London Health Sciences Centre
Multi-Organ Transplant Program

Liver Transplantation

Patient Handbook

After Your Liver Transplant

Last revised 2020/Jun/08

Congratulations on receiving your liver transplant.

This is a new chapter in your journey to a healthy life. This Education Booklet will help guide you through this journey. Your Transplant Team will work through this booklet with you and you can keep it as a resource for any questions in the future.

Patients are usually in hospital for 6 to 10 days after receiving a liver transplant. During this time, the Liver Transplant Team will assist you with your recovery. While the Liver Transplant Team is key in your recovery, you and your family are important members of your team. You need to be actively involved in making your liver transplant as successful as it can be.

Your personal support team is very important during this stage of your recovery. While it is ideal to have your support person with you as much as possible, this may be difficult as they are planning around everyday life, including work. The really important times for your support person to be off work and available at the hospital are:

1) During surgery
2) Time of discharge from the hospital
3) During your outpatient stay in London

It is helpful if your support person can attend as many of your education sessions as possible.

Education is one of the keys to helping you have a successful outcome. You will learn how to manage the changes in your life, including medications, diet and exercise. You will become familiar with potential complications that come with transplant, how to identify them and when and how to get help when needed. You will learn the importance of working with your family doctor and your Transplant Team in keeping you healthy.

Let’s Get Started on your Road to Recovery!

Your Education Plan

Topic		Page	Complete	Initial
1	**Discharge Checklist/ Clinic Checklist**	5		
2	**Post-operative Care**			
	Lines & Tubes	7		
	Routine Tests	8		
	Pain Control	8		
	Wound Care	8		
	Breathing & Coughing Exercises	8		
	Mobility	9		
	Diet	9		
	Daily Routines	9		
3	**Clinical Pathway**	10		
4	**Medications**			
	Anti-rejection Drugs	11		
	Medication Tips	13		
5	**Vaccinations**	15		
	Education Check Point	17		
6	**Potential Complications**			
	Infection	19		
	Rejection	20		
	Cancer Prevention	21		
	Dental Care	21		
	Diabetes	22		
	MedicAlert	23		
	Education Check Point	25		

Discharge Checklist

- ☐ I understand how to properly take my medications.
- ☐ I know the symptoms that may indicate I have an infection or a rejection.
- ☐ I understand potential complications of transplant and how to prevent them when possible.
  - ☐ Diabetic Care
- ☐ I have a thermometer.
- ☐ I understand how to care for my incision and/or drains.
- ☐ I know how to contact the transplant team if I have any concerns.
- ☐ I have a calendar of my follow-up appointments.

Clinic Checklist

- ☐ Bring your Transplant Binder.
- ☐ Bring a list of your medications – your pharmacy can provide you with a list.
- ☐ Do not take your antirejection drugs the morning of your Clinic appointment
- ☐ Have your blood work taken before Clinic and then take your antirejection drugs.
- ☐ Have questions ready for your doctor – it can help to write them down so that you won't forget to ask.

☐ Lines and Tubes

Oxygen

During surgery, the anaesthetist placed a tube in your airway to assist you with breathing. This tube is removed in the Intensive Care Unit when you are able to breathe on your own. Patients often require oxygen through a mask or nasal prongs after the tube is removed. The amount of oxygen you receive will depend on the level of oxygen in your blood. This level is measured through a probe placed on your finger.

Heart Monitor

You will be attached to a heart monitor for the first 24 hours in the Transplant Unit to monitor your heart's rate and rhythm.

Sequential Compression Device

Sequential Compression Devices (SCD) are "sleeves" that wrap around the legs and inflate with air one leg at a time. This imitates walking and helps prevent blood clots from forming in your legs. Once you are up walking regularly, the SCDs are no longer needed.

Central Intravenous Line

A line is inserted by the anaesthetist into a neck vein while you are asleep in the operating room. It provides us with intravenous access to give fluids and medications. This line is usually in for two or three days after surgery, but can be in for longer. The line will only be removed when safe to do so.

Peripheral Intravenous (IV) Line

You will have at least one IV in your arm. This provides additional access for giving IV fluids until you can eat and drink. Medications can also be given through this line. You may require additional IVs to be inserted during your hospital stay– this will be explained to you at the time if needed.

Urinary Catheter

During surgery, a small tube is inserted in your urethra (where urine comes from) into your bladder. The urinary catheter is usually in place for at least three days after surgery.

Surgical Drains (Hemovac and Malecot)

Small surgical drains may be inserted into your abdomen during surgery. The drains prevent fluid from collecting in your abdomen. Drains are usually removed within 5 days of your surgery; however, removal of the drains depends on how much fluid they are draining. The Liver Transplant team will check them daily. More information will be provided by the healthcare team if your drains are still in place at your time of discharge.

☐ Routine Tests

Blood Work

You will have blood taken every morning (between 5-6 AM). Occasionally, you will need it more frequently depending on your condition.

Abdominal Ultrasound

Within the first 24 hours, you will have an ultrasound of your liver. This test helps the physician determine how well the blood in your liver is flowing. This procedure takes about 30 minutes.

☐ Pain Control

After transplant, you will have medication to help control your surgical pain. It is expected that you will experience some pain after surgery. However, by properly managing your pain level, you will be able to do activities important to your recovery, such as walking and deep breathing and coughing. As time progresses and you move about more, your pain will improve and medication will no longer be necessary. Your liver transplant team will check in with you regularly to make sure that your pain is under control. If required, a prescription for pain medication will be provided before discharge to help you control your pain after discharge home.

Pain medication can be constipating. A gentle laxative may be used when necessary and will be managed by the Transplant Team while in hospital. If you experience constipation after discharge home, talk to your Transplant Team about a safe over the counter laxative option.

☐ Wound Care

Immediately after surgery, your incision is covered with a dressing. Your nurse will change this dressing 48 hours after surgery and then daily. Once your wound is dry, the dressing will be removed and your incision will be left open to the air to finish healing. Your incision will be closed with surgical staples which stay in place for at least 14 days. The staples will be removed during a clinic visit when the Transplant Team determines your incision has heal closed.

It is important to keep your incision as clean as possible and follow the incision care instructions provided to you while in hospital. Check with the transplant team before you shower. If you have an open incision, you will need to wash at a sink until directed by the transplant team. Avoid soaking or scrubbing your incision or direct shower spray. Pat your incision dry with a clean towel. Do <u>NOT</u> submerge your incision in water (no baths, hot tubs, swimming pools) until your incision is completely healed. Do <u>NOT</u> apply any lotions, creams or ointments unless otherwise directed by the Transplant Team.

Inspect your incision daily for redness, new or yellow/green drainage, increased swelling, opening of edges, or increased pain. Concerning changes should be reported to the Transplant Team.

