

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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www.lhsc.on.ca/transplant

*Cover photo: Heather received her liver transplant in 1983.
For the past 25 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 liver transplant assessment because you're experiencing some symptoms of liver failure (Appendix I). Usually, the assessment is done on an outpatient basis so you will need to stay in London for 2 to 5 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)
- recipient coordinator (a nurse who coordinates 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 the Nurse Practitioner/Clinical Nurse Specialist, Transplant Unit nurses, Outpatient Clinic nurse, physiotherapist, dietitian, and pharmacist.

Medical tests

Certain tests will be required to evaluate your health. You will have a number of tests done, which **may** include:

- blood tests, including HIV test
- chest x-ray
- abdominal ultrasound and Doppler study (examines the liver's structure and its blood supply)
- electrocardiogram (ECG) (measures your heart's electrical activity)
- echocardiogram (ECHO) (provides an ultrasound of the heart)
- wall motion study (measures how well your heart works)
- 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.



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 living at home until their transplant. The recipient coordinator will arrange for you to have a pager 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

Donors

To increase the number of organs for transplant, our transplant program has used these strategies: living donors, split-liver transplants, and hepatitis-B or hepatitis-C positive donors for patients who already have hepatitis. In some situations, donors may be able to donate a liver after their heart has stopped beating (Appendix II). Information regarding the organ donor is confidential.

Compliance

The transplant team expects that **all patients** on the waiting list will comply with medical advice, which includes clinic appointments, dietary restrictions, treatment requirements, and **abstinence 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.

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. As well as maintaining your permanent residence at home, you will need funds to afford temporary accommodation near the transplant centre. Additional costs include food, personal expenses such as medications, and transportation. 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 decide to 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 expenses.

Once you're discharged from hospital, you will be required to stay in London for some follow-up care before returning home. During this time, you will also be responsible for your own costs, which you should include in your budget. 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.

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 illegal 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 monthly or as requested
- see your family doctor regularly
- apply for provincial drug coverage
- plan for financial expenses (ie: accommodation and food) while in London

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 Standard Parking Of Canada Ltd. 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.

Benefits eligibility

Financial needs can place an enormous strain on your family budget. It's very important that you and your family prepare for the expenses that are an inevitable part of the transplant process. There are several resources that can help lessen the financial burden. Depending on your financial circumstances and geographic location, you may be eligible for assistance with travel, income, and the cost of medications. Assistance programs, designed to help when health emergencies occur, exist at the municipal, provincial, and federal levels of government. Benefits provide long-term financial assistance to people who are unable to be fully employed for an extended time because of illness. **All transplant candidates are strongly encouraged to register with their provincial drug program even if they have private drug plans** (Appendix III). You may need to know the DIN number of prescribed drugs to determine possible coverage ahead of time. This number varies, depending on the dosage of the drug (Appendix III). Also, there are some local and regional organizations across Canada that provide financial assistance to patients and families who must travel to other cities or provinces for medical treatment. For more information about benefits and financial assistance, please contact your social worker, either Stephen Turner (519-685-8500 ext. 32412) or Kelly Thomas (519-685-8500 ext. 32484).

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 MacArthur (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 beyond you now. 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 your cardiovascular fitness. You can start by going for a 5-10 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, 3 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 important before transplantation. You'll benefit physically and mentally by keeping your body in good shape. Try your best to fit exercise into your daily routine by getting your family and friends to join you. Perseverance now will pay off later. Physiotherapist, Nancy Howes (519-685-8500 ext. 35365), can also provide more specific information about exercises that can help you maintain your health while waiting for transplant.

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, pamphlets, and newsletters as well as a computer centre so you can search the Internet for the latest information.

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 IV). Continue to see 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 a 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 sickest patient 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 minutes.** If you must fly to London, arrangements will be made by the recipient coordinator. You are responsible for getting yourself to the local airport, and paying for the taxi trip from the London airport to London Health Sciences Centre, University Hospital.

What to bring

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

- medications
- 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)
- 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, electro-cardiogram, and urine tests.

The transplant surgeon will discuss possible risks of your transplant:

- dying during the operation
- 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. On average, most patients need about four units of blood. 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 hooked 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.

Transplant Unit

Each patient has a private room in the Unit where 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. Educational classes are held on a regular basis, and a schedule will be given to you during your hospital stay.

