

Multi-Organ Transplant Program

Liver Transplant Program



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This handbook provides information about the Liver Transplant Program at London Health Sciences Centre.

It will help answer your questions about the entire transplant process as well as your long-term health care.

Remember to bring this handbook to the hospital when you come for your transplant.



London Health Sciences Centre
Multi-Organ Transplant Program

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*Cover photo: Heather received her liver transplant in 1983.
For more than 30 years, she has helped promote greater public awareness about the success of transplantation, including taking part in the World Transplant Games.*

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Transplant assessment

The transplant team

You have been referred for a transplant assessment because you're experiencing some symptoms of liver disease or you have a condition that could be treated by a transplant (Appendix 1). Usually, the assessment is done on an outpatient basis so you will need to stay in London for two to five days. During this time, you will meet several members of the transplant team as well as have some medical tests. Our staff will talk with you about your illness, and you will have the opportunity to ask the liver transplant team about the program at London Health Sciences Centre. During the assessment, you may meet:

- hepatologists (doctors who specialize in liver diseases)
- transplant surgeons (doctors who perform the transplant surgery)
- anesthesiologist (doctor who administers anesthesia at time of surgery)
- recipient coordinator (a healthcare professional who organizes your care and is your contact person throughout the transplant process)
- social worker (the social worker provides you and your family with emotional and practical support throughout the transplant process)

Other team members include Transplant Unit nurses, Outpatient Clinic nurse, physiotherapist, dietitian, and pharmacist.

Medical tests

Tests will be required to evaluate your health. These **may** include:

- blood tests, including HIV test
- chest x-ray
- abdominal ultrasound and Doppler study (examines the liver's structure and its blood supply)
- echocardiogram (ECHO) (provides an ultrasound of the heart)
- stress test (measures how well your heart works)
- pulmonary function tests (measures lung function)
- endoscopy (checks for abnormalities in the esophagus and stomach)
- colonoscopy (examines the lining of the colon for polyps)

Depending on which tests you need, you will be given more detailed information at that time. The liver transplant process is very stressful so we recommend that you have someone with you for support. They'll be able to provide company and comfort during this important time in your life. It's also very important that you and your family understand the risks and benefits of transplant surgery. The team is available to answer any questions that you have.

Results of assessment

After the assessment, you will return home. The transplant team will meet to review the test results and decide if your name should be added to the waiting list. You will be notified by telephone of the team’s decision. If transplantation is recommended, you will have the final decision on whether your name is added to the waiting list. **To be placed on the list, you must have adequate drug benefits or be enrolled in the province’s Trillium Drug Program (Appendix 2) to ensure that medication costs will be covered.**

Some patients are too well for transplant; if their condition changes, they will be reassessed. Some patients have medical problems, such as severe heart disease, significant obesity or large tumours, which make transplantation too risky.

If your disease is related to alcohol, you must be committed to lifelong abstinence and you will need to attend a relapse prevention program before your name is added to the waiting list. Random alcohol testing will be done; if positive, your name will be removed from the waiting list. **All patients must agree to complete abstinence both before and after the transplant.**

Transplant assessment

You can jot down any questions or concerns that you have so you can discuss with the transplant team.



Waiting period

Length of waiting time

Once the decision to go ahead with the transplant has been made, your name is added to the waiting list. The time spent waiting is one of the most stressful phases of the transplant process because there is so much uncertainty. **You could wait for only a few months or you may wait for several years.** We cannot predict how long you will have to wait for a suitable liver to become available. Most people are able to remain at home until their transplant. The recipient coordinator will arrange for you to have a pager if you wish so you can go about your daily activities, yet remain accessible. You **must** inform the recipient coordinator about:

- **any admission or discharge from hospital**
- change of address or phone number
- weekend trips or holidays away from home

Organ allocation

Donated livers are matched to patients who are waiting on a single, provincial waitlist. This system ensures that patients with the greatest need are prioritized, regardless of where they live. The Sodium Model for End-Stage Liver Disease (Na MELD) is used to determine medical urgency. This numerical scoring system makes accurate predictions of medical urgency using results from routine lab tests including:

- bilirubin
- INR (blood clotting time)
- creatinine
- sodium concentration

In addition to these test results, size (height and weight) and additional medical conditions may be factored into scoring and placement on the waitlist.

While on the waitlist, patients must have their bloodwork done at least every three months to ensure the Na MELD score is current. The Na MELD score can increase or decrease depending on the severity of illness. **Failure to complete blood tests within this timeframe will result in automatic suspension from the waitlist.**

Donors

The need for donated organs exceeds the available supply. To increase the number of available organs, our transplant program uses both deceased and living donors.

Deceased Donors:

Everyone can consider themselves a potential organ donor. Each person's suitability is determined at the time of death, based on medical tests. Health Canada has specific guidelines, and all donors are screened for transmissible diseases before using their organs. We want to avoid passing on any disease to transplant patients. At the same time, we want to use all suitable organs, even those considered "high risk". In these situations, "exceptional distribution" guidelines allow using these organs as long as the benefits and potential risks have been disclosed to the recipient. For example, donors with hepatitis C can be used because there is effective treatment to eliminate the virus. If you receive a liver from a hepatitis C donor, you will receive treatment after your transplant.

Traditional Donor

The traditional donor is a person who has suffered an irreversible brain injury and is being supported by a ventilator in the ICU. Once brain death is established, the donor's healthy organs can be removed and transplanted into people with end-stage disease.