☐ Breathing and Coughing Exercises

A physiotherapist will see you after surgery to help keep your lungs clear. Following any major surgery, it is important that your lungs are fully inflated and clear of secretions in order to prevent pneumonia. Within the first 24 hours after surgery, the nurses will encourage you to practice deep breathing and coughing exercises. This may cause you a temporary increase in pain; a pillow or a folded blanket can be used to support your incisional site during this activity.

☐ Mobility

Along with the breathing exercises, your physiotherapist and nurses will also get you moving. You will be assisted with siting on the edge of the bed within the first 24 hours after surgery. Following this, they will help you sit in the chair and progress you to walking within 2 days of surgery. At the beginning, this will be uncomfortable for you, but after several days it will become easier and you will start to feel better. Plan to do your exercises and activities about 30-45 minutes after you have received your pain medications so you can move about more easily with minimal discomfort.

Once in the Transplant Unit, you will start a supervised exercise program in the Physiotherapy Exercise Room. When you are discharged from the hospital, you will continue to come to exercise class as an outpatient. You will be given a home exercise program when you are ready to head back home.

☐ Diet

Surgery effects the normal function of your bowels. You will be restricted to clear fluids (water, juice, broth, jello) for the first day after surgery. As your bowel function returns to normal, you will be able to start eating a regular diet again at the discretion of your team. This can sometimes take several days. The Liver Transplant Dietician monitors all liver transplants patients and will address any issues or concerns you may have.

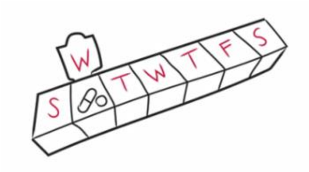
After surgery, you may find it easier to eat 6 small meals per day rather than 3 large meals. Your meals should be nutritious and contain protein. Protein is important for healing and regaining strength after surgery. You should also be drinking 6-8 glasses of fluid a day. Drinking adequate amounts of fluid each day can help with constipation after surgery. Do <u>NOT</u> include coffee, tea or cola beverages as part of your daily fluid consumption.

☐ Daily Routines following Transplant

You will have a liver transplant pathway posted on your wall. This will help you to know what to expect each day. Your nurse will help you work through each step of the pathway. The Liver Transplant Team will check on you progress on the pathway each day.

POD	Consults / Milestones	Bedside Care	Diet	Activity	Education
POD 0	Consult: ☐ Physiotherapy, ☐ ID, ☐ Social Work	☐ Chest AP ☐ 12 Lead ECG	☐ NPO	☐ Dangle at bedside	
POD 1	☐ Transfer to MOTU	☐ Liver US (within 24 hrs)	☐ Clear Fluids	☐ AAT ☐ Chair	
POD 2		☐ D/C Cardiac Monitor ☐ Central line removed ☐ Dressing change (48 hrs post-op)	☐DAT	☐ AAT ☐ Chair for meals ☐ Walk with assist	☐ Transplant Education Binder
POD 3	☐ Consult Dietician ☐ Consult Addiction Counsellor if required	☐ Remove Foley ☐ Remove Malecot	☐DAT	☐ AAT ☐ Chair for meals ☐ Walk 2x	☐ Transplant Education Video
POD 4	☐ Consult Endocrinology if required ☐ Diabetic Teaching if required ☐ Discharge Date Discussed	☐ Dressing change / ☐ D/C dressing to air if dry	☐DAT	☐ AAT ☐ Chair for meals ☐ Walk 2x ☐ Exercise class	☐ Nursing Education - Infection and Rejection ☐ Initiate SMP
POD 5		☐ Remove HMV	☐DAT	☐ AAT ☐ Chair for meals ☐ Walk 3x ☐ Exercise class	☐ Discharge Planning
POD 6			☐DAT	☐ AAT ☐ Chair for meals ☐ Walk 3x ☐ Exercise class ☐ Stair assessment	☐ Discharge Calendar
POD 7	☐ Medication Scripts 24 hours prior to D/C ☐ Discharge from Hospital		☐DAT	☐ AAT ☐ Chair for meals ☐ Walk 3x ☐ Exercise class	☐ Medications - Pharmacist (Day before Discharge) ☐ Patient Visit to Out Patient Pharmacy (Day before Discharge)
POD 8	☐ Medication Scripts 24 hours prior to D/C ☐ Discharge from Hospital		☐DAT	☐ AAT ☐ Chair for meals ☐ Walk 3x ☐ Exercise class	☐ Medications - Pharmacist (Day before Discharge) ☐ Patient Visit to Out Patient Pharmacy (Day before Discharge)
POD 9	☐ Medication Scripts 24 hours prior to D/C ☐ Discharge from Hospital		☐DAT	☐ AAT ☐ Chair for meals ☐ Walk 3x ☐ Exercise class	☐ Medications - Pharmacist (Day before Discharge) ☐ Patient Visit to Out Patient Pharmacy (Day before Discharge)
POD 10	☐ Medication Scripts 24 hours prior to D/C ☐ Discharge from Hospital		☐DAT	☐ AAT ☐ Chair for meals ☐ Walk 3x ☐ Exercise class	☐ Medications - Pharmacist (Day before Discharge) ☐ Patient Visit to Out Patient Pharmacy (Day before Discharge)

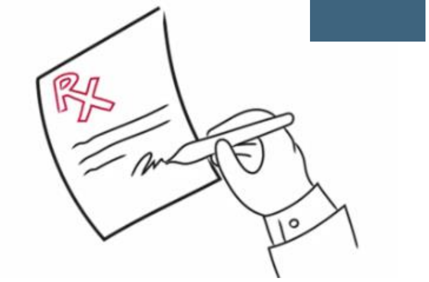
Anti-rejection Drugs



Your transplant nurse will help you learn your new medications, their names, what they look like, what they do, and when to take them. This is called the self-medication program (SMP). This program includes teaching handouts and videos.

The Patient Medication Videos can be found on line:

- Go to www.lhsc.on.ca
- Click **Patient Families and Visitors** tab
- On the left menu bar, click on **Programs and Sevices at LHSC**
- Click on **Mulit-Organ Transplant Program** under Transplantation
- Click on **Pharmacy**



In preparation for your discharge, the doctors will write your prescriptions for the medications you will need to take at home. This will happen a day before you leave the hospital. You should know each drug's brand name (the company name) and the generic name.

We strongly recommend that you have these first prescriptions filled at our hospital pharmacy, which is located in the main lobby. The Pharmacy Prescription Centre is open Monday to Friday 9:00 a.m. to 5:00 p.m., excluding statutory holidays. The telephone number is 519-663-3231. After your first prescription is filled, future prescriptions can be filled at the pharmacy of your choice.

