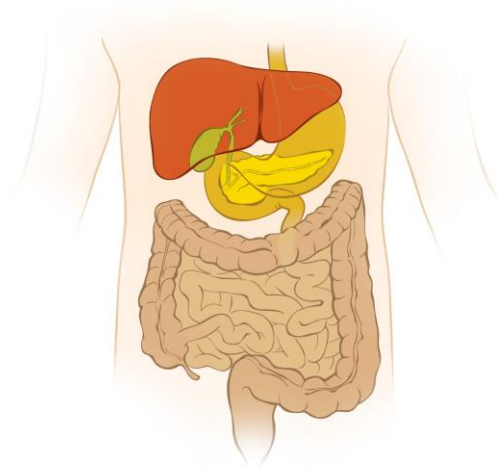


# Intestine Transplant Manual

Toronto

## Intestine Transplant

Program



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

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***Acknowledgements***

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## **Welcome to Soham & Shaila Ajmera Family Transplant Centre & Your Intestinal Transplant Team**

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The Soham & Shaila Ajmera Family Transplant Centre Program at Toronto General Hospital is Canada's largest transplant centre and performs a broad range of transplants. We have a long history of pioneering efforts in the clinical and scientific foundations of transplantation.

When other treatments for 'gut failure' are ineffective, intestine transplantation is a consideration. Depending on the medical diagnosis and patient anatomy, patients may require an intestinal transplant alone, an intestine and liver transplant, or an intestine, liver, pancreas and stomach transplant (also known as a multi-visceral or cluster transplant). This manual reviews the assessment process to determine if an intestine transplant is needed, the surgery, the recovery and the follow up process.

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

### **Our Values and Philosophy of Care**

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- Our team works closely with individuals, families, and the community to promote optimal health and quality of life for patients through all phases of transplantation.
- We strive to create a safe environment that supports individual health goals; enables care to be delivered with comfort and efficiency; and creates a culture of courtesy, respect, dignity, integrity, and empathy.
- We strive to share information and educate patients, providing the knowledge that is needed to exercise rights and responsibilities to make informed decisions about health care.
- Our work is based on the generosity of organ donors. We strive to honour this gift from donors and their families by striving for the best possible transplant outcomes based on patient needs, available resources, and ethical principles.
- We value the care provided by each member of the interdisciplinary health care team. We expect our staff continually maintain a current knowledge base and consistently strive to advance the science and art of transplantation.

### **Our Expectations of You**

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Throughout your transplant experience in the Soham & Shaila Ajmera Family Transplant Centre Program at The Toronto General Hospital you have the responsibility to:

- Work in partnership with the health care team to ensure the best possible treatment, rehabilitation, discharge planning, and follow-up care
- Provide accurate information and to share any concerns with all members of the health care team
- Inform the team if you do not understand or cannot follow the health care instructions
- Respect that the needs of other patients and families may be more urgent than your own needs

- Treat staff, other patients and their families in a considerate, courteous, confidential, and cooperative manner
- Understand the Toronto General Hospital's role as a teaching and research hospital and to partner with health care professionals in training
- Smoking cessation and restricted use of pain medications is strongly encouraged for all of our patients

## **Your Transplant Team**

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

Your transplant team includes:

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

### **Hepatologist**

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

### **Liver - Intestine Transplant Surgeon**

The Liver - Intestine Transplant Surgeon is involved in patient evaluation and selection. The surgeon performs the transplant operation, and is involved in your post-operative recovery in hospital. He/She manages surgical or medical problems and is always involved in your long term follow-up.

### **Gastroenterologist/TPN Team**

A Gastroenterologist is a doctor specially trained in the diagnosis and treatment of digestive problems. They will assess each patient's intestine and nutritional status before and after transplant. They will be responsible for monitoring and prescribing each patient's TPN requirements. Pre-transplant, if you already are followed by a TPN team, they will remain the main providers of your parenteral nutrition.

## **Transplant Coordinator**

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

## **Medical Secretary**

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

## **Social Worker**

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

## **Psychiatrist or Psychiatric Nurse**

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

## **Enterostomal Nurse**

The enterostomal nurse is a registered nurse who teaches and manages ileostomy or 'stoma' related issues. This nurse will follow each patient before and after transplant providing necessary stoma care, monitoring and teaching.

## **Physiotherapist**

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

## **Dietitian**

You will be followed by two dietitians depending on what type of nutrition support you are receiving. While on TPN in hospital, the dietitian that works exclusively with the TPN team will follow you. Upon discharge, as long as you remain on TPN, this dietitian and the TPN team will continue to be involved in your care. Once you are off of TPN, another dietitian will be your main contact. You will meet both dietitians either during your assessment, while in-hospital post-transplant and at clinic visits after transplant. The dietitian will recommend and review a well-balanced dietary program that meets your particular needs after surgery.

## **Other Health Care Providers on the Transplant Team**

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

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



## **Your Abdominal Organs**

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Your doctor has suggested that you may need an intestinal transplant. To understand why, it is important to know where the abdominal organs are and their function.

### **Where are your abdominal organs and what do they look like?**

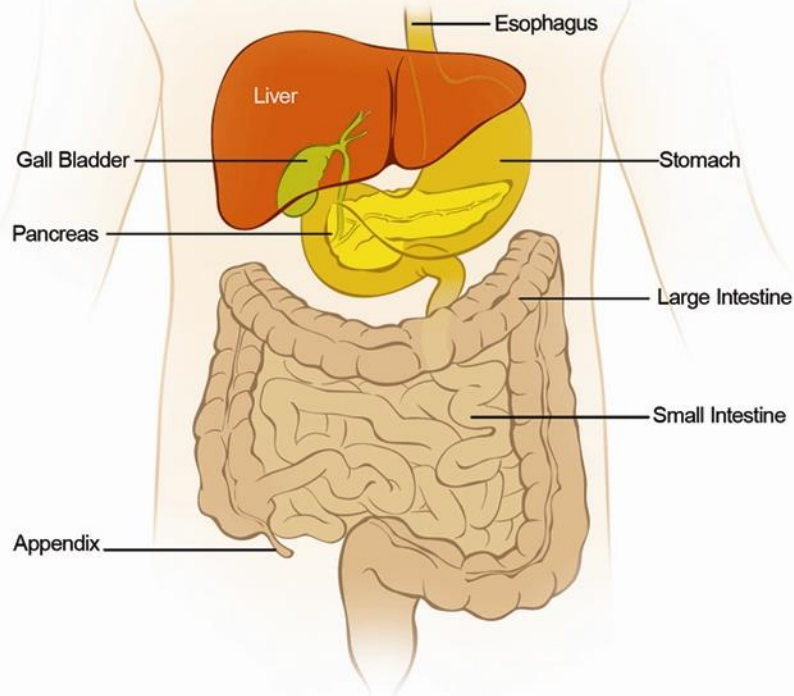
The Intestine is a long (about 20 feet) muscular tube.

The small bowel has 3 parts: the duodenum (nearest to the stomach),  
the jejunum (the middle part),  
the ileum (the end part)

The large bowel (colon) is connected to the small bowel and consists of the following parts: ascending colon, transverse colon, descending colon, sigmoid and rectum where the rectum is the most distal part of the intestine.

The liver is the largest abdominal organ and is connected to the bowel.

The pancreas is located beneath your stomach and is attached to your Intestine.



## **What does your Stomach do?**

The stomach is responsible for beginning the process of digestion of food. It is a muscular pouch that moves food along into the duodenum (Intestine) where digestion and absorption of nutrients continues.

## **What does your Intestine do?**

The Intestine is where most of the digestion takes place. It is a muscular tube that moves food from the duodenum to the anus. As food travels through the Intestine, fluids and nutrients are absorbed through the Intestinal wall. Most nutrients are digested and absorbed by the small bowel, while the large bowel is responsible for fluid absorption. People become dehydrated and malnourished when the Intestine does not function properly.

The intestine is also important for a normal function of the immune system and prevents infections.

## **What is Intestinal failure?**

Intestinal failure occurs when the gut can't digest and/or absorb the calories needed for day-to-day life.

Conditions that can lead to intestinal failure include:

1. **Short Gut Syndrome** – this is when most of the intestine has been surgically removed because of poor circulation, infection, trauma, tumor or disease.
2. **Poor Digestion or Absorption** – even though the entire intestine is present, it is unable to digest or absorb fluids and nutrients properly
3. **Poor Motility** – the Intestine is unable to contract its muscles normally so that it can move food through the intestinal tract.

Patients with intestinal failure require parenteral nutrition (TPN) to avoid starvation and occasionally develop complications due to their condition and the use of TPN. These complications include liver disease, blood infection, imbalance in blood electrolytes and poor quality of life.

## **Signs and symptoms of Intestinal Failure**

A diseased intestine cannot carry out its normal functions. People with intestinal failure may experience:

- Persistent diarrhea
- Dehydration
- Muscle wasting
- Poor growth
- Poor tolerance of food
- Abdominal pain
- Nausea and vomiting
- Weight loss and Fatigue
- Nutritional deficiencies – vitamins and micronutrients

## **What does your Liver do?**

The liver:

- Builds special proteins to prevent bleeding
- Filters blood and helps fight infection
- Makes bile to break down fats from food
- Builds sugar, stores sugar, and releases sugar for energy
- Stores vitamins and minerals
- Helps to break down proteins in the food you eat
- Sends hormones to other organs in the body

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

## **Signs & Symptoms of Liver Failure**

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

- Ascites (fluid in the abdomen)
- Fatigue
- Confusion
- Change in sleep patterns
- Itching
- Easy bruising
- Nausea and vomiting
- Muscle cramping
- Swollen ankles
- Dark urine
- Fever and infections
- Pain over the liver
- Internal bleeding
- Jaundice (yellow colour of the skin or the white part of the eyes)
- Change in appearance of bowel movements (pale stools, black stools or fatty stools)

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

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

## **What does your Pancreas do?**

The two main functions of the pancreas are to:

1. Make enzymes that digest food
2. Produce insulin (needed to change sugar into useable energy)

## **When Does A Patient Need An Intestine Transplant**

To better understand why an Intestine or multi-visceral transplant has been recommended for you, it is important to understand what can cause the Intestine to not function properly.

Intestine transplantation should be considered when patients with poor intestinal function do not respond to standard therapy, which usually includes parental nutrition (TPN), and develop severe complications related to their intestinal failure.