DCD Donor

Donation following circulatory death (DCD) involves patients in the ICU who have no possibility of recovery. They may not meet the specific criteria to be a traditional donor, but death is inevitable. Following discussions with the next of kin, a decision is made to withdraw futile treatment. After their heart stops beating, the liver can be removed for transplantation.

Split-liver

This procedure involves splitting the donated liver from a deceased donor into two sections. The larger piece is transplanted into an adult, and the smaller piece is transplanted into a child.

Living Donors:

Since 1989 many transplant programs have used living donors as an additional option to help patients with liver failure. A family member or friend may wish to donate a segment of their liver. Living donation offers some benefits for the recipient: it significantly reduces the time on the waiting list, it lessens the likelihood that the patient's condition would deteriorate further, and it may prevent the person's death if no deceased donor becomes available. Recent data have shown that there is no difference in organ survival when a segment of liver is transplanted into stable patients, compared with patients who receive a whole liver from a deceased donor. If a patient becomes too ill while waiting, living donation may no longer be an option as they may benefit more from a whole organ.

With a living donor, the transplant surgery can be planned and scheduled. The donated liver segment is transplanted immediately because the donor and recipient are in the same hospital. This may reduce the chance of complications; for example, a liver from a deceased donor is cut off from its blood supply, stored, and may be transported over a long distance, but this can be avoided with living donation. There may be an increased rate of bile duct complications in living donation; however, the majority of these complications are manageable.

Who can be a living donor?

A living donor is a relative or friend who has the following characteristics:

- compatible blood type with the recipient (see table below)
- between 18-55 years old
- large enough to donate sufficient liver tissue (approximately as tall as the recipient, or taller)
- excellent physical and psychological health
- 8-13 kilograms (20-30 pounds) within their ideal weight. People who are quite overweight may have a fatty liver which is not suitable for donation.

If you have blood type:

O

A

B

AB

You can donate to someone with blood type:

O, A, B or AB

A or AB

B or AB

AB

Potential living donors must undergo a complete assessment to ensure that they are healthy and have a compatible liver. We want to ensure that the health of living donors is not compromised and that it is safe for them to donate. Various tests, including imaging studies to assess the anatomy and size of the liver, as well as appointments with physicians and other members of the transplant team are scheduled. Although some testing can be done locally, donors are required to travel to London to complete the assessment process. Liver donation is a major surgical procedure and donors require two to three months recovery time before returning to work.

If you know someone who is interested in being considered as a living liver donor, ask him or her to contact your recipient coordinator. The coordinator will speak with the potential donor to obtain some general health information and to arrange for initial blood tests. Our program provides further information in our patient handbook "Living Liver Donation", which is available online: www.lhsc.on.ca/Patients_Families_Visitors/MOTP/Liver_Transplant/Living_Liver_Donation_Handbook.htm.

To be considered for living donor transplantation, the potential recipient must have already completed the assessment process and be listed on the active transplant waiting list.

Expectations

The transplant team expects that **all patients** on the waiting list will comply with medical advice. This includes attending clinic appointments, following dietary restrictions, treatment requirements and physical activity recommendations as well as abstaining from alcohol. You have a responsibility to preserve and maintain your health as much as possible. **Failure to comply means your name will be removed from the transplant list, and you will no longer be a candidate.** It is our hope that we can effectively assist you in all aspects of your care during the waiting period as well as facilitate a good recovery following liver transplantation.

Your responsibilities while you wait

- do not drink alcohol
- do not smoke
- take your medications as prescribed by your doctor
- do not use herbal preparations or street drugs, including marijuana
- exercise regularly
- follow your recommended diet
- inform your recipient coordinator of any changes in your health
- inform your recipient coordinator if your phone number or address changes
- keep all clinic appointments
- have your blood work taken at least every three months to ensure your Na MELD score is current
- see your family doctor regularly
- ensure drug benefits through private coverage or Trillium Drug Program are current (see Appendix 2)
- plan for medication expenses if you do not have 100% coverage or if you are reimbursed after paying for your drugs
- plan for other financial expenses (i.e: accommodation and food) while in London
- complete a Power of Attorney for personal care and property

Costs and accommodations

Some recipients are fortunate and live close to the transplant centre, but most patients must travel for their transplant. Travel can be expensive, especially if separate visits are required for assessment, transplant, and outpatient clinic appointments. During the waiting period, regular visits to London may be necessary to ensure that medical issues are reviewed and tests updated if necessary. At the time of transplant you will be expected to travel to London by commercial airline. It is important that you are aware of the available flights from your area as well as schedules and cost. We suggest that you develop a travel plan so travel arrangements can be made quickly to ensure arrival in London within the required time. On some occasions transportation will be provided by ORNGE (Ontario Air Ambulance).

As well as maintaining your permanent residence at home, you will need funds for temporary accommodation near the transplant centre. Additional costs include food, personal expenses such as medications, and transportation. If you live more than 40 kilometres from our hospital, you may be eligible for medical deductions on your income tax return. Patients travelling to London from Northern Ontario for medical treatment are eligible for the Northern Travel Grant Allowance. More information is available by calling 1-800-461-4006 or 1-705-675-4010.

