
- Visitors with signs of fever or flu will not be allowed on the unit.
- Visitors may be asked to temporarily leave a patient's room for health care staff to provide personal care or discuss confidential matters with the patient.

Choosing a Spokesperson

Please do not call before 9am for patient information.

During your time in hospital, we ask that you **pick 1 person** to be your family spokesperson to protect your privacy and ensure patient confidentiality. Please advise the nursing staff of the name of your spokesperson.

This person is responsible for calling to see how you are doing and passing this information along to family and friends. Nursing staff cannot accept numerous phone calls.

Flowers

Cut flowers or plants are **not allowed** on the transplant unit. They can carry a significant infection risk to transplant patients.

Your Recovery After Transplant

After your transplant, we will focus on:

1. Monitoring liver function and signs of rejection
2. Adjusting your immunosuppressive medications
3. Recovery and rehabilitation
4. Teaching you about your transplant and medications

Monitoring Liver Function and Rejection

Our first priority is making sure your new liver is working well. Daily bloodwork and other assessments will show if your new organ is functioning properly.

A rejection episode happens when your body's immune system recognizes your new organ as foreign. The body will try to react against your new liver and this process can damage your new liver. Blood tests monitor for changes that may be a sign of rejection. Identifying the early signs of rejection is important so that this process can be stopped and your new organ can continue to work well for you. In most cases, the liver can recover from acute rejection without permanent damage.

Your transplant team will monitor and treat early signs of rejection. They will adjust your medication and therapy accordingly.

We will also teach you the signs and symptoms of rejection so that you know what to watch for at home.

Adjusting your Immunosuppressive Medications

After transplant, you will immediately start taking immunosuppressive drugs. These stop your immune system from rejecting your new liver. It is important that we have you on the right doses of these drugs. You may have many changes in your drugs until we find the right levels for you.

We will adjust your dosages based on your:

- Blood test results
- Symptoms
- Side effects of medication
- Biopsy results (if needed)

Teaching

During your time on the transplant unit, the nursing staff and your transplant team will give you information about taking care of yourself with your new liver transplant. We will share this information with family members and support persons.

We will help you to recover from your surgery and teach you how to return to your normal activities.

You will attend a self medication program to help you understand your new medications and how to take them correctly.

You will be required to view educational videos outlining life after transplant prior to being discharged home.

Recovery & Rehabilitation

As you begin to feel better from your surgery, the nursing staff and the physiotherapist will help you to slowly increase your activity. Day by day, you will increase your level of activity. This is an important part of the healing and recovery process. Pain medication will help keep you comfortable during this time.

It is essential that you work with us to do more and more each day.

After Discharge

You will be expected to attend clinic once a week at first (we encourage you to bring your support person to all clinic appointments).

There may also be additional unscheduled clinic appointments depending on your health.

Blood work will be required twice a week at first, or as instructed by your transplant doctor or coordinator.

Limitations at the Time of Discharge

You will not be able to lift anything that weighs more than 10 lbs (22Kg) for 3 months. You will not be able to drive until your doctor feels that it is safe.

Discharge Checklist

I have seen the following people:

- Discharge Coordinator
- Clinic Secretary
- Pharmacist
- Diabetes Educator (only if I need to learn about diabetes)
- CCAC Coordinator (only if I need homecare)
- Social Worker (only if I need info/ help not provided by CCAC/Homecare)

I have done the following:

- Watched all 4 teaching videos - Lifestyle Adaptations for Transplant Patients (<https://www.youtube.com/watch?v=stQBD2kPdq8&list=PLWYuRSjQI5zHttLJNLPouxSuReouZxZLk>)
- Attended Self Medication class
- Picked up my medications
- Purchased a thermometer

I have received:

- My access to Patient Portal
- My Medication List from the Pharmacist



What is myUHN Patient Portal?

Welcome to myUHN! myUHN Patient Portal is a secure website and app for University Health Network (UHN) patients.

UHN includes Toronto General Hospital, Toronto Western Hospital, Toronto Rehab Institute and Princess Margaret Cancer Centre.

myUHN lets you see your personal health record safely online.

You can:

- Update your demographic details such as address, health card number and emergency contact.
- Update your health information such as allergies and medications.
- Check in and complete questionnaires before your appointment.
- Send messages directly to select clinics and myUHN Support.