Common reasons for the need for intestine transplantation are:

1. Severe liver disease
2. Obstruction of the major blood vessels needed for the infusion of TPN
3. Recurrent blood infection
4. Extremely poor quality of life
5. Significant difficulties with the use of TPN

*We will help you understand the benefits and risks of having a transplant. This will give you the information to make an informed decision. The decision to proceed is up to you. We will support your choice whether you choose to go forward with transplantation or not.*

## **Am I Eligible for an Intestine Transplant?**

Each patient is assessed individually for his/her suitability for transplant. Basic requirements for Intestinal transplant are:

1. Your transplant assessment shows that you:
  - a. Have a gastrointestinal disorder that will not improve without transplantation
  - b. Are able to safely tolerate anesthetic and surgery.
2. You want to have a transplant, and you understand and accept the responsibilities required before and after the transplant.

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

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

## **Advantages & Disadvantages of Intestinal Transplant**

### **Advantages:**

- Successful transplant can save your life
- You do not need TPN
- You have more energy
- Your diet is less restricted
- You do not have fluid restrictions
- Overall, your health is improved

### **Disadvantages:**

- You might die due to complications of the transplant
- You will need transplant medication (immunosuppressants and others) for the rest of your life to prevent rejection.
- You will need follow-up transplant care for the rest of your life.
- You may have side effects from your medications
- You will be at greater risk for infection after transplant
- You will be at greater risk for certain types of cancer
- You may still require TPN
- You will have a temporary ostomy

## **The Transplant Assessment Process**

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

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

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

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

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

There may also be a meeting scheduled with the transplant hepatologist if you are listed for a combined Liver/Intestinal or multi-visceral transplant.

## **The Transplant Work-Up**

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### **Investigations:**

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

10. **Gastric Emptying Study** (to look at how solids/fluids travel through your digestive system)

**Consultations**

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

- Transplant Coordinator
- Anesthesiologist
- Social Worker
- Psychiatrist or Psychiatric Nurse
- Dietitian
- Cardiologist
- Enterostomal Therapist
- Transplant Surgeon
- Gastroenterologist

**Additional Considerations for Diabetic Patients**

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

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

**Active Listing for Intestine Transplant – Placement on the Active Waiting List**

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

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

**Preparing for the Intestine Transplant (Cost of Medications)**

Ensure that you can obtain postoperative transplant medications by registering with Trillium Drug Program

- When you are discharged from the hospital after your transplant, you must be ready to pay for your medications.
- These costs may be as high as \$4,000 per month.

## **The Trillium Drug Program**

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

*All patients must be registered with the Trillium Drug Program before being placed on the transplant waiting list.*

There is no cost to register with Trillium. The application takes only a few minutes to complete. Being registered with Trillium does not interfere with your private drug coverage. Patients with private coverage can still use this program. You can apply to Trillium for assistance with drug costs that are not covered or only partially covered by your private drug benefit plan. You can get applications at the pharmacy, online, or through our social workers. As a transplant patient, you must keep your registration active with Trillium. You must ensure renewal every year prior to August whether you are a pre- or post-transplant patient.

### **What is the Trillium Drug Program?**

The Trillium Drug Program is an Ontario government program that helps people pay for their prescription drug costs. You can apply to Trillium if you have private insurance that pays for a portion of your medication, or if you are without a drug plan.

### **How does the program work?**

People who use the program are required to pay a yearly deductible. Trillium's program year runs from August 1<sup>st</sup> to July 31<sup>st</sup>. You can join partway through a program year and sometimes you can back date your enrolment.

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

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

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

### **Who can apply?**

You can apply to the Trillium Drug Program if:

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



## How do I apply?

Application forms and program guides are available at most drug stores, or you can find them online at: <http://www.health.gov.on.ca/english/public/pub/drugs/trillium.html>. You must complete the application in full and include proof of income for each household member. You can send receipts for prescriptions you may have already paid for, if you are applying partway through a program year, as this can be counted towards your yearly deductible (remember to back date your enrollment). If you have no previous out of pocket drug costs, then you can use the current date as your enrollment date and your deductible may be less as it is prorated after August 1<sup>st</sup>. You will receive a letter within 3-5 weeks confirming you are accepted to the program, and how much your household's yearly deductible will be. Once you are registered with the program, you will need to use your OHIP card when filling your prescriptions at the drug store.

## What if I have more questions?

Contact Trillium directly at:

Address:	Phone (24-hours):	Fax:	Email:
PO Box 337, Station D Etobicoke, ON M9A 4X3	Toronto: 416-642-3038 Toll Free: 1-800-575-5386	416-642-3034	<a href="mailto:trillium@resolve.com">trillium@resolve.com</a>

If you need urgent drug coverage, please speak with a Social Worker.

## **Other Sources of Funding for Drug Coverage – Private Insurance**

**\*\* REGARDLESS OF DRUG COVERAGE THROUGH PRIVATE INSURANCE, YOU MUST HAVE ONTARIO DRUG BENEFIT (ODB) COVERAGE - TRILLIUM, SENIORS BENEFITS, OW/ODSP - IN PLACE\*\***

When evaluating your insurance coverage, please consider the following issues:

- Who is the provider of your private drug coverage (i.e. Sunlife, Manulife, etc.)?
- What is the percentage of medication costs covered by your private insurance?
- Is payment of medications automatic or do you have to pay up-front and get reimbursed later?
- Are there any yearly maximums for drug coverage?
- Are there any lifetime maximums for drug coverage?
- If you pay for your medications up front, how do you plan to pay for your transplant medications? **YOU MUST HAVE A PAYMENT PLAN IN PLACE PRIOR TO TRANSPLANT!!**
  - You should submit a medication list to your insurance company for pre-approval. You can request this list from your social worker or transplant coordinator

- If your transplant team needs to request special approval for medications that your private plan does not pay for, we can only do so with ODB in place; therefore, advanced application and approval to these programs will prevent any delays in providing unexpected treatments.
- **The Transplant Unit will NOT provide you with medications to take home.**
- **Toronto General Hospital does NOT have a drug assistance plan for Transplant patients.**
- **If you have not registered with Trillium and paid the deductible, you will need to pay by:**
  - Using your drug benefit card to directly bill your insurance company (if your company offers this option)
  - VISA or MasterCard
  - Cash

## **Financial Planning**

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Having a transplant can have an impact on your finances. It is important for you to know this and plan ahead. Your income may change and you may have new expenses. Every situation is unique. Use the following information as a guide to see if there are opportunities for financial support.

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

- Insurance – Employment or Sickness benefits
- Employment and retraining funding
- Canada Pension Plan - Disability (CPP-D)
- Ontario Works (OW)
- Ontario Disability Support Program (ODSP)

It is important to know how these programs may assist you with important financial support. Please contact your transplant social worker for assistance and details about these programs to see which ones you may qualify for.

### **Insurance**

#### **a. Employment Benefits**

Some transplant patients are able to return to the job or position they had before transplant. Depending on your employer and the amount of time you are off sick, you may have **short or long term disability (STD or LTD)** benefits. Your employer will be able to tell you more about this.

#### **b. Sickness Benefits**

If your work does not have STD/LTD or the payment is low, you might qualify for Employment Insurance (EI) sickness benefits. EI sickness benefit gives you 15 weeks of income. Contact your local EI office for more information about qualifying.

### **Employment and Retraining Funding**

Some patients may return to work after transplant but need to change their job. In this case, patients may qualify for an Ontario government program for vocational assessment and rehabilitation. This program is for patients who have physical problems that prevent them from finding or keeping their job.

Unfortunately, there is a long waiting list. Once you are accepted into the program, you qualify for financial assistance for retraining costs and a living allowance.

Private companies also offer vocational assessments, counseling and retraining for a fee. Some community agencies offer counseling free of charge or for a small fee.

### **Canada Pension Plan - Disability (CPP-D)**

If you are permanently unable to work after your transplant and you paid into CPP, you can apply for CPP benefits. CPP approves your application based on the medical information that they receive from your doctor. Drug benefits are not included.

Fill out an application as soon as possible. It can take several weeks to process. Benefits are not retroactive. Some restrictions may apply.

### **Ontario Works Assistance**

You can apply for Ontario Works (OW) if you have a low income, few assets and are temporarily not able to work. Your total family income determines if you are eligible. Drug benefits are included. You will have to contact your local OW office for assessment.

### **Ontario Disability Support Program**

If your doctor states you are permanently disabled and cannot return to work, you may qualify for the Ontario Disability Support Program (ODSP). This program is also for patients with low family income and few assets. Drug benefits are included. You will have to contact your local ODSP office for assessment.

## **Other Financial Considerations Related to the Hospital Stay**

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After your transplant, you will have expenses related to doctor and clinic visits. These will be out of pocket expenses. We will describe a few below and offer some brief tax tips to help you recover some of these costs.

### **Parking**

Parking near the hospital is expensive. The closer to TGH you park, the more expensive it is. There are some parking lots a short walk from the hospital. It is worth looking at the costs of nearby lots if you will be coming to TGH often. Consider taking public transit (TTC) or Go Transit whenever possible.

### **Wheel Trans**

If you live in Toronto and are physically disabled, you can apply for Wheel Trans. This service is available to people who are not mobile enough to use the regular transit system.

To get a Wheel Trans number, you must have an interview with the TTC. Call (416) 393 - 4111 to set up an appointment. They may supply transportation to the interview appointment if you are in a wheelchair or use a cane or walker to move around.

### **Housing**

Sometimes patients need to move to Toronto while they are waiting for transplant or for a period of time after transplant. Talk to your social worker about this. **We can give you a list of places to stay.**

### **Travel**

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

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

Social assistance (OW/ODSP) may help you with travel costs, no matter where you live. You must apply at your local office for help.

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

**Toll free: 1-877-346-HOPE (4673)**  
**Toronto area: 416-222-6335**  
**[www.hopeair.org/](http://www.hopeair.org/)**

## **Other Costs**

There will be other costs during your transplant. You may need to buy special supplies that are not covered by private insurance plans. For example, if you become diabetic, you will need equipment that may not be covered.

**Some support services may require documentation in order to offer reduced rates.  
Talk to your social worker or transplant coordinator about this.**

## **Tax Tips**

Call Revenue Canada for information about deductions on your income taxes related to your illness and your transplant.

Here is a recent list that may be helpful. Remember you must have receipts for all your expenses. You **cannot** claim for anything that you have already received re-imbusement for.