During the waiting period, we encourage you to think about who will accompany you to the hospital at the time of transplant, where they will stay, and the cost to you once you are discharged from the hospital. Family members and friends who stay in London should budget a minimum of \$1,000 a month for each person, if staying in a hostel or a room-and-board setting. This budget covers only the basic cost for food, accommodation and local travel.

Once discharged from hospital, you will be required to stay in London for some follow-up care before returning home. **During this time it is necessary to have a dedicated person (family member or friend) who can provide support and assistance.** A variety of accommodation is available in London, ranging from hotels and motels to bed-and-breakfast lodging. An extensive list of possible places to stay can be found at www.londontourism.ca.

Parking at University Hospital

Visitor parking is available on site. The parking garage is located at the North end of the hospital, and is operated by Imperial Parking. This is an automated system, which charges by the hour. Passes are available, however, by the day, week, or month. Depending on the number of appointments and the length of your stay, you may want to purchase a pass. The parking office, located on the ground floor of the parking garage, is open 24 hours a day, 7 days a week.

Research studies

Once your name is placed on the transplant waiting list, you may be asked to participate in a research study. Our transplant program is committed to learning how to improve the results of transplantation, and research is an important part of this. Many companies approach us with requests to perform studies about new medications. Your participation in a study is entirely voluntary. If you decide not to participate or decide to withdraw from a study, your health care will not be affected.

Self-care while waiting – nutrition

Poor nutrition is a common problem for patients with liver disease, and almost all patients are malnourished at the time of transplant. Emphasis is placed on maintaining good nutrition to keep you as well nourished as possible. Patients who are better nourished generally have fewer complications, spend less time on the ventilator in the Intensive Care Unit after surgery, and have a shorter recovery time. In addition, good nutrition combined with an exercise program helps you maintain a reasonable quality of life during the waiting period. You may have problems with fluid build-up in the abdomen (ascites) and legs (edema). It's recommended that all patients follow a low-salt diet to help prevent fluid from building up. You may also need to adjust your energy and protein intake to prevent undesirable weight changes or muscle loss. The transplant dietitian, Lynne Sinclair (519-685-8500 ext. 32449), is available to help assess your food habits and suggest strategies for symptom management together with general nutritional advice.

Self-care while waiting – exercise

Physical fitness is very important as you wait for your liver transplant. It is difficult to remain active when you're feeling poorly, but this remains a priority. Patients who are in better condition generally have shorter recovery times and fewer complications following surgery. "Working out" at a gym may be too strenuous. Light exercises, using cans of soup or small weights, are a good way to get some exercise done at home. Even more important is your cardiovascular fitness. While on the waiting list, walking is the best exercise to maintain cardiovascular fitness. You can start by going for a five or ten minute walk outside or in a nearby mall. Aim to increase the time you spend walking by one minute every day you walk. Your ultimate goal is to walk for 30 minutes, three times each week. Try to walk at a pace that gets you slightly short of breath, but still able to talk. This level of activity is safe for people with health problems, including heart and liver disease. Don't walk immediately following a big meal or on days that are extremely cold, hot or humid. Stop exercising if you feel dizzy, nauseated, unusually short of breath, or generally unwell. Maintaining your physical health is crucial before transplantation. Research has shown that those who are more fit for surgery, recover with fewer complications and leave hospital sooner. Patients

may see a physiotherapist for guidelines about activity and exercise as well as for routine Six Minute Walk testing. If fitness deteriorates beyond an acceptable level, it could compromise the success of transplant surgery. Re-assessment by the whole transplant team might be required in such cases.

Vaccinations

Vaccinations are important for your health. We recommend:

- yearly flu shot
- pneumovax vaccine every six years to protect you from a type of bacterial pneumonia
- hepatitis B vaccine (except for patients previously infected with hepatitis B)
- hepatitis A vaccine

Contacting the transplant team

Despite the uncertainty of the waiting period, we encourage you to lead as normal a life as possible. The recipient coordinator is available if you have any questions or concerns. You may, however, contact any member of the transplant team at any time (Appendix 3). Maintain regular contact with your local doctor or specialist who can also communicate with our transplant team in order to provide you with the best care. **Please remember that you or a family member must inform the recipient coordinator of any admission or discharge from hospital.**

The waiting period during the transplant process can be a difficult time. Clear, direct, and honest communication among all family members will help reduce frustration and tension. If you or your family experience significant difficulty with coping during the waiting period, please get help from a local, qualified health professional or contact the transplant team's social worker.



Surgery and recovery

The call

When a liver becomes available for transplant, the selected recipient is the patient with the highest Na MELD score who has the same blood type and is a similar size as the donor. Once selected, the recipient coordinator will contact the patient by telephone or pager. As soon as you are informed about the transplant surgery, do not eat or drink anything. You should be prepared to leave home within 60-90 minutes. It is important that you develop a travel plan. If travelling by car, it is beneficial to have a driver and route planned. If you live more than six hours from London, it may be necessary to travel by commercial airline. You should check available flights, schedules and cost ahead of time. On some occasions, air transportation will be provided by ORNGE (Ontario Air Ambulance) if flight schedules and timing are not convenient and do not correlate with the OR time.