Important information about myUHN:

- You can see your results as soon as they are ready, even before you see your doctor at your next appointment.
- Your results may change or be updated after you see them.
- If you have questions, your health care team will explain your results.
- Your health care team will contact you if they need to see you before your next

appointment.

- myUHN may not show all your appointments. If an appointment does not appear, follow the instructions your clinic provided you.

How do I register?

Instant Activation

- Ask for an activation code/link at your next visit or by contacting myUHN Support.
- If you have consented to email and/or text communication, staff can send you an instant activation code/link.
- You will receive an email or SMS notification with a code/link to complete your myUHN signup.
- This link will be active for **24 hours**.

Printed Code

- A myUHN activation code can be printed upon request at your next visit or be found on your After Visit Summary (AVS) or enrollment letter.
- Go to www.myuhn.ca or download the free MyChart app on your device from Google Play or the App Store. Click 'Sign up now' and identify yourself with your code and date of birth.

- The printed activation code will be active for **30 days**.

Self-Signup

- If you do not have an activation code/link, you can request one. Go to www.myuhn.ca or download the MyChart app on your device from Google Play or the App Store.
- Click 'Sign up now', then click 'Sign up online'. Fill out the 'Request an Activation Code' form.
- Click 'Submit'.
- Once your information has been verified, you will receive an email or SMS notification with a code/link to complete your myUHN signup. This code/link will be active for **24 hours**.

Watch this [video \(https://www.youtube.com/watch?v=YQgMkyCWHoo\)](https://www.youtube.com/watch?v=YQgMkyCWHoo) for more information on how to download and log in to the MyChart/myUHN mobile app.

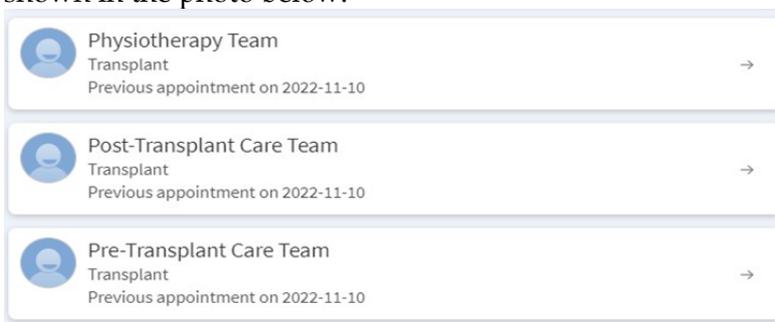
Who can I contact if I have any questions?

- Visit the [myUHN Patient Portal YouTube channel](#) for helpful tips.
- For questions about using myUHN or setting up an account, contact myUHN Support:
 Phone: 416 340 3777
 Email: myuhn@uhn.ca
- For questions about your results, reports or appointments or if you want to correct something in your health record, contact your health care team.

Visit www.uhn.ca to find contact information for your clinic or other information about MyUHN

Sending messages to your care team through myUHN

As a transplant patient, you have the option to send a message to the pre-transplant team, the post-transplant team, or additional teams specific to your organ group, as shown in the photo below:



Send a message to **the pre-transplant care team (response time within 1 business day)** if you have medical questions or concerns for your admin or coordinator and are a pre-transplant patient. You are a pre-transplant patient from the first time you visit the transplant clinic until the time you have been admitted to receive your transplant.

Send a message to the **post-transplant care team (response time within 1 business day)** if you have medical questions or concerns for your admin or coordinator and are a post-transplant patient. You are a post-transplant patient from the time you have received your transplant onwards.

Send a message to the **living donor team (response time within 1 business day)** if you have medical questions or concerns for your admin or coordinator and are a living donor patient (i.e. you are donating an organ and are not a transplant recipient).

Changing your shortcuts in myUHN

Click here to watch a short video on how to change your shortcuts on the myUHN patient portal website.

Change your communication preferences in myUHN

Would you like to change how you receive notifications and communication related to myUHN?

Click [here \(https://www.youtube.com/watch?v=7wCOVWxjcFw\)](https://www.youtube.com/watch?v=7wCOVWxjcFw) to watch short a video on how to manage your communication preferences in myUHN.