Medical expenses that you *may* be able to claim include:

- long distance telephone calls to the hospital
- any diagnostic procedures where you had to pay
- payments to hospitals
- drugs that you paid for yourself
- premiums for private health service plans
- ambulances
- parking
- Out of Canada medical expenses - for the part that OHIP did not cover.

You may claim expenses for yourself, your spouse and, with some limitations, your dependents. You can claim expenses for any twelve-month period ending in the current year.

- If you travel more than 40 km one way for treatment, you may be able to claim transportation costs: train, bus or taxi costs.

- If you used your own car, you can claim a reasonable amount (check with Revenue Canada). You will need to prove the number of trips you made. Keep a travel log with mileage that you traveled. Have your health care provider sign and date it each time you come to the hospital.
- If you travel more than 80 km one way, you are entitled to claim reasonable expenses for meals and accommodation as well.

### **Disability Credit**

If you are disabled, as defined by Revenue Canada, you can ask your doctor to fill out a disability tax credit. Include this in your tax return.

You **may** qualify for a disability credit for the cost of care for a nursing home stay or a full-time attendant.

**Please note:** Many transplant patients do not qualify as disabled within the Revenue Canada definition.

If you have any questions about these topics, please speak to your social worker.

## **Legal Information for Patients**

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### **Powers of Attorney**

It is important that you think about your situation and make plans for your powers of attorney. There are two basic forms of Powers of Attorney (PoA):

- Powers of Attorney for Personal Care
- Powers of Attorney for Finances

### **Powers of Attorney for Personal Care**

Your power of attorney (PoA) for personal care is a person that you choose to make decisions about your care when you are not able to make them yourself. This person is also called your Substitute Decision Maker (SDM).

To appoint a PoA, you need to create a legal document called Powers of Attorney for Personal Care decisions.

If you do not assign a PoA for personal care, the law states who can make decisions, in the following order of priority:

- spouse
- adult children
- parents
- siblings
- extended family members.

If there is no one to make decisions for you, the law states a public official can be appointed to make decisions for you when you cannot.

Sometimes patients have a PoA for health care decisions that is different than their usual substitute decision maker. If this applies to you, make sure this is clearly stated in your PoA document.

Give copies of your PoA document to your doctor, your PoA and the hospital when you have your transplant.

### **Powers of Attorney for Property**

Your power of attorney for property is a person that you choose to make decisions about your finances when you are not able to make them yourself.

To appoint a PoA for Property, you need to create a legal document called Powers of Attorney for Property.

This legal document states who will be responsible for making financial decisions, payments, etc., if you are unable to do so.

## **Advance Care Planning**

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

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

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

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

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

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

There are guides that you can use to help you with Advance Care Planning:

<http://www.citizenship.gov.on.ca/seniors/english/programs/advancedcare/docs/AdvancedCare.Guide.pdf>



## **Waiting for the Intestine Transplant**

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There are 3 goals for the waiting period for transplantation:

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

You will have regular clinic appointments with the transplant team while you are waiting for intestine transplant. You must keep these appointments. They are important opportunities for the experts in the transplant program to monitor your health and ensure your suitability for transplant. At the clinic visit we may adjust your medications and order additional tests. You will also continue with your routine follow up by your primary gastroenterologist who referred you for transplant and by your TPN team during this waiting period.

Assessment testing may be repeated every 6 to 12 months to ensure no new problems have developed. You will need ongoing bloodwork while you wait for transplant. Please have your blood drawn at a local **Life Lab**. These labs are familiar with our routine tests and work with us to complete your tests quickly. They will not charge you for your blood tests. Some other labs may charge you.

**To find the Life lab nearest you, call: 1(877) 849 - 3637 or 416-675-3637**

## **Your Place on the Waiting List**

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In Ontario organs are allocated according to:

- Compatibility of blood types and organ size
- The severity & type of illness of the transplant recipient

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

Your status may change as your health and urgency for transplant changes. It is important to notify your transplant coordinator on any significant change in your health or if you are hospitalized while waiting.

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

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

Patients may be offered an organ from a donor who is older or a liver that may be slightly fatty (*Extended Criteria Donor*); or a donor that does not have all the necessary health history and has had a lifestyle that is associated with a higher risk of infections but has tested negatively for infections (*Exceptional Distribution Donor*); or a donor organ from someone who died after withdrawal of life support (*Donation After Cardiocirculatory*

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

### **Maintaining Contact with the Transplant Team While Waiting**

When an organ becomes available time is critical and we need to get in touch with you right away. We must know how to contact you at all times. For this reason you need to provide your assessment coordinator with all your contact information:

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

**Please keep your contact information up to date at all times.**

You must inform your coordinator immediately if:

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

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

### **Informing the Transplant Team about Changes in your Medical Condition**

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

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

**Toronto General Hospital Locating Services (416) 340-3155**

## **Coping with Stress**

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We do not know how long you will be on the waiting list. You do not have control over the wait list. This can be stressful and discouraging for you, your family and your support network. Feelings such as fear, impatience, even anger are normal.

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

- Social Workers
- Psychiatric Nurses
- Medical Psychiatrists

Our team offers:

- Education and information before and after your transplant.
- Help with financial and family matters
- Counseling and emotional support, both for you and your support persons

It is important for you to talk to someone. Telling us about your feelings, getting help to put your concerns in perspective and relieving your stress can help you feel in control.

## **Transplant Mentor Program**

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The Transplant Mentor Program can match you or your support person with a post-transplant recipient or their support person. These “mentors” are volunteers of the Toronto General Hospital.

You may wish to speak to a mentor if:

- You want to meet another person who has already had the transplant experience.
- You have questions about transplant and would like to hear from another patient or support person.
- You feel you would benefit from having more support.

This is a voluntary program and listed patients and support persons may request a mentor at any time.

To be connected with a transplant mentor, speak to your transplant coordinator or social worker, who will refer you to the transplant mentor program. You may also contact the program directly.

**Toronto General Hospital  
Transplant Mentor Program  
416-340-4800 Ext. 5655  
(Psychosocial Reception)**

## **Maintaining your Health While Waiting for Transplant**

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### **Dental Procedures**

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

### **Alcohol**

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

### **Pain Management Medications**

Reduction and restricted use of painkillers is expected of all our patients. Restricted use of painkillers before the transplant will enhance your recovery after the transplant and the function of your new intestine.

### **Smoking**

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

The benefits of smoking cessation can be seen almost instantly:

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

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

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

### **Travelling / Out of town trips**

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

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

**It is your responsibility to notify the transplant office when you return in order to be reactivated on the waiting list.**

### **Over-the-Counter medications**

Do **not** take:

- Over-the-counter medications
- Aspirin or non-steroidal anti-inflammatory drugs such as Advil or Ibuprofen. These types of medications may cause bleeding or kidney damage.
- Gravol®, Benadryl, cold medications, sleeping pills or anxiety reducing medications. These may cause drowsiness and confusion.

### **Emergency Situations**

If you have an emergency, such as

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

**Call 911 or go to your nearest Emergency Department.**

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### **Becoming Too Sick For Transplant**

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Sometimes, in spite of doing all you can to stay healthy and in spite of all we do to keep you fit for transplant, you can become too sick to undergo transplant surgery.

There are several possible reasons. These include:

- If you become bedridden
- If you develop serious infections and do not respond to antibiotics
- If you develop an uncontrolled bleeding and do not respond to treatment
- If you have no vascular access left

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

## **Organ Donation**

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

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

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

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

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

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

## **Being Offered an Intestine Transplant**

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

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

\* Messages will be left where answering machines are available.

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

If you are unable to reach the person who called you, contact the **Transplant Inpatient Unit at 416-340-5163**. Ask to speak to the Charge Nurse.

Tell the nurse that you are waiting for an Intestine transplant and you received a message regarding a potential transplant organ offer.

The charge nurse will put you in touch with the Recipient On-Call Coordinator.

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

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

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

If they have no concerns regarding your present condition they will ask you to come to hospital as soon as possible.

**Do not eat or drink anything from the time that you are called in for transplant. It is very important that you follow these instructions.**

## **Cancelled Transplants**

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Not every organ that becomes available will be right for you. We use blood typing to match an organ with your blood type as well as other factors (such as size) to be sure it is right for you.

### **Please Note:**

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

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

Your surgery can be cancelled for many reasons:

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

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

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

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

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

## **Getting to the hospital when called for transplant**

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



We want you to arrive safely to hospital.

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

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

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

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

**Between 6 am to 11 pm**

*Admitting Department*

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

**Between 11 pm and 6 am**

*Emergency Department, Toronto General Hospital, Elizabeth Street Entrance*

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

We will:

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

**Please Note:**

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

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

## **What Items Should be Taken with You to Hospital**

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### **Bring these items with you to hospital:**

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

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

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

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

### **Do not bring:**

1. Any valuables such as rings, watches, jewelry.
2. Large amounts of cash
3. Any large electrical equipment that needs to be plugged in (you may bring an electrical razor or hair dryer).
4. Cellular phone (you cannot use this in the hospital)
5. Laptop computer

## **UHN Patient Personal Property & Valuables Policy**

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

## The Operation - Your Transplant Surgery

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The transplant team will recommend on one of the following 3 surgical options after your transplant assessment:

### Isolated Intestine Transplant

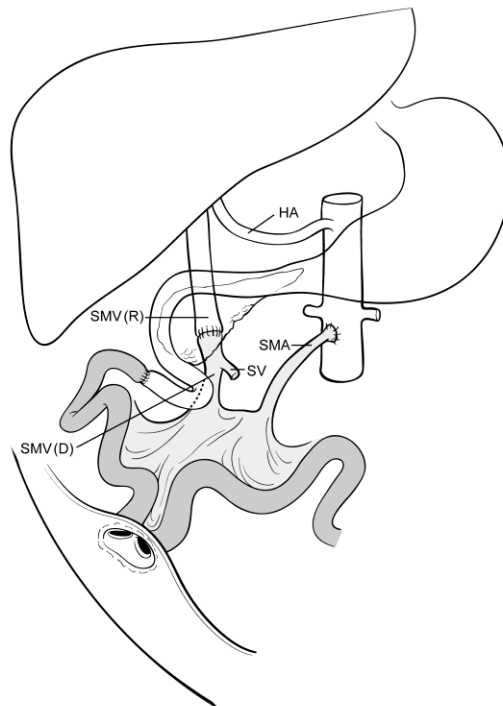
This technique is recommended for patients with a diseased bowel and normal liver function.