What to bring

Here are some suggested items that you should pack for your stay in London:

- all your medications
- diabetic supplies or other medical devices
- provincial health card
- private insurance card or information
- toiletries (toothbrush & paste, brush, scent-free deodorant)
- soap, shampoo, razors & shaving cream (all scent free)
- pyjamas, housecoat and slippers (non-skid), running shoes, walker/cane (if needed)
- underwear and socks
- loose-fitting pants (such as sweatpants)
- tops that are easy to get on and off
- books, magazines or hobbies to pass the time

Surgery

After arriving at the hospital, report to Patient Registration on the main floor. When your paperwork is completed, you will go to a hospital room to be prepared for the surgery. You will meet the nurses as well as the transplant surgeons, and have tests done such as blood work, chest x-ray, electrocardiogram, and urine tests.

The transplant surgeon will discuss any relevant information about the donor's medical history and possible risks of your transplant:

- surgical complications, including the **possibility** of dying
- clotting of veins & arteries in the liver (further surgery or a second transplant may be required)
- biliary leaks
- infections (wound or other)
- long ICU stay
- the need for re-transplantation if the liver does not function

Remember, most transplants are successful; however, complications may occur. While you are getting prepared for surgery, the transplant team is retrieving the donated liver. **It is possible the liver will not be suitable for transplant; in this case the surgery is cancelled. If this happens you will return home. The cost of your trip home is your responsibility.** Once confirmed that the liver is suitable for transplant, you will be brought to the operating room. The transplant surgery usually lasts five to eight hours, and you may require a blood transfusion. During the surgery, your family and friends can wait in the ICU waiting room on the second floor. The surgeon will speak to them once surgery is completed.

Intensive Care Unit

Following surgery, you will be transferred to the ICU. When you wake up, you will have a tube in your throat. The tube is connected to a ventilator, which will do all the breathing for you until you are alert enough to breathe on your own. While this tube is in place, you will not be able to speak or drink. As soon as you're able to breathe on your own, it will be removed. You will be attached to a heart monitor and have a urinary catheter and several intravenous lines. You may have a tube inserted into your abdomen behind the liver. It will drain the extra fluid that builds up after surgery, and will be removed several days after the surgery. Your surgical incision will span from one side of the abdomen to the other, held together with staples that will stay in place for two to three weeks. You will be very drowsy from the anesthesia and pain medication. Some patients experience dreams, confusion, and the inability to focus on conversations for the first few days. The length of time in ICU varies from person to person. When your condition is stable, and you can breathe without assistance from the ventilator, you will be transferred to the Transplant Unit.

Multi-Organ Transplant Unit

Each patient has a private room in the Transplant Unit. During your stay in the Unit you will increase your independence by:

- doing exercises and physiotherapy, which improve your strength and mobility, and
- learning about your medications and ongoing self-care.

A small percentage of patients may remain confused even after they leave the ICU, and this can last for several days. Many patients have difficulty sleeping after the transplant. Lack of sleep may lead to irritability and frustration. This problem, which is related to your body adjusting to the medications, will resolve over time.

Occasionally, stable patients may be transferred to another ward prior to discharge from hospital.

Patient Education Centre

Located in the Transplant Unit, many patients and family members find the resources in the Education Centre to be helpful. There are books related to nutrition, exercise, healthy lifestyles, and the transplant process, including some personal narratives. Other resources include videos and pamphlets as well as a computer centre so you can search the Internet for the latest information. You may want to visit our website (www.lhsc.on.ca/transplant) to read specific information about our program.

Discharge

At LHSC, our focus is not only your care and treatment while in hospital, but also your discharge from hospital. A discharge policy is in place to ensure that patients who no longer need acute care services are discharged in order to accommodate other patients who require admission. The involvement and cooperation of patients and families in discharge planning not only helps to meet their needs, but also balances the use of precious health care resources.

Your hospital stay may be as short as seven days. You may be discharged directly from the Transplant Unit or from the general ward. **Discharge time is 11:00 am.**

You should expect to stay in London for at least one to two weeks after discharge, before returning home. It is important that you have someone who can stay with you when you are an outpatient. During this period, you will attend physiotherapy classes and appointments in the Transplant Outpatient Clinic. Before discharge, you will be given a calendar with your scheduled appointments, along with an information booklet that contains specific follow-up care for you.

Infection

You will take anti-rejection drugs to suppress your immune system and prevent rejection. Although your body is still able to fight infections, you will be more prone to infection especially during the first few weeks after transplant. A fever is usually the first sign of infection. Although it's helpful to take your temperature when you don't feel well, it's not necessary to take it on a routine basis. Signs of infection include fever (38°C/100°F or higher), cough or sore throat, burning sensation when you urinate, or redness, pain, swelling or drainage around the incision. If infection is suspected, you should call your doctor.

Rejection

Your immune system protects you from infection (bacteria and viruses) by recognizing and attacking foreign substances. The transplanted liver is seen as a foreign tissue so your body tries to reject the new liver. **You will need to take anti-rejection drugs for the rest of your life to prevent your body from attacking the new liver.** Some patients experience rejection episodes in the first few weeks. Rejection is usually easily controlled by adjusting your anti-rejection medications. Rejection is less likely to occur as time passes, but the risk is always present.

Anti-rejection medications

There are several anti-rejection medications, including tacrolimus (Prograf®, Advagraf®), cyclosporine (Neoral®), sirolimus (Rapamune®), mycophenolate (CellCept®, Myfortic®), and prednisone. After transplantation, patients are usually prescribed a combination of drugs. Some of these drugs will be continued life-long. After your transplant, you will be given additional information about your anti-rejection drugs by the transplant team.