Community pharmacies may not stock the anti-rejection drugs you need. Shortly after returning home, you should speak to your community pharmacist and tell them what medications you are taking. They may be able to order your anti-rejection drugs, but it will probably take a few days. You need to give your pharmacist lots of notice when you are running short on medications.

It is important that you never run out of medicine. It is recommended to have at least 2 weeks' worth of medication on hand at all times.

If you need financial help in obtaining your medications, please speak with the Pharmacist or Social Worker concerning this issue.

No matter how long it has been since your transplant, there is always a risk of rejection and losing your liver. **NEVER STOP TAKING YOUR MEDICATIONS OR CHANGE THE DOSAGE WITHOUT YOUR TRANSPLANT TEAM'S APPROVAL.**

Medication	**Start Date:**															
1. Prograf (Tacrolimus)	**Day:**	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat
		00	01	02	03	04	05	06	07	08	09	10	11	12	13	14
	08:00 AM															
	08:00 PM															

Take twice a day; The dose may change daily depending on your blood work – you may be asked to skip a day.

- This is an Antirejection Drug
- Pills available in 5mg, 1mg and 0.5mg doses
- Take at same time every day
- Don't let anyone else touch the pills with their bare hands
- If you vomit within 30 minutes of taking the pills, take the pills again. If it is more than 30 minutes, do not take the pills again.
- You have up to 6 hours to remember to take your pills if you have forgotten a dose. If it is longer than 6 hours, skip the dose and take your next dose at your normally scheduled time.
- **Do NOT take before you have your blood drawn on Clinic days – Your blood work needs to be done before you take Prograf. Bring your medications with you to your Clinic visit.**
- Side Effects: Tremors

2. Mycophenolate Mofetil (CellCept)	**Day:**	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat
		00	01	02	03	04	05	06	07	08	09	10	11	12	13	14
	08:00 AM															
	08:00 PM															

Take twice a day; Your Transplant Team will determine your dose.

- This is an Antirejection Drug
- Don't let anyone else touch the pills with their bare hands
- If you vomit within 30 minutes of taking the pills, take the pills again. If it is more than 30 minutes, do not take the pills again.
- You have up to 6 hours to remember to take your pills if you have forgotten a dose. If it is longer than 6 hours, skip the dose and take your next dose at your normally scheduled time.
- Side Effects: This drug may cause your stomach to be upset or cause heart burn. You may get diarrhea. Please tell your Transplant Team if you have any problems with this.

3. Prednisone	**Day:**	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat
		00	01	02	03	04	05	06	07	08	09	10	11	12	13	14
	08:00 AM															

Take once a day; This will be a tapering (slowly decreasing) dose.

- This is an Antirejection Drug
- The pills come in 1, 5 or 50 mg pills – you may have to mix and match and take many pills to get the right dose for you.
- Side Effects: This drug does not taste good. You may be more emotional than usual. It may cause you to be short tempered or anxious. It can cause weight gain.

☐ Medication Tips

- ✓ To prevent rejection of your new liver, anti-rejection drugs are necessary. You will need to take these drugs for the rest of your life.
- ✓ It is very important to learn the names of these drugs, what they do, and possible side effects. You should know each drug's brand name (the company name) and the generic name. View the medication videos prior to being discharged and speak to the pharmacist about any concerns with your medications.
- ✓ These drugs must be carefully monitored (through blood work) especially in the first months after transplantation to ensure you are getting the correct dosage.
- ✓ If your antirejection drugs include Tacrolimus, Sirolimus or Cyclosporine, you MUST NOT take the medication before having your blood tests to measure your drug levels. Bring your medication to the hospital and take it immediately after your blood is drawn.
- ✓ Check with your pharmacist before taking any non-prescription medications, such as cold capsules, aspirin, cough syrups, vitamins, and herbal remedies. Other medications can affect how well your anti-rejection drugs work.
- ✓ Cannabis products may affect your transplant medications. Let the Transplant Team know if you use any marijuana products.
- ✓ It is strongly recommended that you don't eat or drink products with grapefruit and pomegranate due to drug interactions.
- ✓ If you miss a dose of your anti-rejection medication, the general rule is to take the missed dose when you remember. Check your medication sheet for specific instruction.
- ✓ If you vomit within 30 minutes of taking your medication, repeat the dose when your stomach settles. If you vomit more than three times within a few hours, notify your doctor.
- ✓ Make sure you always have two to three weeks' worth of medication on hand. Do not allow your prescriptions to run out.
- ✓ Before clinic visits, check to see if you need a refill on any prescriptions. The label on your medication package indicates if there are refills still available.
- ✓ The transplant team can ONLY give you a prescription for anti-rejection medications if they are following you and see the results of your blood tests. If you do not have bloodwork done regularly and do not see a physician, the transplant doctors can NOT write a prescription for you.
- ✓ When on vacation, take enough medication with you to last well beyond the time you plan to return home. If you travel by air, carry your medication in hand luggage rather than in checked luggage. Carry a list of your medications with you.
- ✓ Store medications at room temperature, away from direct heat or cold and always away from children's reach.

Vaccinations

After your transplant, you will be on medications that suppress your immune system. You are at a higher risk for infections and will benefit from immunization.

Patients are encouraged to get the necessary vaccinations while waiting for transplant. This is important as not all vaccinations are safe to be given after transplant.

Tips about Vaccinations:

- ✓ Some vaccines are not required after transplant if you have been vaccinated before your transplant. When sorting out which vaccinations are needed, it is helpful to know which ones you’ve had – **Bring your vaccination records with you to Clinic.**
- ✓ If you have had your spleen removed, check with your doctor about your vaccinations.
- ✓ The flu shot is recommended for transplant patients. If you receive your transplant during flu season, wait 1 month after your transplant before having the flu shot.
- ✓ Wait 3-6 months after your transplant for all other vaccinations.
- ✓ All vaccines are covered by OHIP with the exception of SHINGRIX and HPV. These may be covered by some private insurance plans.
- ✓ **Transplant patients should NOT receive live vaccines.**