#### The steps in an isolated intestine transplant include:

- The removal of your diseased Intestine
- The sewing in of your new Intestine
- The creation of an ileostomy

Your new Intestine is sewn into place in 4 areas. These reconnected areas are referred to as **anastomoses**. Two of these areas are in blood vessels: the **Superior Mesenteric Vein (SMV)** and the **Superior Mesenteric Artery (SMA)**. The two other areas involve the proximal and distal bowel. The large bowel (colon) might be also included in your transplanted organs based on your transplant team recommendation.

When the surgery is complete, the muscle layers of your abdomen are stitched together and the skin is closed with staples. The staples will be removed in clinic 2-3 weeks after surgery. Some patients may have drainage tubes placed in their abdomen to allow any extra fluid to drain for a few days after surgery. These tubes will be removed before you are discharged.



\* HA - hepatic artery, SMA - superior mesentery artery, SMV - superior mesentery vein, SV - splenic vein

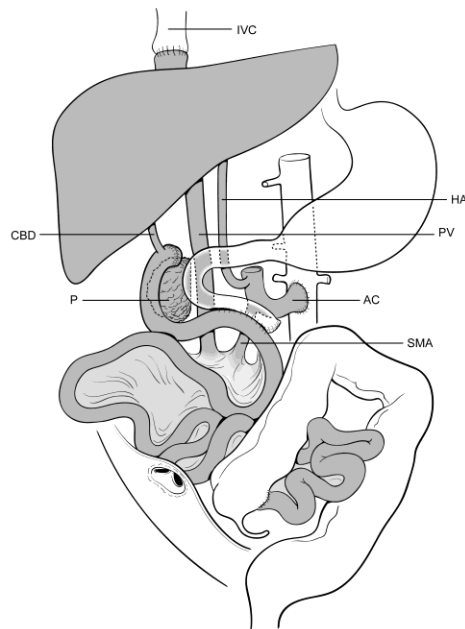
## Intestine and Liver Transplant

A combined liver and intestine transplant is recommended for patients with both intestine and liver failure where the replacement of both organs is needed to achieve a full recovery.

In almost all cases, members of our surgical team will participate in the surgery to remove the liver from the deceased donor. Only after our surgeon examines the donor liver and intestine can we say for sure that the organs are safe to transplant. The liver and intestine will be transported to our hospital and we will send you to the operating room for the transplant surgery. Rarely we find that the donor organs are unsuitable after you are anesthetized. However, we do our best to ensure that we never take irreversible surgical steps until your surgeon is satisfied that the donor organs are suitable for you.

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

Your new liver and Intestine are sewn into place in 4 areas. These reconnected areas are referred to as **anastomoses**. Two of these areas are in blood vessels: the **Inferior Vena Cava vein (IVC)** and the **Aorta**. The two other areas involve the proximal and distal bowel. The donor intestine includes not only the small bowel but also the duodenum and head of the pancreas for surgical reasons. The large bowel (colon) might be also included in your transplanted organs based on your transplant team recommendation. Ileostomy is created in this surgery too as in isolated intestine transplant.



\* HA - hepatic artery, PV - portal vein, AC - celiac artery, SMA - superior mesentery artery,

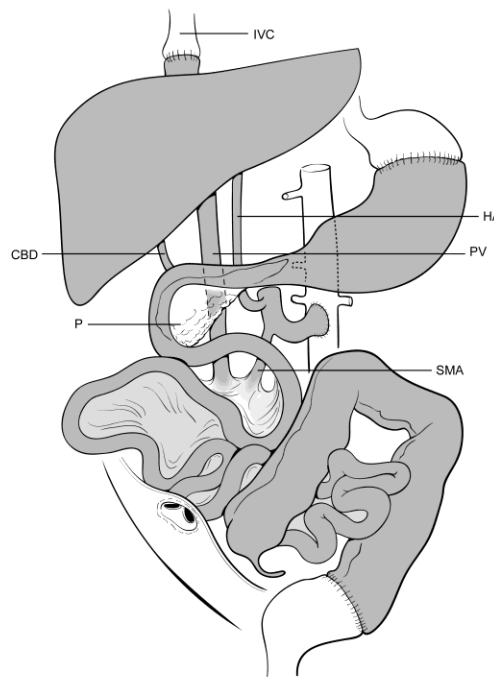
P - pancreas, CBD - common bile duct, IVC - inferior vena cava

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

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

## Multi Visceral Transplant

This operation is very similar to an intestine/liver transplant except that the stomach is also included in the graft and the proximal connection is with the stomach. The technique is done in patients with intestine and liver failure with severe and extensive motility disorders or in patients that require a total removal of the abdominal organs due to surgical and technical considerations.



\* HA-hepatic artery, PV - portal vein, SMA-superior mesentery artery, P-pancreas, CBD-common bile duct, IVC-inferior vena cava

The transplant surgery, in any technique, can take up to 16 hours. You may receive blood products such as packed cells, plasma, or platelets during the operation. There is a small chance (10-15%) you will go on a bypass machine to keep your blood pressure stable during surgery. If this happens, you will have 2 small incisions: one in your left groin and one in your left armpit.

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

## **Post-Operative Care after your Transplant**

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

### **Before surgery**

You will be admitted to the Soham & Shaila Ajmera Family Transplant Centre Unit on 7 West NCSB or 10 West NCSB

### **After surgery – Care in MSICU**

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

Various equipment is used to monitor and support your health needs. Intestine Transplant patients usually stay 2-5 days in MSICU as long as there are no complications and you are responding well after the transplant surgery. Visiting is limited in this area.

### **After the MSICU – Care in the ACU**

We will transfer you to the Acute Care Unit (ACU) of the Soham & Shaila Ajmera Family Transplant Centre Unit which is located on 10 West - A.

Specially trained Transplant nurses will closely monitor your condition until you further improve and your recovery is progressing well. Some monitors will still be used in the ACU. Patients usually spend another 2-4 days in this area. Visiting is also limited.

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

### **After the ACU – Care on the Ward**

You will complete your recovery back on the Soham & Shaila Ajmera Family Transplant Centre Unit on 7 West – NCSB. Our transplant nurses will help you continue to recover, gain strength, and learn how to manage with your organ transplant.

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

## **Possible complications in the Immediate Post-Operative Period**

Ideally, you could have a transplant operation and not experience any complications. Unfortunately, it is very unusual to have a perfect situation and at least one complication is likely to arise. This is not a cause for panic, and a complication definitely does not mean a failure. Our transplant team will constantly monitor your recovery and immediately respond to any complication.

It is often difficult to understand why one patient develops a complication while others have completely smooth post operative courses. Rather than dwelling on this question however, it is more useful to focus your energy on understanding the complication, its treatment and working with your health care team toward your recovery. Always feel free to ask questions and be assured that should you develop complications, that you will be able to discuss it with your caregivers.

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

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

### **Potential Surgical Complications related directly to the transplant operation include the following:**

- 1) The liver transplant may fail to function immediately after the transplant – this is called primary non-function (PNF), and is extremely rare (<0.5%). This may require another transplant to be performed very urgently.
- 2) Blood clots may form in arteries or veins carrying blood to the new intestine and liver (vessel thrombosis). This is very rare (1%), but may severely damage the new graft if it cannot be corrected immediately by surgery or blood thinners. In some cases, another transplant may be required because of this.
- 3) Internal bleeding may occur and may require blood transfusion or surgery (<5% risk).
- 4) Intestinal obstruction may occur and in some cases it may require another surgery to relieve the obstruction.

### **Leg and abdominal Swelling**

You may have had this issue prior to your transplant as well. Fluid retention is a common problem in patients with liver disease. This will eventually resolve in the majority of cases but due to the amount of fluid we give you during surgery and the course you experience in

hospital post transplant, you may still have significant swelling in your legs and abdomen when you go home. Even patients who do not have leg and abdominal swelling pre-transplant, may have swelling post transplant. Until the excess fluid is gone, you should follow a low salt diet and keep your legs elevated when you are sitting down. You should monitor your weight daily at home and report any weight gain over 1kg in a 24hour period especially if you are experiencing any shortness of breath with the weight gain. We sometimes use diuretics to help eliminate the fluid but you must not use these medications on your own.

## **Wound Infection**

Your incision is an area for potential infection until it heals. As noted earlier in this booklet, your risk for infection is increased as a side effect of your anti-rejection (immunosuppressive) medications. Your incision will be examined at each clinic appointment but it is important for you to monitor and report any increase of redness or swelling, pus along the incision or fever to your transplant coordinator. While the staples are still in and until the incision is healed, you may have a shower but avoid baths unless the water comes to below the incision line.

## **Diabetes**

This is a common side effect of prednisone as well as some of the other commonly used medications to reduce the risk of rejection. Patients who controlled their diabetes before transplant with pills or by diet will often require insulin afterwards at least for a short time, while the prednisone dose is highest. If you had diabetes prior to transplant, your insulin dose will require adjustment or sometimes the type of insulin will need to be changed. Even individuals without a history of diabetes, can develop this complication after their liver transplant and require medication to maintain a normal blood sugar. As the prednisone and other medications are reduced, your blood sugars will be easier to control. If you have diabetes post transplant, it is very important to see your family doctor regularly, closely monitor your blood sugar, and have your insulin adjusted as necessary.

You will be taught to monitor your blood sugar at home using a glucometer. You will be given guidelines to follow if you do develop diabetes.

## **Rejection**

It is necessary to alter your immune system to prevent rejection. Your transplantation organs are viewed as invading foreign matter and come under attack by your immune system. This process is known as rejection, which can be mild, moderate or severe. In order to prevent it from interfering with the normal function of your new organs, it is important to detect rejection early and to treat it promptly.

Rejection is common. Most times it can be effectively treated.

Rejection is determined by biopsy, and careful monitoring for signs and symptoms of rejection. Small intestine biopsy is a diagnostic procedure in which a tiny portion of the small Intestine lining is removed for examination. A flexible fiber-optic tube (endoscope) is inserted through



your stoma, mouth or anus and into the gastrointestinal tract from which a tissue sample is removed.

Rejection does not mean that you will lose your new organ, or that it will be permanently damaged (in most cases). However, rejection **MUST** be diagnosed and treated promptly. Treatment usually involves adjusting or giving additional anti-rejection medication.