The use of alternative therapies, such as herbal remedies or marijuana, is not recommended. Interactions between these drugs and your prescribed anti-rejection medication can affect the concentration of medication in your blood. You want to keep your blood levels as consistent as possible, without becoming too high (with side effects) or too low (with possible rejection). Discuss **any** use of alternative therapies with a member of the transplant team.

Follow-up care

You will need frequent bloodwork immediately after the transplant (2-3 times per week), and this will be reduced when your results are stable. **All transplant patients require ongoing bloodwork to assess liver function and check for possible complications. Prescriptions will not be renewed unless bloodwork is being done and you are being followed by the medical team.**

You must renew the Trillium Drug Application Form yearly to ensure that you have drug coverage unless you have 100% from a private plan.



Resuming your lifestyle

Quality of life

Most liver transplant recipients can look forward to leading normal lives. We encourage recipients to pursue good health habits.

Alcohol

Alcohol is harmful to the liver so its use must be avoided following transplant. Abstinence is still required.

Work and activity

You can expect an improved or normal activity level within three to twelve months after surgery. Your tolerance for activity will depend on how ill you were before surgery. As your energy level rises, you will be able to return to your former activities. Within six months you will be expected to return to work. As a general policy, patients are considered to be fully recovered by three to six months following liver transplantation, and will no longer qualify for long-term disability or illness pensions (ODSP or CPPD).

Sexual activity

There are no restrictions on sexual activity after liver transplantation. You may resume activity whenever you and your partner feel comfortable. Previously non-menstruating women may resume menstruation and become pregnant. It is important to use birth control. The use of birth control pills is reasonable, but those agent's "hormones" can affect the liver. You must inform your hepatologist if you intend to use oral contraceptives. These are not recommended for the first six months after liver transplantation. We recommend using a double barrier method for birth control – either condoms and contraceptive foam *or* diaphragm and contraceptive foam. Although many women have given birth to healthy babies after a liver transplant, **it is recommended that women do not become pregnant for the first year following transplant. If you are considering having children, discuss this with the transplant team before becoming pregnant. Some of your medications may need to be changed.**

Driving a car

Most people can resume driving two to three months after they are discharged from hospital, but it is recommended you first discuss the timing of this decision with your doctor. It is important that you are not taking narcotics when you resume driving as they can affect your driving ability. Remember, you're still required to wear a seatbelt. If the belt bothers your incision, place a towel or blanket between you and the seatbelt.

Dental care

Dental hygiene is a very important part of your health management. Eating a healthy diet will help maintain strong healthy teeth. Using a soft-bristled toothbrush, brush and floss your teeth at least twice daily. Examine the inside of your mouth for any lesions, mouth sores or swelling of gums. Notify the transplant team or your dentist of any issues. Have regular dental check-ups. It is essential that you inform your dentist that you have had a transplant and are taking anti-rejection drugs which suppress your immune system. You do not usually need to take antibiotics before dental procedures; however, if a more invasive procedure is being done with increased risk of infection, your dentist may choose to give you an antibiotic.

Cancer prevention

You are at a **slightly** higher risk of developing cancer as a result of taking anti-rejection medications. Skin cancers are commonly found on the back, calves, arms, ears and the back of the neck. Inspect these areas frequently and report any new moles or skin changes to your physician. Avoid suntanning, and always wear sunscreen (with a minimum SPF 30) when you are in the sun. Don't forget to apply lotion to your ears, face, and nose. Re-apply the sunscreen frequently – especially if sweating or after drying off from a swim. It's important that you have yearly check-ups and cancer screening through your family physician.

Travelling

You are able to travel as often as you wish after the transplant, although it's recommended that you do not leave the country for the first six months. Always discuss your travel plans with your physician. Some countries require that you are vaccinated. Please discuss this issue with the transplant team prior to receiving any vaccines. Do not take vaccines made from live viruses. It is important that you obtain medical insurance, bring your own supply of medications, and store the medications in your carry-on luggage. Always take extra medications with you in case of emergency or delay.

MedicAlert

In an emergency, a MedicAlert bracelet or necklet shows others that you are a liver transplant patient. We recommend that you buy a MedicAlert bracelet, necklet or an equivalent as soon as possible. Application forms are available at London Health Sciences Centre and at most drug stores. You can also find information at the MedicAlert web site (www.medicalert.ca). Your bracelet or necklet should be engraved: Liver Transplant / Immunosuppressed.

Community follow-up

Visit your family physician shortly after returning home to make arrangements for follow-up care. Blood tests should be scheduled as directed by the Clinic upon discharge home. **Remember, do not take your anti-rejection drugs until after your blood sample is taken.** You will be provided with information for your laboratory and family doctor as well as prescriptions for your local pharmacy.

Appendix 1

Your liver and signs of failure

Causes of liver disease

There are more than 100 causes of liver disease. A few examples include viral hepatitis (hepatitis B and hepatitis C), excessive alcohol use, inherited or congenital diseases (Wilson's disease, hemochromatosis), bile duct diseases (primary biliary cirrhosis, primary sclerosing cholangitis), autoimmune diseases, fatty liver disease, and severe reaction to drugs and toxins. In many cases, liver disease can eventually cause cirrhosis (scarring) of the liver. Cirrhosis occurs when normal liver cells are damaged and replaced by scar tissue, and eventually the liver is unable to perform its functions (liver failure).