Infection	Recommended Vaccine	Cautions
1) Influenza (the flu)	**Get the flu shot!** High dose (one-time dose) OR Regular dose (need 2 doses, 1 month apart)	Do **NOT** use live inhaled flu vaccine.
2) Pneumonia	There are two pneumococcal vaccines recommended – you should receive both. 1. **Prevnar® 13** (conjugate vaccine) 2. **pneumovax® 23** These vaccines should be given 8 weeks apart.	This vaccine is not required again if you vaccinated before transplant.
3) Shingles	**SHINGRIX** – 2 doses, 2 months apart You can still get the SHINGRIX vaccine 6 months after you have had Shingles. Do **NOT** use Zostavax – this is a live vaccine.	This vaccine is not required again if you vaccinated before transplant. SHINGRIX is not covered by OHIP but may be covered by some private insurance plans.
4) Tetanus, Diphtheria, Pertussis	**Tdap Vaccine** – required every 10 years There are 2 different Tdap vaccines – either is okay based on your age. Boostrix for people age 10 years and older Adacel for people age 10-64	
5) Meningitis	There are different types of meningitis and therefore different vaccines. We recommend getting **Menactra** which covers the most common types of meningococcal groups (A,C,Y,W). **Bexsero®** covers meningococcal group B. Men-C (**Menjugate)** vaccine only covers group C (given to those who have had a splenectomy).	It is important to know which type of vaccine you have had – please check with your family doctor.
6) Haemophilus Iinfluenza B	**Haemophilus influenzae B vaccine** (Hib vaccine) should be given after transplant	
7) Hepatitis B	**Hepatitis B vaccine** Being vaccinated to Hepatitis B does not mean that you are immune – it may take several boosters. After transplant it may be more difficult to achieve immunity. Your Transplant Team will have checked your immunity level using a blood test. If you are not immune, it is recommended that you get a booster or complete the 3-dose series. Immunity needs to be retested after vaccination.	
8) Hepatitis A	If you are planning to travel to a country where Hepatitis A is common, you should be vaccinated. This needs to be done well in advance of your travel. Check with the Transplant Team at least 2 months prior to departure. You will need 2 doses of the vaccine. The last dose needs to be at least 2 weeks before departure.	
9) Human papillomavirus (HPV)	**4-Valent HPV vaccine** (4vHPV) is recommended for anyone less than 45 years old.	4vHPV is not covered by OHIP but may be covered by some private insurance plans.

10) Measles	**Do NOT vaccinate for measles after transplant – MMR vaccine is live vaccine.** Protection against measles is usually checked before transplant and MMR vaccine maybe given then if your transplant doctor approves.

Education Check Point

- ☐ I have watched the medication videos.
- ☐ I have my SMP (Self-Medication Program) sheets.
- ☐ I can recognize my pills and understand my doses.
- ☐ I have my specific drug information sheets:
  - ☐ Prograf / Tacrolimus
  - ☐ CellCept / Mycophenolate
  - ☐ Prednisone
  - ☐ Cyclosporine
- ☐ I understand vaccinations and know which ones I've had and which ones I need.

Questions / Comments

Refer to LHSC transplantation website if you lose any sheets or as a quick reference.
https://www.lhsc.on.ca/multi-organ-transplant-program/patients-families-visitors

Post-Transplant – Identifying and Preventing Potential Complications

☐ Infection

You will be taking anti-rejection medications which 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 your transplant.

Fever (a temperature >38°C or 100°) is often the first sign of infection. However, transplant patients do not always present with a fever when they have an infection. Because you are immunosuppressed, your body's reactions to infections may also be suppressed. If you do develop a fever, you need to seek medical attention immediately – either go to see your family doctor or go to your local emergency room. The Transplant Team is always available for consultation.

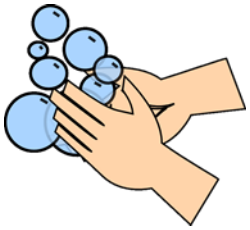
If you have any other symptoms of infection (listed below) but no fever, you may still have an infection and should seek medical attention.

Signs of infection may include:

- Fever (38ºC/100ºF or higher) ... generally feeling unwell
- Cough or sore throat, green/yellow sputum, shortness of breath
- Burning sensation when you urinate, foul smell to urine, frequent urge to void
- Redness, pain, swelling or drainage around the incision If an infection is suspected, you should call your doctor

Ways to prevent infections:

- Wash your hands frequently
- Good general hygiene
- Good dental care - see the dentist every 6-12 months
- Healthy lifestyle including rest and exercise
- Nutritious balanced diet
- If possible, avoid direct contact with people who have a cold or infection
- Get your vaccinations as recommended (see vaccination section)



❑ Rejection

The immune system is the body's internal defense system. It protects you from infection (bacteria and viruses) by recognizing and attacking foreign substances. The transplanted liver is seen by your body as a foreign tissue and, therefore, it tries to attack it. Anti-rejection drugs help to suppress your immune systems response to foreign substances to prevent your body from rejecting the new liver.

Some patients will experience rejection episodes in the first few weeks. Rejection is usually controlled by adjusting your anti-rejection medications. Rejection is less likely to occur as time passes, but the risk is always present.

Signs of rejection may include:

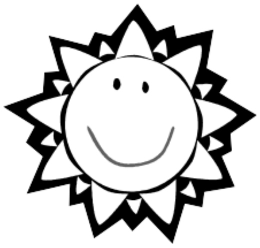
- Fever (38ºC/100ºF or higher)
- Fatigue and feeling unwell
- A change in your liver function determined by blood tests
- Jaundice (yellow skin)

It is very important to report any symptoms promptly. Be sure to take all medications as prescribed. Attend clinic visits as scheduled and complete blood work as instructed.

If rejection is suspected, a liver biopsy may be done. Doctors remove a small piece of tissue from the liver which is examined under a microscope. Microscopic examination is the only reliable way to diagnose rejection.

☐ Cancer Prevention

You are at a slightly higher risk of developing cancer as a result of taking anti-rejection medications. Skin cancers are the most common form of cancer after transplant and 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.



Always wear sunscreen (SPF of at least 15-30) when you are in the sun. (Do not forget to apply lotion to your ears, face and nose). Reapply the sunscreen frequently – especially if sweating or after drying off from a swim. Avoid the mid-day sun (10 a.m. - 2 p.m.) when the ultra-violet rays are strongest.

It is important that you have yearly check-ups and cancer screening through your family physician. This includes breast examinations, pap smears and prostate exams as applicable.

☐ Dental Care

Because your risk of infection is highest in the months following your transplant, the Transplant Team recommends that you <u>NOT</u> go to the dentist for any procedures including cleaning for the first 3 months after your transplant and if possible avoid the dentist for up to 6 months. After this, you should see your dentist every 6-12 months for regular check-ups.

There is no requirement by the Transplant Team that you have antibiotics before any dental procedures. The need for antibiotics is at the discretion of your dentist.

Some transplant medications can increase the risk of gum disease like infections and overgrowth of the gums. It’s very important that you take good care of your teeth and gums after your transplant – <u>brush and floss your teeth regularly.</u>

☐ Diabetes/ High Blood Sugars

While you may never have had a problem with your blood sugars or diabetes in the past, it is a potential complication following transplantation. This is called new-onset diabetes. Some studies have shown that up to 30% of recipients develop diabetes within 5 years after transplant.

Several things may make you more likely to develop new-onset diabetes including age, ethnicity, family history, obesity and your anti-rejection drugs. Prednisone is associated with the greatest risk of developing diabetes. Tacrolimus may also contribute to developing diabetes.