In order to detect rejection as early as possible you will have repeated endoscopies and biopsies mainly through your stoma to look for rejection. The frequency changes over time with bi-weekly endoscopies initially up to none after closure of the stoma. In addition you will need endoscopy if your stoma output will be higher than usual or with additional symptoms such as fever, vomiting, abdominal pain or gastrointestinal bleeding.

## **Infection Risks with Transplantation**

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Infection can occur because your immune system is being altered. The immune system is the body's defense system. The bone marrow produces white blood cells, which control and carry out most immune responses. Immunity is the way the body protects itself from foreign matter such as bacteria, viruses and foreign tissue cells.

Infections are an unavoidable risk of transplantation. They are the most common complication after transplantation, occurring in about 50-80% of patients. The risks of developing an infection must be balanced against the benefits of a transplant.

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

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

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

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

### **Multi-drug Resistant Bacteria**

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

### **Viral Hepatitis (Hepatitis B, C)**

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

### **Cytomegalovirus (CMV)**

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

### **Epstein - Barr virus (EBV)**

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

### **West-Nile Virus**

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

### **AIDS (Human Immune Deficiency Virus)**

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

### **Unknown Infections**

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

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

- 1) Cardiovascular problems such as heart attack, arrhythmia, or stroke
- 2) Kidney failure – acute or chronic
- 3) Neurological problems such as seizures, tremors, or confusion

- 4) Respiratory problems such as pneumonia or pulmonary embolism
- 5) Infections of the surgical wound, IV sites, or urine

Most of these are rare and some depend on your condition prior to the transplant.

## **Guidelines on the Transplant Unit**

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### **Visiting**

- Visiting hours are from **10 am to 9 pm**.
- In the ACU, a patient rest period is enforced from **3pm to 5pm** to allow patients uninterrupted time to rest.  
*Visitors are not permitted at this time.*
- All visitors must sign in at the reception desk & wear a “visitor” sticker while on the unit. This is for patient safety.
- Only **2** visitors are allowed in a patient’s room at one time.  
If there are more people who would like to visit at once, this must be done in the visitor’s lounge or other part of the hospital.
- Children under 12 are **discouraged from visiting** in patient rooms because of the risk of infection to the child.  
Any child visiting must be supervised by an adult. If children are disruptive or noisy, they cannot be allowed to disturb other patients, and visitors will be asked to leave the unit and visit with the patient elsewhere in the hospital.
- Staying overnight for family and friends is **not allowed** on the transplant unit.
- Visitors for isolation patients must fully respect precautions in place to protect the patient, themselves, and others on the unit.
- Visitors with signs of fever or flu will not be allowed on the unit.
- Visitors may be asked to temporarily leave a patient’s room in order for health care staff to provide personal care or discuss confidential matters with the patient.

### **Choosing a Spokesperson**

**Please do not call before 9am for patient information.**

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

This person is responsible for calling to see how you are doing and passing this information along to family and friends.

Nursing staff need to take care of you and other patients; they cannot be dealing with numerous phone calls.

## **Flowers**

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

## **Preparing To Return Home After the Transplant**

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When you are getting ready to return home, we will focus on:

- Adjusting your immunosuppressive medications
- Recovery and rehabilitation
- Teaching you about your transplant and medications
- Creating a diet plan

Please review the Discharge Contract at the end of this manual (**Appendix 5**). Members of the transplant team will see you each day and they will determine when you will be discharged home. You and your family will be advised a day in advance of your discharge date to ensure all preparations are in place.

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

If you live outside the greater Toronto area you might have to stay in town for the first 2-4 months after transplantation based on your health and the supporting health systems at your residence.

## **Adjusting your Immunosuppressive Medications**

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

We will adjust your dosages based on your:

- Blood test results
- Side effects of medication
- Symptoms
- Biopsy results

## **Recovery & Rehabilitation**

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

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

## **Teaching**

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

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

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

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

## **Preparing for Self-care and Monitoring at Home**

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As you recover from your transplant, it is important that you know what to watch for at home and what important issues you should report to your transplant coordinator. You will be going for regular blood tests and attending clinic as well and further information is obtained by these assessments. Part of the information you are given is covered by 4 video presentations which you and your family are required to watch. The rest will be covered by the discharge nurse and this written information. Complications are not uncommon, and most can be treated by procedures and medication adjustments. Early detection of complications and avoiding them if possible are important to the success of your transplant.

### **1. Monitoring for Rejection**

Your immune system protects you from foreign proteins such as bacteria and viruses. Your immune system also recognizes your new organ as a foreign protein and will try to reject it. Immunosuppressive medications are meant to prevent this, but it is difficult to know exactly which medications and what dose to give you to prevent this complication from ever occurring in you. Rejection is less likely to occur if you take your medications correctly, and do your blood tests with the correct timing, but it can still occur. Having a rejection episode does not mean your intestine or liver is destroyed. We do try to avoid rejection if at all possible as it results in the need for additional medications. Lab test results and surveillance biopsies are the key way we monitor for rejection. The signs and symptoms we ask you to watch for at home and to report are:

- fever of 38° C or more (check your temperature twice a day for the first 3 months)

- High stoma output (more than the usual daily output) or a significant reduction in the stoma output. You should know your regular stoma output and measure it for the first few months.
- Bleeding from the stoma, rectum or emesis with blood
- Vomiting
- Distended abdomen
- Fatigue
- Dull ache in your abdomen
- Sudden weight gain of a kilo or more in 24 hours (weigh yourself daily if you have scales)
- Jaundice (yellow colour best seen in the white part of your eyes)

## **2. Monitoring for Infection**

Your immune system also protects you from infections. Your immunosuppressive medications interfere with your ability to fight infections, thus detecting and treating infections promptly is important. Signs and symptoms of infection that we ask you to watch for at home and report are:

- fever of 38°C or more (check your temperature twice a day for the first 3 months and thereafter when you feel unwell)
- chills and flu-like symptoms
- redness and pain around your incision
- redness and pain on any part of your skin - such as your legs especially if the skin is broken
- cough - especially with colored sputum
- pain when you pass urine
- diarrhea
- rash or sores
- High stoma output (more than the usual daily output)
- Bleeding from the stoma, rectum or emesis with blood
- Vomiting
- Distended abdomen

It is important to take precautions to avoid infection. The most important thing you can do is to remember to wash your hands. This is the single most important way to avoid infection – after using the bathroom, after touching doors in the mall, grocery carts etc. You can carry a small bottle of hand sanitizer to use if a sink is not readily available. Avoid contact with people you know are sick or who have infections. This does not mean that you can't go out to public places such as restaurants, place of worship or malls – but remember to wash your hands. You will get the same type of infections such as colds as people without transplants. We do not recommend that you take antibiotics unless we are sure you have an infection.

## **3. Activity**

Remember the following about activity after discharge:

- You can shower – even before your incision staples are removed. We do not recommend that you take a bath until your incision is completely healed.

- You should not lift more than 10 pounds for the first 3 months - lifting more than this amount may cause stress on the incision and result in a hernia. For the same reason avoid abdominal strengthening exercises or upper body exercises such as sit-ups and push-ups for the first 3 months. This means that even grocery bags must not weigh more than 10 pounds. If you have small children you will not be able to lift them for 3 months
- You can walk as soon as you are able and this is excellent exercise. At first you may only be able to walk short distances but the goal should be to gradually increase the distance and pace at which you go.

#### **4. Avoiding Skin Cancer**

Transplant patients are at increased risk for skin cancer as a result of taking immunosuppressive medications. It is important to remember that the sun exposure you have had in the past is an additional risk factor for developing skin cancer. It is therefore important to decrease additional risk by taking precautions against sun exposure. The following are important points to remember:

- Avoid sun exposure between the hours of 10:00 AM and 3:00 PM when the sunlight is most intense
- Use sunscreen when you are going to be in the sun at any time
- Use a product with a sun protection factor (SPF) of 30 for good protection.
- Select a product that blocks both UVB (shorter rays) and UVA (longer rays). For example PABA only filters UVB rays.
- Consider using a stronger product on very susceptible areas – face, ears, scalp
- Use a lip balm with sun screen
- Wear a hat with a wide brim
- Apply the sunscreen 30-60 minutes before going outside
- Reapply sunscreen if swimming or perspiring profusely
- Overcast days do not protect you – 70-80 % of the UV rays still come through
- Wear UV-filtering sunglasses – UV light can cause cataracts
- Outdoor winter activities such as skiing can still expose you to sun damage
- If you have a personal or family history of melanoma have regular skin check-ups by dermatology
- Be a mole-watcher and report concerns – watch for moles that grow or change color, watch for moles with irregular borders, watch for moles that are itchy or ooze.
- Report any new skin lesions that are growing, which scale or bleed

#### **5. Nutrition**

- Nutrition is an important part of helping you rebuild your muscles and to help with healing after surgery.
- While the end goal of intestine transplantation is to have you meeting your nutritional needs through regular food intake (by mouth), it will take a few months to achieve this. If you were on parenteral nutrition (PN) before the transplant, you will still need to be on this for a while post-transplant. Usually after intestinal transplant - while in hospital - your nutrition needs will be met through a combination of PN, enteral nutrition (EN) (also called tube feeds) and oral intake. We will work with you to taper you off of PN and EN and onto oral intake alone. You may need to keep a record (calorie count) of

how much food you are eating so we can see your progress. Your medical situation, weight gain and appetite will determine how fast we can taper the PN and EN.

- You may require IV fluids to stay hydrated even after stopping the PN as you may not be able to meet your needs just by drinking.
- You will need to follow a *modified diet* for a while post-transplant while your abdominal organs begin to function regularly and while you have a stoma/ileostomy. This diet will be **low in fiber, lower in fat and low in simple sugars** (e.g. juice, pop, sweetened drinks, candy, sweet sauces and desserts). You **may also need lactose-free milk products**. The purpose of these dietary restrictions is to reduce/slow your stoma output, to improve the absorption of nutrients from what you consume and to avoid dehydration. See **Appendix 6** for some specific ileostomy guidelines.
- It is important to follow the diet guidelines provided by your dietitian very strictly to meet your nutritional needs while also minimizing side effects (e.g. high output stoma or obstruction). See **Appendix 7** for a sample one-day menu early post-transplant.
- The dietitian will meet with you while you are in hospital to give you more information on the types of foods and drinks that may be best for you.