Liver function

Your liver has many important functions:

- stores glucose
- produces bile
- produces protein, and
- breaks down and removes toxins from your blood

Stores glucose

Your liver changes the food you eat into glucose (sugar), and stores it until you need it. When you have liver failure, you feel tired because your liver isn't able to use the stored sugar properly.

Produces bile

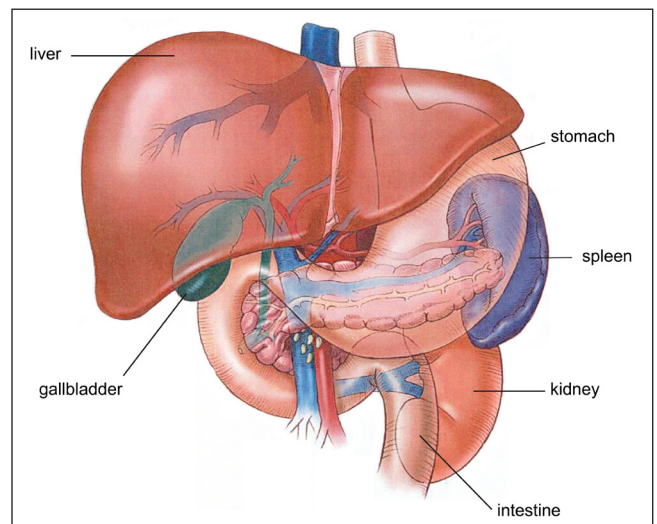
The bile that the liver produces normally drains into your bowel where it helps to digest food and absorb food nutrients. With liver failure, bile production and drainage are affected so the food you eat is not digested or absorbed properly. As a result, you will lose weight and develop jaundice (yellowish skin and eyes).

Produces protein

The body needs protein for growth, fluid regulation, blood clotting, and muscle building. When the liver is not functioning properly, your body is unable to produce and use the protein. You may experience muscle loss, ascites (a build-up of fluid in the abdomen), and bleeding problems.

Removes toxins

The liver filters your blood and removes harmful substances. When the liver fails, it is not able to do this, causing a build-up of toxic substances. For example, when the liver is not able to completely break down protein, ammonia builds up in the body. A high level of ammonia can affect the brain, causing confusion and sometimes coma.



Diagnosis and treatment

The onset of cirrhosis is often silent. Many people are unaware they have a liver disease because they may experience few symptoms in the beginning. If a doctor suspects liver disease based on your medical history and a physical exam, you may need blood tests and x-rays of the liver (ultrasound, CT scan) to see if there are any abnormalities. If cirrhosis is suspected, it may be confirmed by a liver biopsy.

Treatment of cirrhosis is aimed at stopping or delaying its progress, minimizing the symptoms, and reducing the damage to the liver. For instance, with alcoholic liver disease, ceasing to drink alcoholic beverages may stop the disease from progressing. Sometimes, medications can help prevent further damage to the liver cells. Symptoms can be controlled by dietary changes and treated with medications, as mentioned in the following section. Patients with cirrhosis may live a healthy life for many years. In some cases, a liver transplant is needed when the liver disease is severe and patients experience life-threatening complications.

Signs of liver failure and treatment

People with liver disease may experience a number of symptoms, many of which can be relieved with medications and other treatments. Not everyone gets all of the symptoms, but it may be helpful to know what to expect and how best to cope with the disease. **If you experience serious complications, such as bleeding or confusion, please seek immediate medical attention. The transplant team is also available if you have questions about your symptoms.**

Ascites, effusion and edema

If the liver cannot make enough albumin (a protein), patients may have fluid build up in the abdomen (ascites) and chest (effusion) and get swollen feet (edema). Decreasing the amount of salt in your diet may prevent fluid accumulation; however, many patients also need medications, such as lasix or aldactone, to get rid of the fluid. If the ascites cannot be managed with medications, you may need to have the fluid drained with a needle (paracentesis) from time to time. Some patients also benefit from a TIPS procedure that re-routes the blood in the liver.

TIPS (transjugular intrahepatic portosystemic shunt)

A TIPS procedure may be done for patients who have ascites (build-up of fluid in the abdomen) or frequent bleeding caused by liver disease. This procedure can relieve pressure and decrease the chances of ascites or bleeding. Using a general anesthetic, the radiologist makes a tunnel through the liver to connect the portal vein to one of the hepatic veins, using a small tube called a stent. You will be in hospital overnight, and will have an ultrasound before going home. We will schedule an ultrasound every 3-6 months to check that the stent doesn't become blocked or too narrow. Although the TIPS procedure can be very helpful for most patients, it can increase the chance of encephalopathy (confusion) so you will need to take regular medication to prevent this.

Bleeding

Poor liver function makes people prone to nosebleeds and bleeding from swollen blood vessels (varices) in the esophagus, stomach and intestine. Nosebleeds can usually be controlled by pinching the bridge of the nose for five minutes, but in severe cases hospital treatment may be required. Bleeding varices may cause patients to vomit blood or pass blood in their stool. **This can be a medical emergency, and patients should seek immediate hospital care.** The varices can often be controlled by medications that decrease your blood pressure, or by placing bands around the swollen veins. Some patients require a TIPS procedure. This involves putting a catheter into a vein in the neck, then inserting a small tube into a vein in the liver to redirect the blood flow and relieve the pressure.