New on-set diabetes occurs when your body doesn't use insulin properly. You produce insulin but your body is unable to use it effectively. The result is you blood sugar level becomes too high.

What are the symptoms of diabetes?

- Fatigue
- Extreme thirst
- Frequent urination
- Extreme hunger
- Weight loss
- Frequent infections
- Slow wound healing
- Blurry vision

What are the consequences of having diabetes that is not treated properly?
Other than the symptoms listed above that can greatly affect your quality of life, uncontrolled diabetes can increase the risk of complications such as:

- Heart disease
- Blindness
- Nerve damage
- Kidney failure
- Amputations of limbs

How is new-onset diabetes treated?
Diabetes can be treated with:

- Physical activity and a healthy diet
- Oral medication and/or insulin

The type of treatment you receive will depend on your blood sugar levels.

If the Transplant Team suspects that you have new-onset diabetes before you leave the hospital, you will be seen by the LHSC endocrinologist and the diabetes educator. The endocrinologist will prescribe the best treatment option for you and the diabetic educator will assist you in understanding and managing your diabetes.

If new-onset diabetes is suspected during one of your Clinic visits after you are home, the Transplant Team will refer to you a specialist in your community to diagnose and treat you.

Usually diabetes is not curable. New-onset diabetes after transplant however may be related to your prednisone or tacrolimus. These drugs are necessary for the health of your liver. Prednisone is eventually tapered off and you no longer require it. Tacrolimus dose may decrease as time passes after transplant. Both of these mean that your blood sugars may become normal and you no longer require oral medications or insulin. It is important that your diabetes be closely followed so that treatment is appropriate for your situation.

☐ Medic Alert

In an emergency, a Medic Alert bracelet or necklace shows others that you are a liver transplant recipient. We recommend that you buy a Medic Alert bracelet or necklace as soon as possible. Medic Alert brochures including an application form are available in the Transplant Unit and at most drug stores. You can find more information at the Medic Alert Website (www.medicalert.ca).

Your bracelet or necklace should be engraved with:

Liver Transplant/Immunosuppressed
(and any other pertinent information like allergies, diabetes, etc.)

London Health Sciences Centre (519-685-8500)

Education Check Point

- ☐ I have a thermometer or will get one for use at home.
- ☐ I know how to identify signs of infection or rejection.
- ☐ I have a Medic Alert Form or know how to get one.
- ☐ I know which vaccinations are safe and which vaccinations I should have.
- ☐ I have any specific information sheets that apply to me:
  - ☐ Hepatitis C FAQ

Questions / Comments

Refer to LHSC transplantation website if you lose any sheets or as a quick reference.
https://www.lhsc.on.ca/multi-organ-transplant-program/patients-families-visitors

Discharge and Follow-up Appointments

You are being discharged from the hospital!

The Transplant Team has said that you can go home from the hospital. This is an exciting time but also can be a little frightening.

REMEMBER:

The Transplant Team would not discharge you from the hospital if they did not feel that you were ready to go!

Please feel free to talk to the doctor or the nursing staff about any concerns you may have about going home.

Before leaving the hospital, you will be given a schedule of appointments for clinic visits, blood tests and physiotherapy. Your first clinic visit will be within a few days of your discharge.

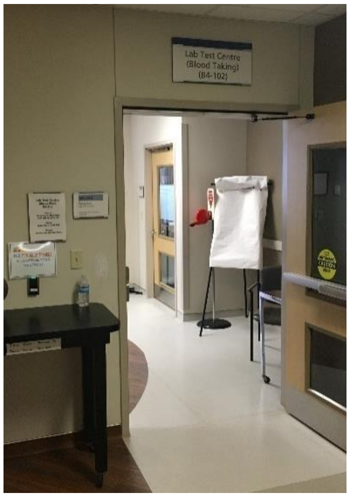
After leaving the hospital, it will be necessary for you to stay in London for 1-4 weeks. The Liver Transplant Team will see you regularly during this time and help manage any medical and surgical issues and adjust your medications are needed. You will also be expected to go to physiotherapy daily.

You will need to find accommodations in London for the duration of your stay in London. A list of accommodations is available in the Transplant Unit or on our website (https://www.lhsc.on.ca/multi-organ-transplant-program/accommodations). Most local hotels offer a hospital rate to help you with the financial burden you may experience with surgery. If you have any problems with setting up a place to stay, your Social Worker will be happy to help you.

Who do I call if I have problems before my first visit?

There is a list of transplant telephone numbers included at the back of this booklet. Any member of the team will be happy to answer your questions. It is important that your concerns are addressed as early as possible to prevent them from developing into more serious health concerns. If you are unable to reach the Transplant Team or if the matter is urgent, please go to the closest Emergency Department or call 911.

What happens at my follow-up appointments?



☐ Blood Work

The first thing to do when you come to the hospital is get your blood work done at the Lab Test Centre (Blood Taking) on the 4th floor (Room B4-102). You should come to the hospital one hour before your appointment to have your blood drawn. The requisitions for this blood work will be at Lab Test Centre.

Blood is taken to check:

- your liver function tests, electrolytes, and hemoglobin
- your anti-rejection drug levels

To test your anti-rejection drug levels, your blood needs to be taken before your morning dose. It is very important that you do <u>NOT</u> take your anti-rejection medication until after you have had your blood drawn. You should bring your medications to the hospital with you and take them after your blood has been drawn. You may eat and drink normally unless told otherwise.

After you leave the hospital, blood tests should be done:

- Week 1
- Week 2
- Week 4
- Week 6
- Once a month after week 6

Blood work may be ordered more frequently at the discretion of the Transplant Team.

<u>Remember; do NOT take your antirejection drugs until after your blood sample is taken.</u>

☐ Clinic Visits

Bring a list of your medications with you to the Clinic. Your pharmacist can provide you with this list. The nurse will review your medication list with you and ask if you require any repeat medications. The nurse will take your weight and blood pressure, and also review how you have been feeling since the last clinic visit. The doctor will then see you and review your blood work results with you. Your visit may require that you remain at the clinic for two to four hours so please be prepared for this wait.

☐ Next Appointments at the Transplant Clinic

It is important that you continue to visit your liver transplant specialist as directed – they are the experts at monitoring your liver function and adjusting your medications as needed.

You are required to have regular blood work and clinic visits – prescriptions can be completed based on the results of your tests.

Before you leave the Transplant Clinic, make sure that you check in with the Clinic Nurse or Clerk.

Schedule your next appointment before you leave the Transplant Clinic.

☐ The Role of your Family Doctor

The Liver Transplant Team provides care directly related to your transplant. This includes providing you with prescriptions for anti-rejection drugs and transplant related medications. Remember that prescriptions cannot be given if the Liver Transplant Team has not seen recent blood work.