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. (Appendix VI)

Your hospital stay may be as short as seven days. You may be discharged directly from the Transplant Unit or from the general ward. You can expect to stay in London for at least one to two weeks after discharge, before returning home. During this period, you will attend physiotherapy, teaching sessions, and 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 that prevent rejection by suppressing your immune system. 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 take anti-rejection drugs to prevent your body from attacking the new liver. Many 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 drugs, including FK506 (Prograf®, tacrolimus), cyclosporine (Neoral®), sirolimus (Rapamune®), mycophenolate mofetil (CellCept®), and prednisone. Usually, patients are prescribed a combination of drugs. After your transplant, you will be given specific information about your anti-rejection drugs. The use of alternative therapies, such as herbal remedies and marijuana, is not recommended. Interactions between these drugs and your prescribed anti-rejection medication can affect your blood levels. You want to maintain your blood levels as consistently 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.



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.

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 do not qualify for long-term disability or illness pensions.

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. Any member of the transplant team is available to discuss family planning and birth control with you. 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.**

Driving a car

Most people can resume driving two to three months after they are discharged from hospital, but this is an individual decision. It is important that you are not taking narcotics when you resume driving as this 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

You should see your dentist every six months. Dental procedures can be performed as necessary after consultation with a physician. You must take antibiotics before undergoing any dental procedure such as probing, deep cleaning, extractions, or oral surgery. You will receive information to give your dentist regarding the antibiotics you should take.

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 tanning, 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. Your doctor may be able to give you the names of physicians in the area or region to which you are travelling. 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. You should be prepared to return home if you become ill during your vacation.

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 or necklet 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

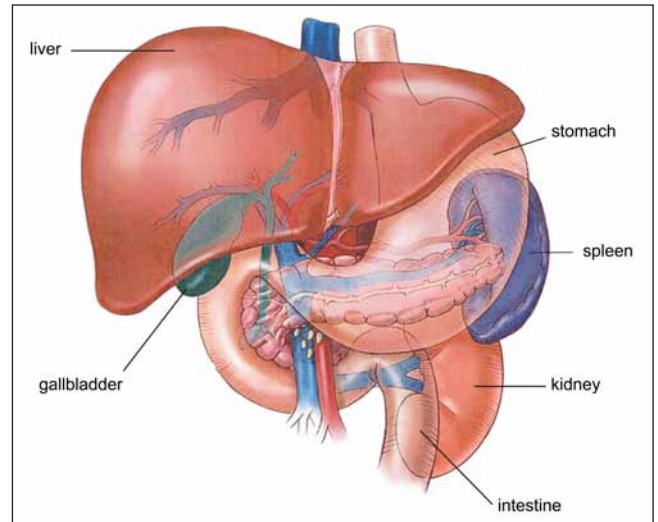
Visit your local physician within the first week after returning home, and each week or two for the first two months. After two months, you can see your physician less often as your physician decides. Blood tests should be taken every one to two weeks for the first three months you are at home, then you will require blood tests once a month. **Do not take your anti-rejection drugs until after your blood sample is taken.** Your family doctor will receive information about your health and guidelines for your long-term care. Your pharmacist will receive information on the medications that you are presently taking.

Appendix I

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, 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 transjugular intrahepatic portosystemic stent (TIPS) procedure that re-routes the blood in the liver and allows the ascites to drain more easily.

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 5 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 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 food and drugs 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 salt deposits 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.

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 and some other medications.

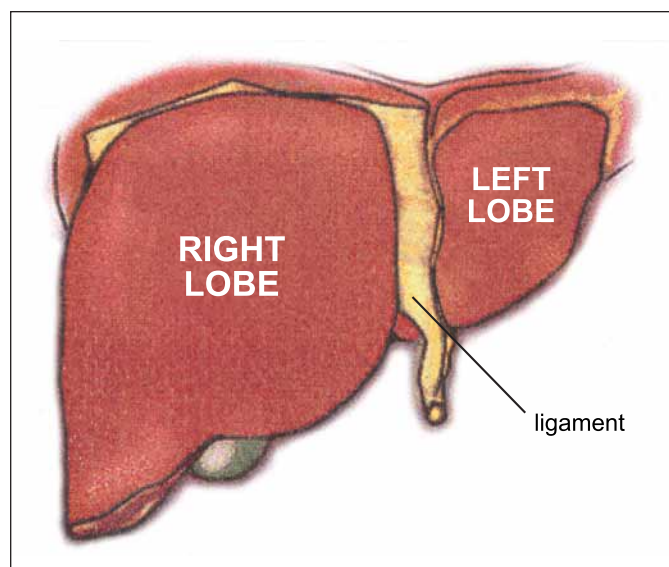
Appendix II

Living donation and other options

Living donors

A family member or a close friend may want to donate a segment of their liver to you. The donor must be healthy, have a compatible blood type, and be large enough to donate sufficient tissue to the recipient. Living donors must be between the ages of 18 and 55. If you know someone who wants to be assessed as a living donor or would like more information about the procedure, he or she should contact one of the recipient coordinators (refer to Appendix IV).