Confusion or coma

When the liver is not effectively metabolizing drugs and protein, patients may have periods of confusion (encephalopathy) and even coma (loss of consciousness). This is more likely to happen when you take pain pills, sleeping pills or tranquilizers, if you become dehydrated, eat a lot of protein, have an infection, or if you are bleeding. Confusion can often be prevented by changes in diet and medications. Some patients need lactulose, which is a medication that increases bowel movements so that toxins are cleared from your system. Signs that a patient is becoming less alert include slurred speech, difficulty remembering names, restlessness, drowsiness, and irritability. **If the problem gets worse, you will need to be hospitalized.**

Fatigue and sleep patterns

People with liver disease often feel very tired even when they are quite inactive. Patients may find that they sleep better during the day than they do at night. This is called sleep/wake reversal, and is a mild form of encephalopathy. Even when you are fatigued, it is important to do some exercise every day in order to maintain your strength. Regular exercise may also improve your sleep pattern.

Itch

This is a sign that bile salts are building up in the skin. If the itch isn't relieved by lotions, you may require medications, such as cholestyramine or rifampin.

Jaundice

Yellowing of the skin and eyes is caused by a build-up of bilirubin in your system. It's a sign that the liver is not working properly. Patients may notice that they are more jaundiced when they also have an infection. At times, they may also find that their urine is very dark yellow. There is no treatment for jaundice, but it usually resolves within a few weeks after the transplant.

Liver Cancer

Liver cancer sometimes occurs with liver disease. There are some medical and surgical treatments, and liver transplantation can be effective for small tumours that have not spread beyond the liver. To prevent the spread of a liver tumour, patients may receive trans-arterial chemo-embolization (TACE), radio-frequency ablation (RFA) or surgery. TACE involves having a chemotherapy drug given directly into the blood vessel (near the tumour). RFA uses an ultrasound-guided probe to deliver an electric pulse that burns the tumour.

Malnutrition and muscle wasting

When the liver is not working well, fat is not absorbed effectively from the diet and protein is not well utilized. This may lead to weight loss and decreased muscle (especially in the face and arms). Patients with liver disease are generally advised to eat a balanced, low-salt diet. Although some patients may become confused if they eat too much protein, it is important to eat some protein-rich food in order to maintain muscle strength. Liver disease may cause a decrease in appetite and some patients require supplements such as Ensure[®] or Boost[®], and in some cases extra nutrition is given by tube feedings. All patients awaiting liver transplant are encouraged to be physically active in order to preserve as much muscle as possible.

Muscle cramps

Many patients with liver disease get severe muscle cramps in their hands and feet. This may be relieved with vitamin E.

Appendix 2

Ontario's Trillium Drug Program

Dear Ontario Resident,

Our transplant program usually uses tacrolimus (Prograf®) and mycophenolate mofetil (CellCept®) to prevent rejection. These medications are extremely costly. Not all insurance providers will cover the brand name options as there are generic alternatives on the market. Your transplant and pharmacy teams will assess brand options at the time of transplant.

You may have a private or work-related drug insurance plan. Some drug plans may not pay for new, expensive medications. Some plans may require that you pay a portion of the cost of the drug every year. If you have a plan, you should check if there is an annual or lifetime maximum amount that you can claim. You should also ask your company whether your drug plan covers tacrolimus and mycophenolate mofetil. You should also check for sirolimus and valganciclovir. The DIN numbers have been included for your reference.

Prograf® (tacrolimus) 0.5mg (#02243144) 1mg (#02175991) 5mg (#02175983)

CellCept® (mycophenolate mofetil) 250mg (#02192748) 500mg (#02237484)

Rapamune® (sirolimus) 1mg/ml liquid (#02243237) 1mg tablet (#02247111)

Valcyte® (valganciclovir) qw tablet (#02245777)

For Ontario residents, assistance is available from the provincial government through the Trillium program. This program helps Ontario residents who must spend a large part of their income on medications by paying a portion of the drug costs. **All Ontario residents are eligible for this program.** There is a deductible that you are required to pay. The deductible, however, varies from patient to patient based on household income and the number of family members with whom you live. Once approved, the Trillium Drug Program will cover all your family members.

Trillium application forms can be obtained from your community pharmacy or online. The application asks for information about your family, your drug costs, and your previous year's income, and you must complete your income tax return before you can apply. The form is easy to complete and there is no fee to apply. **Please complete the form and mail it as soon as possible. This application form must be renewed EVERY YEAR.**

London Health Sciences Centre and its Liver Transplant Program are not responsible for providing medication funds; therefore, we ask you to apply to the Trillium Drug Program immediately, even if you do not have enough receipts to reach your deductible yet. By applying before surgery while you are at home, you will have access to all your income and prescription information. You and your family may also be able to take advantage of the Trillium program for pre-transplant drug costs.

If you need help to complete the form, there is a telephone help line. If you are still having difficulty completing the form, please contact the social worker at your local hospital. If you are unable to get help, contact the social worker at the transplant centre. You are responsible for your drug costs after transplant. The province has created the Trillium Drug Program to help you, but it is your responsibility to apply for this help.