Your family doctor continues to be your primary care provider. Your family doctor will manage your overall health care including vaccinations. If you do not have a family doctor, it is important that you find one.

Visit your family doctor within the first week after returning home, and each week for the first two months. After two months, you can see your physician every two weeks, and then less often as your physician decides. Your family doctor will receive information about your health and guidelines for your long-term care. You will be given information to take to your pharmacist on the medications that you are presently taking.

☐ Ontario Telemedicine Network (OTN)

Telemedicine (called OTN) uses video computer technology to move your appointment with your doctor from in the hospital to your home. You stay at home, your doctor stays in the hospital and you connect through the internet.

OTN can be arranged for recipients who live quite a distance from the hospital. OTN is not an option if you need any tests to be done during your visit (including listening to your lungs, checking your blood pressure or doing a physical exam).

To have an OTN appointment, you will need:

1) One of the following:
    - Desktop computer with webcam/microphone/speaker
    - Laptop with webcam/microphone/speaker
    - Android Tablet or iPad
    - Smartphone (excluding Blackberry)
2) Internet access
3) Email address

Check with your doctor to see if OTN is an option for you – your transplant team will be happy to facilitate.

Our Transplant Out-patient Clerk will set up OTN for you. You will receive an email appointment from OTN when it is scheduled as well as a reminder email 24 hours before your appointment.

Education Check Point

☐ I have my Out Patient Appointments Schedule.

☐ I have the OTN Patient Information sheet.

Questions / Comments

Refer to LHSC transplantation website if you lose any sheets or as a quick reference.

https://www.lhsc.on.ca/multi-organ-transplant-program/patients-families-visitors

Life after Transplant

Most transplant recipients can look forward to resuming a normal lifestyle. We encourage recipients to follow good health habits.

❑ Diet and Nutrition

Good nutrition is an important part of your recovery following liver transplantation. The purpose of your post-transplant diet is to help prevent high blood pressure, high blood sugar, excess weight gain and promote good overall health and wellness.

- **What is Good Nutrition?**

Good nutrition means eating a variety of foods that give you all the nutrients you need to maintain your health~~,~~ and feel strong. Nutrients include proteins, carbohydrates, fats, vitamins, minerals and trace elements. Your meals should include whole, unprocessed, nutrient rich foods.

Examples of whole, unprocessed, nutrient rich foods are:

- Red meat (beef, pork)
- Poultry (chicken, turkey)
- Fish
- Eggs
- Leafy vegetables (kale, spinach)
- Nuts
- Legumes (lentils, kidney beans, chickpeas)
- Dairy (milk, yogurt, cottage cheese, hard cheese)
- Whole grains
- Starchy vegetables (potatoes, beets, turnip)

- **Food safety** is also important following organ transplant and includes:
  - ✓ Hand washing before and after handling food
  - ✓ Cooking foods to the correct internal temperature before eating
  - ✓ Ensuring foods are stored correctly and not used beyond expiration date
  - ✓ Using care to avoid potentially high-risk foods (raw and undercooked meats, eggs, poultry, and seafood, or unpasteurized dairy) because they may contain bacteria that can cause infection

- **Will I Need to Change My Diet?**

If necessary, your healthcare team can help you understand which foods you should avoid or limit – and why. Dietary changes that may be required are:

- ✓ Avoiding certain fruits (grapefruit and pomegranate) as they can affect the level of medications in your blood (see Medication Tips on page 13)
- ✓ Eating a low salt diet to reduce swelling and limit fluid retention
- ✓ Eating more protein throughout the day to help with energy and muscle development
- ✓ Limiting sugary and over processed foods to help control blood sugar levels

- **Sugar Recommendations**

Health Canada recommends a healthy eating pattern where most sugars come from fruit, vegetables and unsweetened dairy products such as plain milk or yogurt. Other sources of sugars can increase calories without benefiting our health.

World Health Organization (WHO) recommends that the intake of free sugars not exceed 10% of total energy. This means that the average person should not eat more than 50 grams of sugar per day.

After your liver transplant, it is important to limit the amount of sugar you eat because it can lead to too many calories being consumed. Eating more calories than you are burning can lead to problems with obesity and increases your risk of chronic diseases such as:

- ✓ Type 2 diabetes
- ✓ Some forms of cancer
- ✓ Cardiovascular disease

- **The Role of your Dietitian**

The dietitian at your transplant center can guide you on which diet is right for you. If you have questions or need more information about healthy eating after your liver transplant, you can request a referral to see the dietitian who works within the liver transplant program.

☐ Exercise and Activity

Your tolerance for activity will initially depend on how sick you were before surgery. While recuperating from surgery, you exercised regularly in physiotherapy which helped you to recover enough function to get out of the hospital. Once home from the hospital, the exercise routine you learned while in physiotherapy should be continued. It is very important to your mental health and physical well-being.

During the first six weeks after your transplant, you should not lift anything heavier than ten pounds. Lifting, pushing, or pulling too much weight too soon could possibly cause a hernia to develop.

A liver transplant recipient should avoid abdominal exercises (sit-ups, crunches, etc.) for 8 weeks following surgery in order to ensure proper healing of the incision. After 8 weeks, it is important to gradually begin abdominal exercises since weak abdominals increase your risk of back pain and injury. As a general policy, patients are considered to be fully recovered by 3-6 months following liver transplantation, although some report feeling decreased energy levels for up to a year.

Specific exercise information will be given to you by the physiotherapist before you go home. Exercise has many benefits:

- ✓ improved blood pressure control
- ✓ improved muscle strength
- ✓ lowered level of blood fats
- ✓ better control of body weight
- ✓ stronger bones
- ✓ better sleep with improved energy level

To benefit from an exercise program, you should try to exercise at least three days a week. It's best to exercise on non-consecutive days, and always wait one hour after eating. Find an activity you enjoy and have fun! Please speak to your transplant team about the potential risks of participating in contact sports, such as hockey, karate, or football.

❑ Returning to Work

Most recipients are off work for about three months after transplant surgery. The time that you need before returning to work will depend on how fast you recover and the type of work that you do. These and other factors can influence your decision when to return to work. Depending on your job, you may be able to return to work part days to start.

You should discuss this issue with your doctor and employer before making a decision.

❑ Driving

Most people can usually resume driving two months after transplant, but this is a case by case decision. You should be off strong pain medications if you are operating a vehicle. Check with your doctor before resuming driving.

Remember, you are still required to wear a seatbelt. If the belt bothers your incision, place a towel or blanket between you and the seatbelt.

❑ Travelling

You are able to travel as often as you wish after the transplant. It is not recommended that you leave the country for the first 6 months.