A liver segment may be removed from a living donor for transplant into a recipient.



Split-liver transplant

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.

Donors with hepatitis B or hepatitis C

Occasionally, a deceased donor with hepatitis B or hepatitis C is used, but only if the liver is still healthy and suitable for transplant. This is only used with recipients who already have hepatitis.

Livers from 'DCD' donors

Donation following cardiac death involves patients in the ICU who have no possibility of recovery. They are on life support and, following discussions with their family, a decision is made to withdraw this futile treatment. After their heart stops, the liver can be removed for transplantation.

Appendix III

Ontario's Trillium program

Dear Ontario Resident,

There have been some recent changes in the use of new anti-rejection drugs, which may affect patients currently on the transplant waiting list. Our Transplant Program has begun using tacrolimus (Prograf®, FK506) and mycophenolate mofetil (CellCept®, MMF) to prevent rejection when cyclosporine is not effective. These medications are extremely costly, and are not covered by the Ontario government. You are responsible for payment of these expensive medications. In the future, Neoral® cyclosporine may not be covered by the government; therefore, you would also be responsible for its fee.

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 may also want to check for sirolimus, ganciclovir, and valganciclovir. The DIN number has been included for your reference.

Prograf® (tacrolimus, FK506) 0.5mg (#02243144) 1mg (#02175991) 5mg (#02175983)

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

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

Cytovene® (ganciclovir) 250mg caplet (#02186802) 500mg caplet (#02240362)

Valcyte® (valganciclovir) 450mg 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.

Trillium application forms can be obtained from your pharmacy. The application asks for information about your family, your drug costs, and your previous year's income. 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 program immediately, even if you do not have enough receipts to reach your deductible yet. This has benefits for you. Because 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 program to help you, but it is your responsibility to apply for this help.

Appendix IV

Contact information

Transplant Program's general number	519-663-3354
Toll-free number	1-800-500-9845
Transplant Outpatient Clinic	519-663-3818
Transplant Unit (Inpatient)	519-663-3015
Prescription Centre	519-663-3231
Transplant Program's fax number	519-663-3858
Intensive Care Unit	519-663-3361, 519-663-3362
Dr. Ghent	519-642-3232
Dr. Levstik	519-663-3165
Dr. Marotta	519-663-3406
Dr. McAlister	519-663-2920
Dr. Quan	519-663-3355
Dr. Wall	519-663-2940
Liver Transplant Fellow	519-685-8500 to page
NP/CNS - Cheryl Dale	519-685-8500 ext. 35242
Recipient Coordinator - Grant Fisher	519-663-3760 (519-685-8500 to page)
Recipient Coordinator - Kathleen Larkin	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
Social Worker - Stephen Turner	519-685-8500 ext. 32412
Dietitian - Lynne MacArthur	519-685-8500 ext. 32449
Physiotherapist - Nancy Howes	519-685-8500 ext. 35365

For more information, please visit these websites:

Canadian Liver Foundation
www.liver.ca

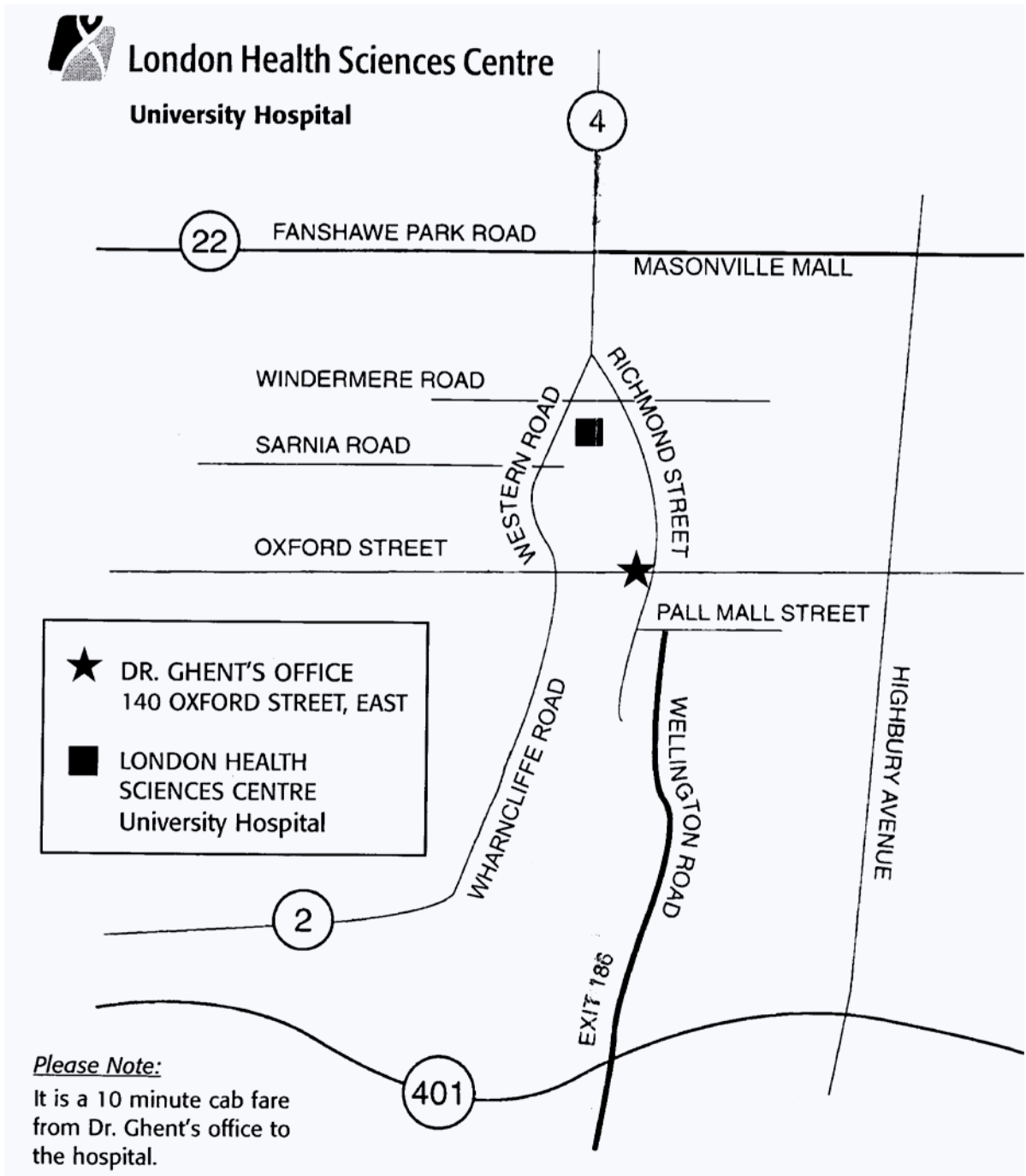
Canadian Organ Replacement Register
secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=services_corr_e

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

Surviving Transplantation
<http://www.sjhc.london.on.ca/sjh/programs/mental/survive/index.htm>

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

Appendix V



Appendix VI

Letter to all patients



Dear Patient,

I am writing to welcome you to London Health Sciences Centre. Our goal is to do everything we can to make your stay comfortable, and to provide the care and treatment that is medically necessary.

Our focus is not only your care and treatment while in hospital, but also your discharge from the hospital. The hospital is not the best environment for patients who no longer need acute hospital care. We start planning for your discharge as soon as possible. This helps ensure that we meet your needs on the day of your discharge, and that the appropriate services are in place, if needed, when you leave hospital.

LHSC is an acute care hospital and provides care to those who are most critically ill. We are committed to working with patients and their families to improve health and provide compassionate, high quality care.

Most patients return home when they are discharged. However, if you need more care, your health care team will work together with you and our community partners to plan for an appropriate discharge. This will ensure that your health care needs can be met when you leave the hospital.

We want to ensure that we provide the right care in the right place and the right time.

If you have any questions about discharge planning, please talk to your health care team. They will have a fact sheet for you with more information.

J. Kenneth Deane

Chief Operating Officer
London Health Sciences Centre



Liver Transplant Program