Appendix 3

Contact Information

Hospital	519-685-8500
Toll-free number	1-800-500-9845
Transplant Outpatient Clinic	519-663-3818
Transplant Unit (Inpatient)	519-663-3015
Pharmacy	519-663-3231
Transplant Program's fax number	519-663-3858
Intensive Care Unit	Intensive Care Unit

Dr. Brahmania (liver specialist)	519-663-3002
Dr. Marotta (liver specialist)	519-663-3406
Dr. McAlister (surgeon)	519-663-2920
Dr. Quan (surgeon)	519-663-3355
Dr. Qumosani (liver specialist)	519-663-3002
Dr. Skaro (surgeon)	519-663-2904
Dr. Teriaky (liver specialist)	519-663-3165
Liver Transplant Fellow	519-685-8500 to page
Recipient Coordinator - Amy Chambers	519-685-8500 ext. 34991 (519-685-8500 to page)
Recipient Coordinator - Terry Ward	519-663-3815 (519-685-8500 to page)
Recipient Coordinator - Sandy Williams	519-663-3933 (519-685-8500 to page)
Social Worker - Kelly Thomas	519-685-8500 ext. 32484
Dietitian - Lynne Sinclair	519-685-8500 ext. 32449
Physiotherapist - Kristin Morris	519-685-8500 ext. 35365
Pharmacist	519-685-8500 ext. 35259

For more information, please visit these websites:

Canadian Liver Foundation
www.liver.ca

Canadian Transplant Association (Transplant Games)
www.organ-donation-works.org

Multi-Organ Transplant Program, London Health Sciences Centre
www.lhsc.on.ca/transplant

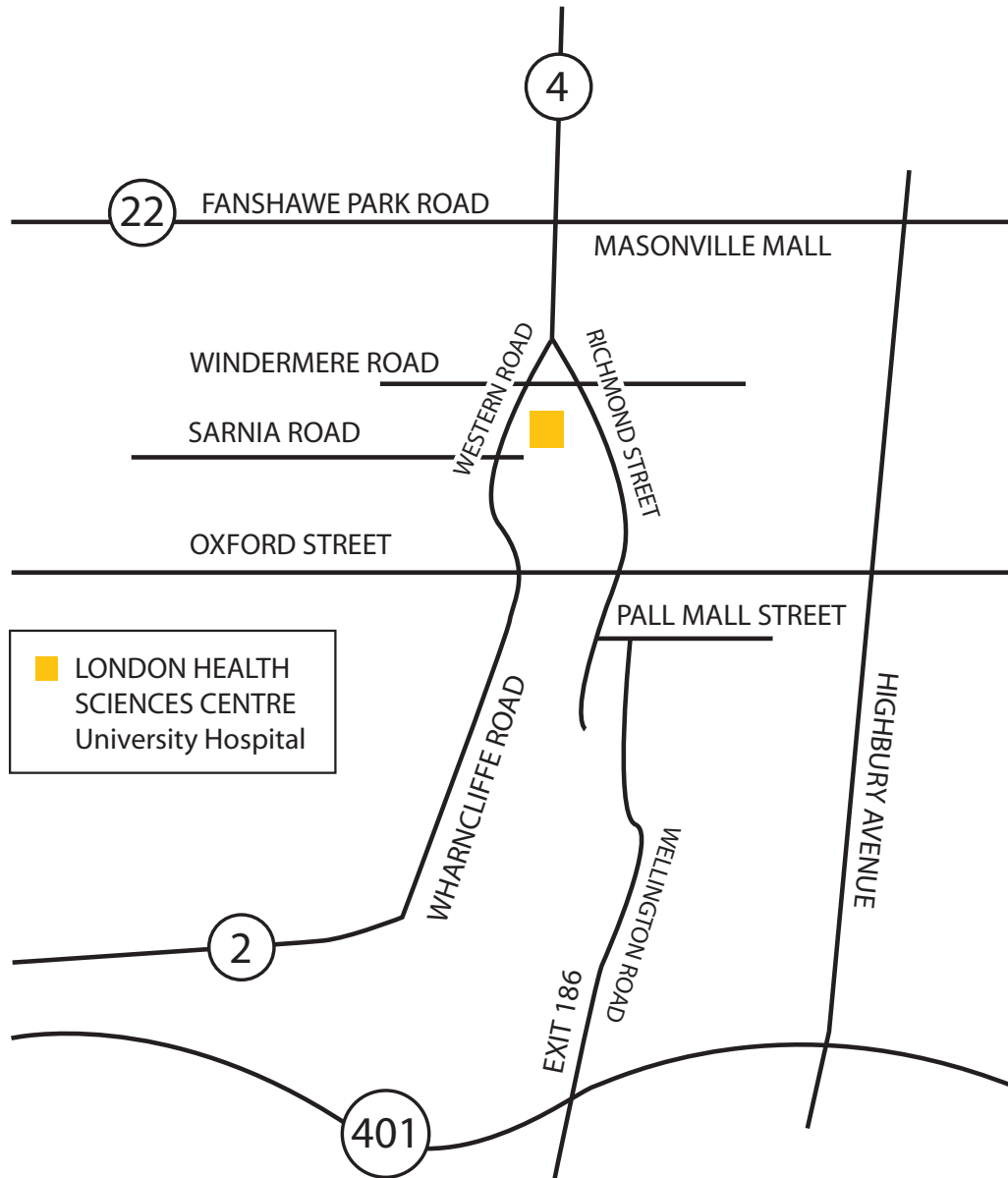
Trillium Gift of Life Network
www.giftoflife.on.ca

Appendix 4



London Health Sciences Centre

University Hospital





Liver Transplant Program