Always discuss your travel plans with your physician.   Your doctor may be able to give you names of physicians in the area where you are travelling. Some countries will require that you get vaccinated.   Please discuss this issue with the transplant team prior to receiving any vaccines. You must 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.

What about time differences? If you are away a short time, take your medications at the same time as you would at home. If you are away a longer time, then you may wish to adjust your dosing to the time of the new place.

☐ Sexual Activity

There are no restrictions on sexual activity after liver transplant. You may resume activity whenever you and your partner feel comfortable.

For women, it is important to use birth control. The use of birth control pills is not recommended. We recommend using the double barrier method for birth control, that is, condoms and contraceptive foam or diaphragm and contraceptive foam. Previously non-menstruating women may resume menstruation and become pregnant. Any member of the transplant team is available to discuss family planning and birth control with you.

☐ Pregnancy

For females of child bearing years, starting or enlarging their family may be one of the goals of retuning to a 'normal' life. Successful pregnancies have been reported within our program and worldwide. However, there can be an increased risk to both the mother and the child. 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.

Your Transplant Physician may wish to change your anti-rejection medications prior to conception and/or during pregnancy.

During your pregnancy, you will need to be monitored closely for:

- rejection
- fetal development during pregnancy
- maternal complications such as gestational diabetes, hypertension, pre-eclampsia, and infection

Consultation to the FRAME (Fetal Risk Assessment from Maternal Exposure) Clinic for all female patients considering pregnancy and a high risk OB/GYN is recommended.
After delivery, the team will discuss with you're the risks of breast feeding.

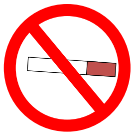
Check with your transplant physician about pre-conception and pregnancy.

☐ Alcohol

Because of the effects of alcohol on the liver, liver transplant recipients are advised **NOT** to consume alcohol after transplantation.

☐ Smoking

Liver transplant recipients are advised **NOT** to smoke cigarettes.



☐ Cannabis

There is not a lot of research looking at the effects of marijuana in transplant patients and therefore we neither recommend nor prohibit the use of marijuana for transplant patients. Please advise the Transplant Team of any marijuana use as it may impact your health.

If you choose to use any form of marijuana, it is important for you to know:

1. Cannabis (both THC and CBD oil) may affect the levels of many drugs in your blood. If you use marijuana regularly, you will need to test your transplant drug levels more often. This is to make sure that your drug levels are at the best possible level to prevent rejection. Irregular and/or infrequent marijuana use can cause variation in your transplant drug levels and make it difficult for the transplant team to adjust your drugs accurately.
2. Due to the risk for fungal infection when inhaled, transplant recipients should **NOT INHALE** any marijuana products.

If you choose to use marijuana, the Transplant Team strongly advises transplant recipients to obtain their cannabis products from legitimate sources only and never use ‘street’ products. This is because of the risk of contamination of the marijuana.

☐ Gardening

Wear gloves when doing dirty work like gardening to prevent puncture wounds and because of bacteria in the dirt.

☐ Pets

While household pets increase the risk of infection, they also increase quality of life. Mainly, avoid contact with excrement. If you can’t get someone to clean a cage or litter tray for you, always use gloves and mask.

☐ Emotional Support

Liver transplant surgery can be a very emotional experience. You may have many different feelings. On one hand, you may be happy that you are now feeling better and have an opportunity for a second chance at a healthier life. On the other hand, you may also have feelings of sadness and grief for the donor and their family. You are not alone. Many transplant patients feel this way. It may take some time to work your way through these complex feelings. Your transplant team is available to help you through this time. Some useful tips for dealing with these feelings are:

- ✓ Talk About Your Feelings
  Opening up and being honest about what you are feeling can be very helpful. This can be to your family, support person, friends or the Transplant Team. The Social Worker with the Transplant Team can be an excellent resource if you are struggling to identify and cope with what you are feeling.
- ✓ Speaking with other transplant recipients
  You will have many opportunities during your transplant journey to meet with other recipients (e.g. physio class). This is a great chance to talk about how you feel and how they managed.
- ✓ Writing the Donor Family
  If you are interested, recipients are able to write to the donor family. It is recommended that you wait at least three months before doing this. The decision to write to a donor family is yours to make. There are no expectations from the Transplant Team or donor family. A brochure has been included in this binder outlining the process should you wish to write a letter.
- ✓ Getting Involved
  Sharing your story and becoming an advocate for organ and tissue donation has helped many feel as though they are giving back. Opportunities are available for transplant recipients to help increase organ donation awareness. If you are interested in getting involved, please speak to the Transplant Team.

Returning to your previously healthy self after transplantation may be an adjustment for both you and your family/support team. Transplantation cannot be done alone; you need the ongoing support of your family and friends to be successful.

It is also important to remember your family/support team is also going through a change. Their role in your life is also undergoing change as you recover from surgery and your overall health improves. It is not uncommon for your family/support team to need support of their own. Patience is required on both sides as you find your 'new normal'.

Do not hesitate to contact members of your Transplant Team or your Local Health Care Team, (e.g. family doctor) if you or your family/support team need additional assistance. Resources are available in your local area to help you and your family/support team cope with the changes transplantation bring.