#### **Long-term nutrition considerations:**

- Your immunosuppressive medications may contribute to the development of high cholesterol or elevated blood sugars. Some people also find that they gain too much weight after their surgery especially when the prednisone doses are higher. In the long run, we advise you to follow a healthy, balanced diet such as Canada's Food Guide. You can get a copy from the discharge nurse or look it up on the internet.
- Patients who have diabetes will need to pay special attention to the amount of carbohydrates in their diet and may need to meet with the dietitian.
- You may require other diet modifications depending on your situation (e.g. lower potassium diet)
- Consumption of simple sugars can lead to high stoma output or diarrhea after the stoma closure. You may need to avoid simple sugars for long periods after the transplant.
- Because you will be on immunosuppressive medications, it is especially important that you use safe food handling practices. Because your immune system will be suppressed, it can be difficult to fight off harmful foodborne bacteria. This situation can lead to serious complications. Go to: <http://healthy Canadians.gc.ca/eating-nutrition/safety-salubrite/immune-immunitaire-eng.php> for information on how to properly handle and cook food to reduce your risk of foodborne illness. You can also ask your dietitian or coordinator if you have any questions.
- You will have to avoid grapefruit juice after the transplant because it reacts with your immunosuppressive drug (tacrolimus) and may lead to abnormal drug levels in your blood.



# University Health Network's Discharge Policy



**Dear Patient/Family of the University Health Network:**

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

## **Leaving the Hospital**

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

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

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

## **Returning Home**

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

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

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

## **Rehabilitation (Therapy)**

Your health care team may feel that you need special rehabilitation services such as occupational therapy, physiotherapy or speech therapy. If so, we will assist you in sending applications to all facilities that offer the services you need.



## **Chronic Care (Ongoing Care)**

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

## **Palliative Care**

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

## **Long Term Care (Nursing Home):**

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

## **A Chronic Care/Long Term Care Daily Fee**

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

## **Completing Applications**

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

## **Retirement Home, Other Housing:**

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

## **Questions?**

If you have questions or concerns please talk to the social worker, or call the number listed below. **Toronto General Hospital: (416)340-3616**

## **Convalescent Care**

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

## **Life at Home After Discharge**

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

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

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

## **Communication After Discharge**

We have a special communication system called “Easy Call” that we use both to receive messages from you and also to send messages to you after transplant. One of the secretaries from the clinic will meet with you and review the system before you go home. Important points about the system to note:

- This is an efficient system that can be accessed from anywhere in the world at any time of the day
- The system will not work if you have a rotary phone or if you have “call privacy” on your phone
- If English is not your first language you must have someone who speaks English and is able to access messages for you
- We pick up messages from you from 8:00 AM to 4:00 PM Monday to Friday. You can leave messages at any time.
- We can send you messages by activating the computer to call your phone with a “hail” or “urgent” message. We use this when we want to tell you about a medication change or an appointment. Your phone will ring hourly until you pick up the message, but will not ring between 10:00 PM and 08:30 AM
- You should also check regularly for messages – in the first 3 months check daily and thereafter check weekly as well as a couple of days after a blood test
- We will still call you directly if we need to discuss something with you in greater detail – for example if you report an illness. If you want us to call directly, then leave this information with your message
- If you change your telephone # you must let us know right away or the system will not work
- **DO NOT USE EASY CALL in an EMERGENCY** – After hours if you need immediate advice or have an urgent health problem call **Telehealth Ontario @ 1-866-797-0000** or go to your local emergency department
- Make sure that another family member or friend knows how to use the system

## **Out of Town Patients**

If you live more than 2-3 hours outside Toronto, you will **need** to stay in the city for the first few **months** after discharge. This period is a time when you need to be closely monitored and it is a time when complications are common so it is safest to stay nearby. If you need a list of accommodations located near the hospital our social worker can

provide you with one. Planning for this should take place before you are admitted for transplant.

### **Home Care**

If you have a dressing on your incision or have a special reason to need a nurse to visit such as diabetes support, then we can arrange a visiting nurse. This is not a routine practice for all patients. Each patient is assessed at the time of discharge regarding the need for home care.

### **Paying for Medications**

As discussed previously, every patient is expected to pay for their medications when they are discharged and discharge cannot be delayed because of issues related to drug coverage. All patients except seniors and those who receive a monthly drug card as part of their disability benefits are expected to be registered with Trillium before their surgery. If you have private insurance you will need to have the insurance information for pharmacy.

### **Transportation**

It is your responsibility to make arrangements for a ride home from the hospital by 11:00 AM on the day of discharge. You will also need to plan for rides to clinic and to the lab for blood tests. It is also likely that you will need to make extra trips to hospital for additional blood tests or scans after discharge. These test arrangements are often made suddenly and you need to have a plan about how you will travel to the hospital should one of these situations arise.

### **Clinic and Blood tests after Discharge**

You will be given a date and time for your first clinic visit before you go home. You will also be given a schedule for lab tests that need to be done prior to the clinic visit. We will give you a new blood requisition for your lab as the tests that are done may be different and will also include a drug level each time. Clinic is usually once weekly at first and blood tests, one of which is done in clinic, are twice a week. At each clinic visit you are given further instructions to guide you until the next clinic.

## **Living with an Ileostomy**

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All patients after intestine transplantation will have a stoma after their transplant. The stoma is used for routine biopsies to look for rejection or other problems in the function of your intestine. The stoma is usually closed 9-12 months after the transplant.

### **What is an Ileostomy?**

Ileostomy surgery is typically done to cure or alleviate symptoms of disease. In intestine transplantation ileostomy is created to achieve an easy access point for repeated small

bowel biopsies. The ileostomy may be permanent or temporary, depending on your disease process.

### **What is a Stoma?**

During ileostomy surgery, the end or a portion of the small bowel is brought through an opening on the surface of the abdomen. The part of the bowel you see on your abdomen is called the **Stoma**. The stoma is where the stool will now pass from your body. It may or may not stick out from your abdomen. A healthy stoma is red or pink in color and moist. There are no nerve endings in the stoma, so it will not hurt when touched or during an endoscopy with biopsies. Your stoma may move slightly which is a normal process that pushes stool through the intestine.

### **Care of your Stoma**

Just like your gums sometimes bleed when you brush your teeth, your stoma may also bleed slightly. However, if your stool is bloody, or you have constant bleeding, you should contact your doctor. Since the ileostomy has no sphincter muscles, you will not be able to control when stool comes out. You will need to wear a pouch to collect the stool. The stool coming out of the stoma is a liquid to pasty consistency. This occurs because less water is being absorbed from the stool, compared to when your large bowel was in place. The nature and frequency of the output may be affected by food and fluid intake, as well as some medications and treatments prescribed by your doctor. The stoma output also increases during rejection and infection of the bowel.

Your enterostomal nurse will teach you to care for your stoma and change your pouching system. It is important to take good care of your skin around the stoma (peristomal). If the pouching system does not fit securely, or if stool leaks beneath it, the skin can become red and sore.

### **Emptying and Changing your Pouch**

You should empty your pouch when it is about one-third to one-half full (or when needed or desired). A full pouch can become heavy and break loose from the skin. Also, emptying is more difficult when the pouch is full.

Plan on changing your pouch in the morning, before your ostomy becomes active. You may shower with your pouching system on or off. If you spend time in a sauna or hot tub, the heat may loosen the pouching system. Always check to make sure you have a good seal.

## **Post Discharge “To Do” List**

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### **Complete your “Contacts” List**

Please complete this list and bring it to your first clinic. This is important so that we have accurate phone information so that we can contact you when necessary. This list also includes the information about your pharmacist and family doctor.

### **Complete Medic Alert Bracelet Form**

If you need assistance completing this form, you can bring it to your first clinic. We do recommend that you have a Medic Alert bracelet.

### **Thanking Your Donor family**

It is important to do this when it feels right but it is very meaningful to the donor family to receive a note from you. If you need assistance, please ask us in clinic. (See Appendix 1 for additional information)

## **Monitoring and Care after Discharge**

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### **Clinic location : 12th Floor Clinical Services Building (West Elevators)**

You will be given a date and time for a follow up appointment to see your transplant doctor and nurse coordinator in clinic. Generally, patients are seen within a week after discharge but this can vary slightly, depending on your post operative course in hospital, length of stay and general health.

We initially see our new transplant patients every 1-2 weeks in clinic. Clinics become less frequent as your health stabilizes over time. It is important to attend all scheduled appointments, as routine clinic assessment is an essential part of your follow -up. If you need to change your appointment, please call *Easy Call* (416-351-0793 + your PIN #), at least 72 hours in advance. Missed appointments or “No Shows” will be documented in your chart.

### **We ask that you bring the following to your clinic appointments:**

- Your OHIP card and blue hospital card
- Your medications or medication list with names, doses and pill size.
- A list of the medications which require renewal prescriptions
- Information on your regular daily stoma output, diet, amount of drinking and TPN or IV fluids information
- Contact information (see previous page) &/or changes in contact information. Once you are further out from your transplant date, it is important to keep us updated with any changes to your personal information, new family doctor, change in pharmacy etc.
- A list of concerns or questions.

**We will review the following in clinic:**

- We will ensure your medications and medication list match with the list in your chart.
- We will assess for side effects and effectiveness of these medications.
- We will adjust medications if required.
- Review your most recent blood work.
- Assess your nutrition and hydration status
- Review any questions or concerns you may have.
- Physical assessment to assess fluid retention, wound healing, blood pressure etc. Staples are usually removed three weeks after surgery.
- Review the plan of care until your next clinic appointment.

**At the end of every clinic you will be given:**

- A prescription for your transplant medications, which should provide enough of a supply to last until your next scheduled appointment.
- All medications except for cyclosporine can be obtained at your local pharmacy. Cyclosporine must be filled at the Toronto General outpatient pharmacy for it to be paid for by the special government program for this drug. It is important to drop off your prescriptions at the appropriate pharmacy after each clinic. If you don't need a particular medication filled, simply ask the pharmacist to keep the prescription ``on file``. When you need a refill, please call the pharmacy directly.
- After the first month we will give prescriptions for the immunosuppressive medications only – you will need to see your family doctor for the other prescriptions.
- A diet plan after a meeting with the dietitian
- An Appointment for your next Clinic -You will be asked to take your clinic chart to the reception desk, where you will be given a card with the date of your next appointment and a schedule for your blood work.
- New lab requisition(s) for your local lab – each requisition is valid for 6 months.