Note: we strongly recommend that you make sure your myUHN notifications are turned on, so that you are aware when your care team sends you a message.

If you have any questions

Questions about sign-in, registration, or using myUHN? Please contact the myUHN team.

Email: myuhn@uhn.ca

Phone: 416-340-3777

Hours: Monday – Friday, 9:00am – 5:00pm

How to send a message on myUHN Patient Portal

1. Sign in to www.myUHN.ca
2. Click [Messages](#) in the shortcut bar at the top of the page.
3. Click [Send a message](#).
4. For a non-urgent medical question, click [Medical or Appointment Question](#).



For a non-medical concern, click [Contact myUHN support](#).



5. Select the type of question from the list below.

What type of medical or appointment question?

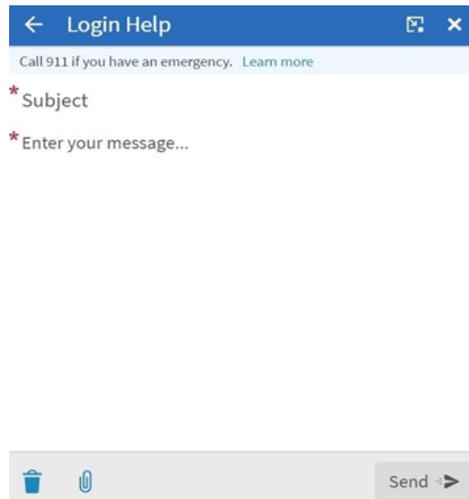
What type of myUHN support question?

- If you selected a medical or appointment question, select the messaging pool to send a message.



- Please allow 1 business day for a response. *Do not send a message if this is an emergency. For immediate help, call 911 or go to your nearest Emergency Department.*

6. Enter a subject and message, and attach relevant files.



To discard your message, click 

To attach a file, click 

7. When you enter a subject and message, the Send button will turn green. If you are happy with your message, click [Send](#).

Transplant Resource List

Soham & Shaila Ajmera Family Transplant Center
http://www.uhn.ca/Focus_of_Care/MOT/index.asp

Trillium Gift of Life Network:
<http://www.giftoflife.on.ca/>

LIVING DONOR:

http://www.uhn.ca/Focus_of_Care/MOT/Living_Donor/index.asp

ALCOHOL TREATMENT:

Connex Ontario 1-866-531-2600
<https://www.connexontario.ca/en-ca/>

SMOKING CESSATION:

Smokers' Helpline: 1-877-513-5333
www.smokershelpline.ca

Smoke-Free Ontario:
<http://www.mhp.gov.on.ca/en/smoke-free/default.asp>

Health Canada Health Concerns:
<http://www.hc-sc.gc.ca/hc-ps/tobac-tabac/index-eng.php>

FOR FURTHER INFORMATION AND SUPPORT:

Canadian Liver Foundation: 1-800-563-5483
www.liver.ca

Getting to Toronto General Hospital

Public Transit (TTC):

The Toronto General Hospital is well served by public transit. The Queen's Park subway station is located at the corner of College St. and University Ave. The College subway station at College St. and Yonge St. is only two blocks east of the Eaton Wing. Streetcars service College St. in both directions. Buses on Bay St. and University Ave. also have stops close to the Toronto General Hospital. For Toronto Transit (TTC) information, please call: **416-393-INFO (4636)**

Parking:

Toronto General Hospital:

Elizabeth St. garage (weekdays 7am - 3pm, floors 1-2 are reserved for patients and visitors only)

Gerrard St. underground (connects directly to the hospital and is for patients and visitors only)