Education Check Point

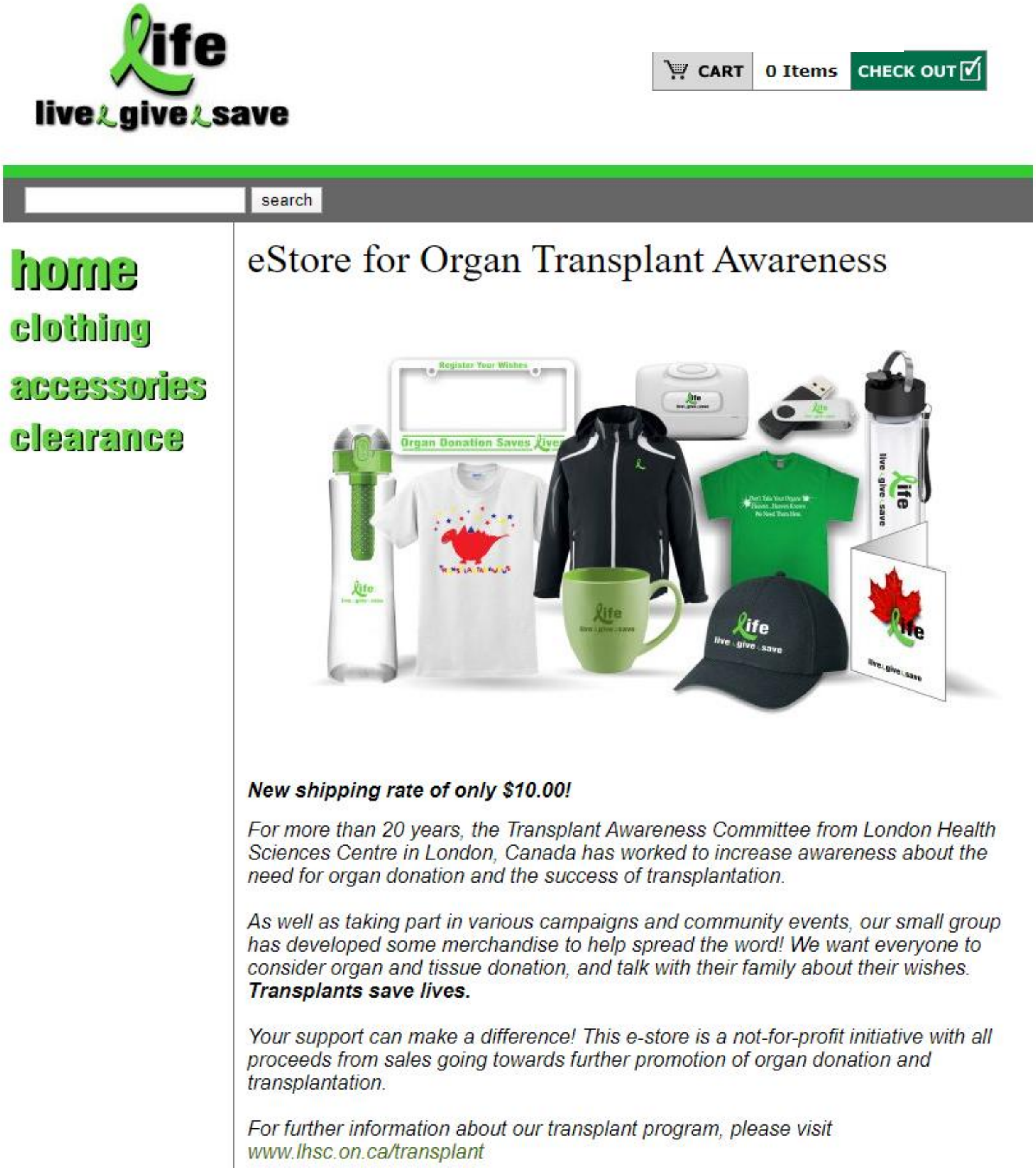
- ☐ I have my home exercise program.
- ☐ Information sheets I might be interested in:
  - ☐ Cannabis FAQ
  - ☐ Writing to Donor Families

Questions / Comments

Refer to LHSC transplantation website if you lose any sheets or as a quick reference.

https://www.lhsc.on.ca/multi-organ-transplant-program/patients-families-visitors

E Store for Organ Transplant Awareness



eStore for Organ Transplant Awareness

New shipping rate of only $10.00!

For more than 20 years, the Transplant Awareness Committee from London Health Sciences Centre in London, Canada has worked to increase awareness about the need for organ donation and the success of transplantation.

As well as taking part in various campaigns and community events, our small group has developed some merchandise to help spread the word! We want everyone to consider organ and tissue donation, and talk with their family about their wishes. ***Transplants save lives.***

Your support can make a difference! This e-store is a not-for-profit initiative with all proceeds from sales going towards further promotion of organ donation and transplantation.

For further information about our transplant program, please visit www.lhsc.on.ca/transplant

London Health
Sciences Foundation

Supporting our Multi-Organ Transplant Program

The Multi-Organ Transplant Program at London Health Sciences Centre is one of the leading transplant programs in Canada, performing nearly 200 transplants annually. Almost 6,000 Canadians have received transplants, including kidney, liver, heart, kidney-pancreas, pancreas, and multi-organ transplantation.

London Health Sciences Foundation provides patients and their families with an opportunity to show gratitude to those who played a special role in the care they received.

Whether you choose to salute a special doctor, nurse or allied health member, or our transplant program in general, your donation is a meaningful way to say **"thank you".** Your gift will help create life-changing moments for our patients by funding the transplant program's highest priority needs in patient care, research, and education.

Yes! I'm a grateful patient and would like to support:
☐ **Multi-Organ Transplant Program Fund (#77-680-01)** for highest priority needs in patient care, education, equipment
☐ **Multi-Organ Transplant Program Research Fund (#78-680-01)** for innovative clinical and laboratory research
☐ **Transplant Patient Assistance Fund (#14-690-05)** for much-needed financial assistance during the transplant process
☐ **Transplant Staff Education Fund (#12-680-21)** for professional development and mentorship

I'd like to say thank you to:

____

I'd like to make a single gift of: ○ $50 ○ $100 ○ $500 ○ $1,000 ○ Other: $___________
I'd like to make a monthly gift of: ○ $10 ○ $15 ○ $20 ○ $25 ○ Other: $___________

Payment Options (*please choose one payment option*)
○ Cheque (Payable to **London Health Sciences Foundation**)
○ Credit Card: ○ Visa ○ MasterCard ○ Amex

____
Card Number *Expiry Date* *Security Code*

○ Automatic Bank Withdrawal (*Canadian financial institutions only*). *Please include a blank cheque marked "VOID".*
I authorize installments of $____________ ○ monthly ○ quarterly ○ annually - Commencing (M/Y) _____ / ______

Contact Information:
Name: ____
Address: ____
City: ______________________ Province: _________ Postal Code: ______________
Telephone: ______________________ Email: ______________________
Signature: ______________________ Date: ______________________

○ I'd like to arrange an interview to share my story. Please contact me at the above information.

Please mail your completed form with your gift to:
London Health Sciences Foundation
747 Base Line Road East
London, ON N6C 2R6

df**gp

Contacts

University Hospital	519-685-8500
To have someone paged, push 0 and ask the switchboard operator to page the person you need.	
Transplant Outpatient Clinic	519-663-3818
Toll-free number	1-800-500-9845
Transplant Unit (Inpatient)	519-663-3015
Direct	519-685-8500 ext 37015
Prescription Centre Pharmacy	519-663-3231
Physiotherapy Transplant Gym	519-685-8500 ext 35365
Recipient Coordinators	
Amy Chambers	519-685-8500 ext 34991
Grant Fisher	519-663-3760
Sandy Williams	519-663-3933
Social Worker	
Kelly Thomas	519-685-8500 ext 32484

Who to Call and When

- **<u>If you are experiencing a medical emergency, go to your local ER. Call 911 if necessary.</u>**

  If you are admitted to your local hospital for any reason, please notify the Transplant Clinic during regular hours. If it is a weekend, leave a message. If the local doctor wants advise, advise him to call the Transplant Hepatologist on call through University Hospital.
- **During Regular Hours (8:00 – 4:00), call the Out Patient Clinic with any questions**
- **After Hours and on Weekends and Stat Holidays, if you have an urgent issue, you may page the Recipient Coordinator on Call through University Hospital switchboard.**