**Lab Tests****Routine blood work**

Blood tests are an essential tool to help us monitor your transplant and overall health. We are able to assess for the following by monitoring your blood work including:

**Rejection (for recipients of liver):**

Often an episode of rejection of a liver transplant is detected by blood work. A rejection episode may also be accompanied by other symptoms such as an increase in temperature, jaundice etc.; as mentioned in the previous section, but it is important to remember that sometimes, rejection can be present without any visible symptoms. Doing your blood work as advised by your liver transplant team is vitally important in detecting this complication early.

**Assess Drug Levels:**

We have guidelines for the blood drug levels we aim for. Early after transplant you will need higher blood drug levels as this is the time you are at a greater risk for an acute rejection. Over time, this risk becomes slightly less and we usually can reduce the target level you need to avoid rejection and reduce the risk of side effects. *Medications can only be adjusted safely if the blood work has been done regularly and with correct timing depending on the drug you take. If you are not sure what correct timing is, please ask us for advice.*

**Drug side effects:**

The absence of rejection will indicate that you are adequately immunosuppressed but we also watch for side effects of these medications by reviewing your blood work. We monitor for drug side effects such as impaired kidney function, low white blood cell counts and increased potassium.

**Nutrition status:**

Blood work helps us to determine your nutrition and hydration status. We determine your kidney function, blood electrolytes levels, micronutrients and vitamin levels. Your TPN, IV fluids and diet will be adjusted according to your blood work results.

**Blood work on Clinic day:**

New transplant patients usually require blood work on the day of clinic. We have a blood technician in the clinic area on the 12th and blood tests are done soon after you arrive in the clinic. We will let you know if we plan to do labs when we remind you about clinic.

If you take *Tacrolimus (Prograf)*, please bring your morning dose with you to take after the blood work has been drawn. (This applies to every set of blood work). The blood test should be drawn 11 to 13 hours after your previous dose.

If you take *Cyclosporine (Neoral)*, please ensure you have taken this medication 2 hours prior to arriving for your appointment. (This applies to every set of blood work).



## **Clinical Trials**

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

Some of the clinical trials include looking at medications that:

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

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

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

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

## **Transplant Resource List**

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**Toronto General Hospital Multi-Organ Transplant Program:**

[http://www.uhn.ca/Focus\\_of\\_Care/MOT/index.asp](http://www.uhn.ca/Focus_of_Care/MOT/index.asp)

**Trillium Gift of Life Network:**

<http://www.giftoflife.on.ca/>

**DRUG COVERAGE:**

**Trillium Drug Program: 1-800-575-5386**

<http://www.health.gov.on.ca/english/public/pub/drugs/trillium.html>

**FINANCES:**

**Canada Pension Plan – Retirement Pension: 1-800-277-9914**

<http://www.servicecanada.gc.ca/eng/isp/pub/factsheets/retire.shtml>

**Canada Pension Plan – Disability Benefits: 1-800-277-9914**

<http://www.servicecanada.gc.ca/eng/isp/cpp/disaben.shtml>

**Employment Insurance – Sick Benefits: 1-800-206-7218**

<http://www.servicecanada.gc.ca/eng/sc/ei/benefits/sickness.shtml>

**Employment Insurance – Compassionate Care Benefits: 1-800-206-7218**

<http://www.servicecanada.gc.ca/eng/sc/ei/benefits/compassionate.shtml>

**Ontario Works:**

<http://www.mcass.gov.on.ca/en/mcass/programs/social/ow/index.aspx>

**Ontario Disability:**

<http://www.mcass.gov.on.ca/en/mcass/programs/social/odsp/index.aspx>

- **Ontario Social Assistance Office Finder:**

<http://appow.mcass.gov.on.ca/OfficeLocator/index.aspx>

**CANADA REVENUE AGENCY: <http://www.cra-arc.gc.ca/>**

**Medical and Disability-Related Information:**

<http://www.cra-arc.gc.ca/E/pub/tg/rc4064/rc4064-e.html>

**Travel Expenses:**

<http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330/llwbltrvl-eng.html>

**Meal and Vehicle Rates Used to Calculate Expenses:**

<http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns248-260/255/rts-eng.html>

**Disability Tax Credit Certificate:**

<http://www.cra-arc.gc.ca/E/pbg/tf/t2201/README.html>

**T.I.P.S - Tax Information Phone Service:**

<http://www.cra-arc.gc.ca/esrvc-srvce/tps/menu-eng.html>

**SUBSTITUTE DECISION MAKING:**

**Power of Attorney and Living Wills:**

<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.asp>

**A Guide to Advanced Care Planning Booklet:**

<http://www.culture.gov.on.ca/seniors/english/programs/advancedcare/docs/AdvancedCare.Guide.pdf>

**CHILDREN:**

**The Inside Story: A Kid's Guide to Kidney and Liver Transplants:**

<http://www.bridges4kids.org/Disabilities/InsideStory.pdf>

**LIVING DONOR:**

[http://www.uhn.ca/Focus\\_of\\_Care/MOT/Living\\_Donor/index.asp](http://www.uhn.ca/Focus_of_Care/MOT/Living_Donor/index.asp)

**ALCOHOL TREATMENT:**

**Drug and Alcohol Registry of Treatment (D.A.R.T): 1-800-565-8603**

<http://www.dart.on.ca/>

**SMOKING CESSATION:**

**Smokers' Helpline: 1-877-513-5333**

[www.smokershelpline.ca](http://www.smokershelpline.ca)

**Smoke-Free Ontario:**

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

**Health Canada Health Concerns:**

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

## Getting to Toronto General Hospital

### Public Transit (TTC):

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

### Parking:

To improve access to the hospital for our patients and visitors, specific parking lots have been designated.

#### Toronto General Hospital:

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

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

#### Toronto Western Hospital:

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

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

### What are parking rates? (current as of January 2011)

#### Monday to Saturday - 7am to 6pm:

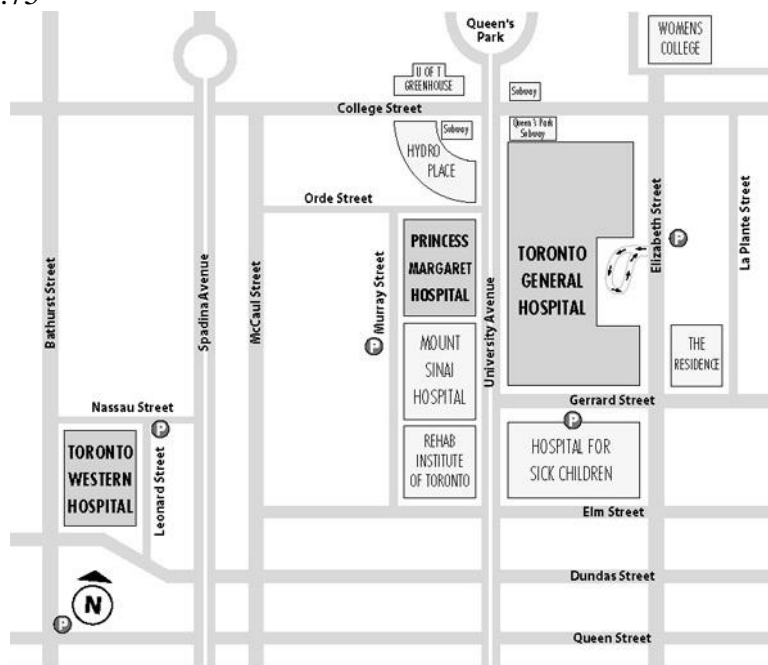
\$4.00 for each 1/2 hour or less with a daily maximum of \$25.00 at the Gerrard Street lot and \$21.50 at all other lots.