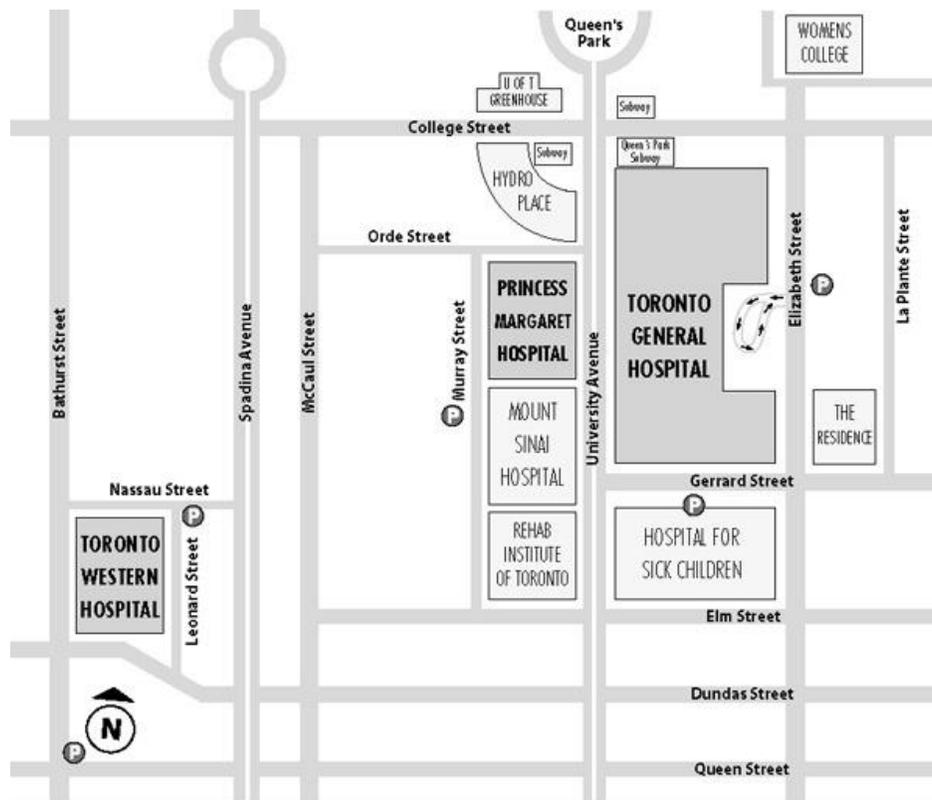
University Avenue - MARS Underground (connects directly to the hospital)

Toronto Western Hospital:

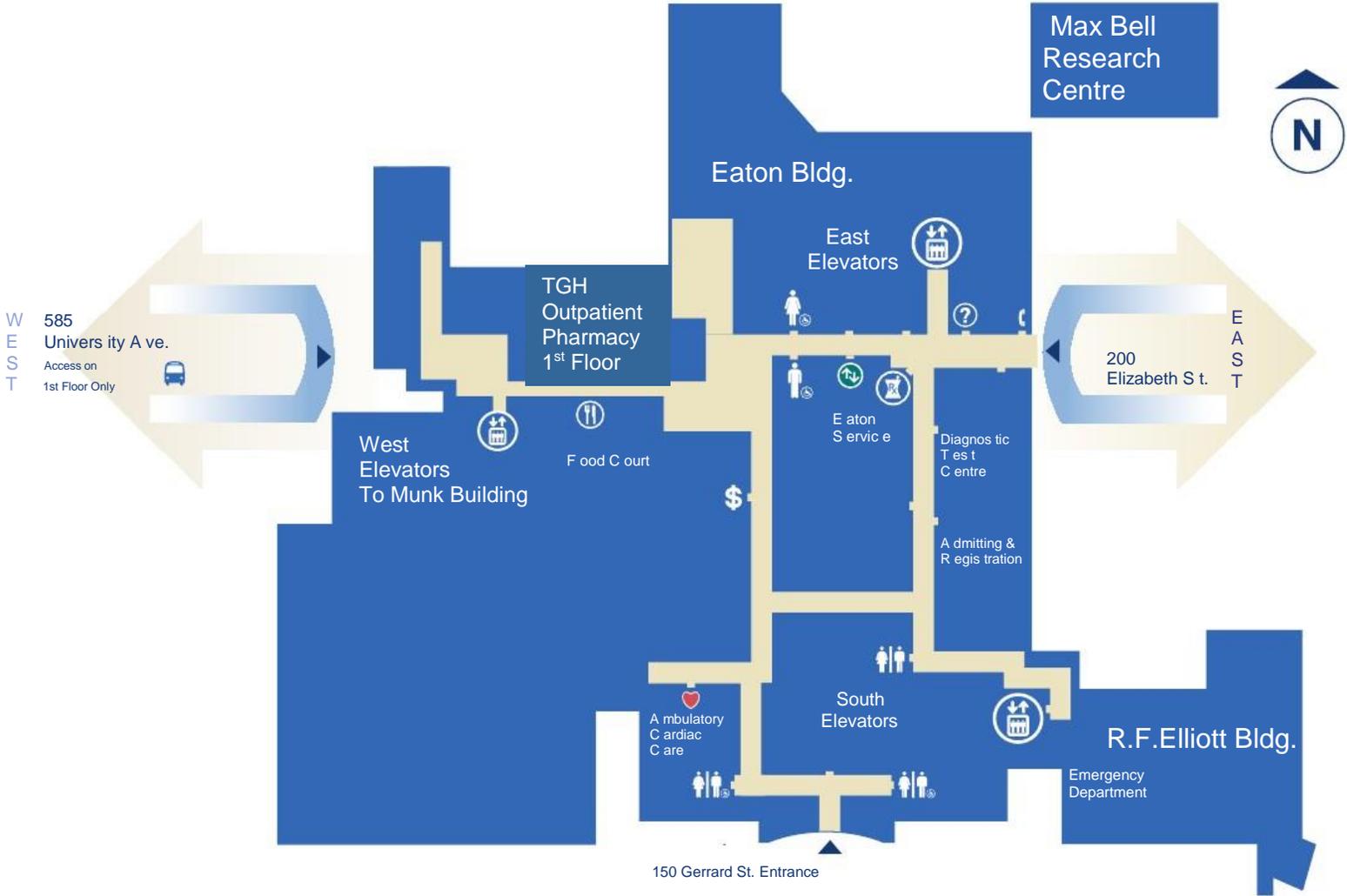
Nassau St parking lot (reserved for patients and visitors only)

Leonard St. parking lot (1st floor reserved for patients and visitors only)

For current parking rates or for multi-day reduced rate passes, please contact the parking office at 416-595-7136



Toronto General Hospital, Ground Floor



Vaccines in Adult Solid Organ Transplant Recipients

Inactivated Vaccine	Risk / Condition	Dosing schedule	Vaccine needed (Yes/No)	Vaccine received (Yes/No)
Tdap (tetanus, diphtheria, acellular pertussis)	All	One dose – if not received in the last 10 years		
Hepatitis B	All (if anti-HBs negative)	3-dose series - 0,1,6 months Accelerated schedules: Can combine with Hepatitis A as Twinrix		
Influenza	All	Annually – use injectable vaccine High Dose Recommended		
Shingrix	VZV IgG positive and age > 50 years	Two doses, 3 months apart. Should be able to wait 4 weeks for transplant		
Hepatitis A	-all patients waiting for liver transplant or -any underlying liver disease or -wish to travel in the future	Two doses Can combine with Hepatitis B as Twinrix		
Pneumovax	All	One dose – If not received in the last 6 years		

Live Vaccine	Risk/Condition	Dosing schedule	Vaccine needed (Yes/No)	Vaccine received (Yes/No)
Varicella vaccine (Varivax)	VZV IgG negative	Two doses 4 weeks apart. Should be able to wait 8 weeks for transplant.		
MMR	Measles IgG negative (check serology if born after 1970)	Two doses 4 weeks apart. Should be able to wait 8 weeks for transplant.		

TB Skin Test: Date administered:
Date Read:
Result:

Important Contact Numbers

Contact	Telephone Number
Emergency	911
Toronto General Hospital - Main	(416) 340-4800
Locating - Toronto General Hospital	(416) 340-3155
Main Pharmacy - Toronto General Hospital	(416) 340-4075
Transplant Outpatient Pharmacy	(416) 340-8107
Transplant Physician:	(416) 340-4800 Ext:
Transplant Coordinator (Pre Transplant)	(416) 340-4800 Ext: 8072 or 6103
Transplant Clinic	(416) 340-4800 Ext 4113
Living Donor Liver Program	(416) 340-4800 Ext 6581
Center for Living Donation	(416) 340 - 5400
Transplant Inpatient Unit	(416) 340-5163
Transplant Psych/Social Office	(416) 340-4800 Ext 5655
Patient Relations - University Health Network	(416) 340-4907
Clinical Trials	(416) 340-3125
Connex Ontario	1-866-531-2600
Registered Dietician - EatRight Ontario	1-877-510-5102
Life Labs	1-877-849-3637 or 416-675-3637