#### Monday to Saturday - 6pm to 7am:

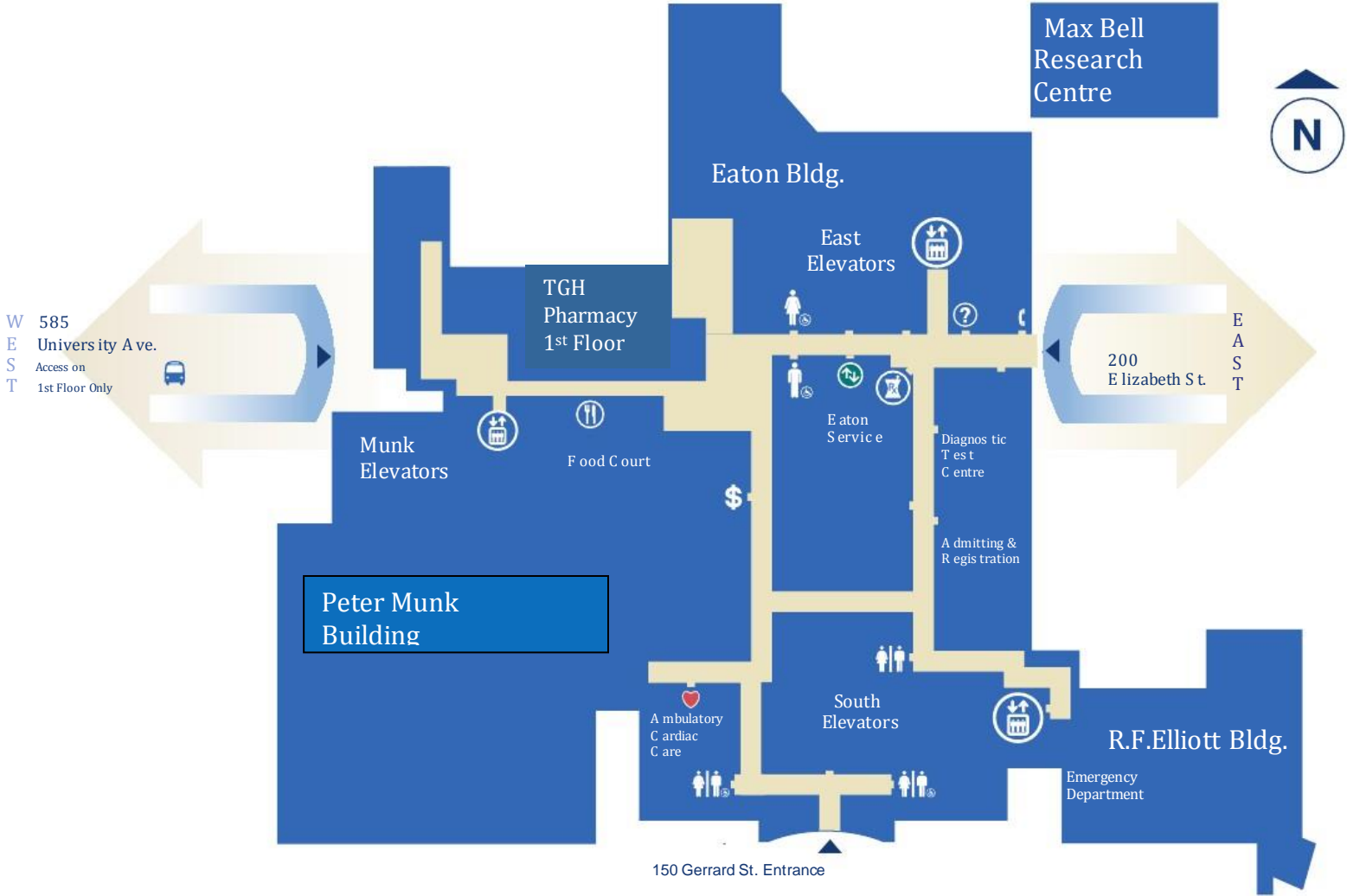
Flat rate of \$7.75

#### Sunday & Holidays - All Day

Flat rate of \$7.75



# Toronto General Hospital, Ground Floor



## **Important Contact Numbers**

<b>Contact</b>	<b>Telephone Number</b>
Emergency	<b>911</b>
Toronto General Hospital - Main	416-340-4800
Locating - Toronto General Hospital	416-340-3155
Pharmacy - Toronto General Hospital	(416) 340-4075
Transplant Physician:	(416) 340-4800 Ext:
Transplant Coordinator (Pre Transplant)	(416) 340-4800 Ext: 8072 or 6103
Transplant Clinic	(416) 340-4800 x 4113
Living Donor Liver Program	416-340-4800 x 6581
Transplant Inpatient Unit	(416) 340-5163
Transplant Psych/Social Office	416-340-4800 x 5655
Patient Relations - University Health Network	(416) 340-4907
Clinical Trials	(416) 340-3125
D.A.R.T	1-800-565-8603
Telehealth	1-866-797-0000
Registered Dietitian	416-340-4800 x 2738
Life Labs	1-877-849-3637 or 416-675-3637

## **APPENDIX 1 – Saying Thank You**

Transplant recipients often wonder how to say “Thank you” to their donor.

If your donor is a friend or relative, saying thank you can be done in the traditional way.

When your donor is an anonymous person whose organs were donated by their family at the time of their death, a “Thank You” can be difficult.

We encourage you to write to the donor’s family to express your thanks. Although it may be a challenge to write a letter, many transplant recipients welcome the opportunity to express their gratitude. We have also found that such thank you letters, or cards, can be a comfort to donor families as they deal with their loss.

There is no right or wrong time to write to the family. Some recipients feel that they want to write immediately. But you might need time to recover from your surgery before you are able to write. We encourage you to write sometime within the first year after your transplant.

Under the Human Tissue Gift Act, the government of Ontario requires we keep your identity and your donor’s identity confidential. For this reason, we ask that you do not include your name, where you live, your cultural background, religious affiliation or workplace, or where you had your transplant in your letter. Some things you may want to include are:

- how long you waited for your transplant
- how you felt while you waited
- how you feel now
- what you are looking forward to doing in the future

Many recipients want the donor family to know that they appreciate the courage it took to make the donation, and that the donor family is often in their thoughts.

The letter can be as long or short as you wish. Please remember this is a letter of thanks. If you need some help with your letter, do please ask your transplant team for advice.

When your letter is complete, give it to your transplant coordinator in an unsealed envelope so that it can be reviewed before being sent to the donor. Your coordinator will then forward your letter to the staff at the Trillium Gift of Life program. It is the Trillium Gift of Life staff that sends your letter to the donor family.

Occasionally donor families will send correspondence to recipients through the Trillium Gift of Life Program. If this happens, your coordinator will let you know.

## APPENDIX 2 – Medication Reference for Other Providers

Most conditions affecting Intestine transplant recipients are treated as they are in any other patient with the following cautions and exceptions

<b>Avoid</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> All NSAIDS – worsening of (subclinical) Cyclosporin/Tacrolimus-induced renal dysfunction and G.I. irritation</li> <li><input type="checkbox"/> Macrolide antibiotics (e.g. Erythromycin) inhibition of drug metabolizing enzymes in the liver with significant increases in the cyclosporine/tacrolimus levels. Azithromycin seems to be an exception and has minimal impact on the levels and thus is acceptable</li> </ul>
<b>Vaccines</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> <b>NOT</b> to receive vaccines with live virus or bacteria thus no herpes zoster vaccine, MMR etc</li> <li><input type="checkbox"/> Annual flu shot is recommended preferably after the first 3 months post-transplant to improve benefit</li> <li><input type="checkbox"/> Pneumovax recommended q 5 years for all patients rather than single dose in lifetime</li> </ul>
<b>Antibiotics</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> No contraindications except macrolides (see above) and rifampin. Rifampin induces the drug metabolizing enzymes in the liver and therefore causes a marked decrease in Cyclosporin/Tacrolimus levels. If it is used close monitoring of the Cyclosporin/Tacrolimus levels and respective dose adjustment is necessary</li> </ul>
<b>Cholesterol Rx</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Lipid lowering meds well tolerated</li> <li><input type="checkbox"/> Agent we have most experience with is atorvastatin – start at lowest possible dose due to potentiation effect with immunosuppressives , -increase dose gradually if necessary</li> <li><input type="checkbox"/> LFTs monitored q 2 weeks x 3</li> <li><input type="checkbox"/> Limited experience with rosuvastatin (Crestor), but has been used, again starting with the lowest possible dose</li> </ul>
<b>Hypertension</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Follow usual guidelines with some caution related to diuretics, ACE inhibitors and ARBs due to commonly encountered baseline renal dysfunction and risk for hyperkalemia</li> </ul>
<b>Gout</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Colchicine in small doses the usual choice since no NSAIDs allowed: Brief course of prednisone acceptable unless patient has Hep. C.</li> <li><input type="checkbox"/> If recurrent acute attack: Allopurinol acceptable provided patient not on azathioprine (Imuran).</li> </ul>
<b>Seizures</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Many antiepileptics such as phenytoin and carbamazepine induce the drug metabolizing enzymes in the liver and therefore cause a marked decrease in Cyclosporin/Tacrolimus levels. If these drugs have to be used, close monitoring of the levels is advised and respective dose adjustment if necessary</li> </ul>
<b>Erectile Dysfunction</b>	<ul style="list-style-type: none"> <li><input type="checkbox"/> No specific transplant concerns, use usual risk assessment</li> </ul>



## APPENDIX 3 – Vaccinations

### Vaccines in Adult Solid Organ Transplant Recipients

#### RECOMMENDED VACCINES

Vaccine	Inactivated/ live attenuated (I/LA)	Recommended before transplant	Recommended after transplant	Monitor vaccine titers
Influenza	I	Yes	Yes *	No
	LA	No	No	No
Hepatitis B	I	Yes	Yes	Yes
Hepatitis A	I	Yes	Yes	Yes
Tetanus	I	Yes	Yes	No
Pertussis (Tdap)	I	Yes	Yes	No
Inactivated Polio vaccine	I	Yes	Yes	No
Pneumovax	I	Yes	Yes **	No
<b>OTHER VACCINES</b>				
N. meningitidis (MCV4)	I	Yes	Yes	No
Rabies	I	Yes	Yes	No
Human papilloma virus (HPV)	I	Yes	Yes	No
Varicella (live- attenuated; Varivax)	LA	Yes	No	Yes
Varicella (live- attenuated; Zostavax)	LA	Yes	No	No
BCG	LA	Yes	No	No
Smallpox	LA	No	No	No

\* In new patients we recommend that the flu shot be delayed until 3 months post-transplant to improve response

\*\* Repeat dose every 5 years

Reference: Danzinger-Isakov L, Kumar D et al. Am J Transplant 2009;9(Suppl 4):S258-S262

Note : Reference Information courtesy of Dr. C. Rotstein MD FRCPC FACP, Co-Director Transplant Infectious Diseases, University Health Network

## **APPENDIX 4 – Organ Donation and Listing Practices**

In accordance with the Ontario *Human Tissue Gift Act*,

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

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

What they are suggesting is illegal.

The Toronto General Hospital & the Soham & Shaila Ajmera Family Transplant Centre Program do not support or accept payment of any kind from patients, organizations or any party for organs for transplantation.

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

## APPENDIX 5 – Discharge Planning Consent Form

### DISCHARGE PLANNING CONSENT FORM Multi-Organ Transplant Program University Health Network University of Toronto

#### Introduction

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

#### Consent:

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

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



## APPENDIX 6 - Ileostomy Diet Considerations:

Some foods may cause a food blockage which means that undigested food 'clumps up' and blocks the bowel. A food blockage can cause cramping, pain and a watery output with a bad odour or the blockage may cause you to have no output. Your abdomen and stoma may become swollen and you may feel sick to your stomach, or begin to vomit. If you think you have a blockage, call your coordinator or go to your closest emergency department.

### General Guidelines:

1. Start by having smaller meals, more often
2. Limit fruit to canned and skinless fruit packed in water or drained of liquid; choose fruits with no sugar added (e.g. unsweetened applesauce, pureed fruits); ripe bananas.
3. Limit vegetables to vegetable juices; tender cooked vegetables like asparagus tips, beets, broccoli tips, carrots, peeled eggplant, peeled potatoes, peeled tomatoes, pumpkin and squash; other vegetables that are pureed.
4. Use white breads, pasta, rice and cereals (avoid sugary cereals) without seeds or nuts.
5. Choose well-cooked, lean and tender meat, poultry, fish, eggs and low-fat cheese. Avoid meat and shellfish with tough connective tissue or gristle. Avoid meats in casings (e.g. hot dogs and sausages).
6. Chew all foods thoroughly.

Foods that may cause blockages include:

Nuts	Corn
Popcorn	Mushrooms
Coconut	Celery
Dried fruits (raisins, dates)	Meats with casing (sausages)
Chinese vegetables	Raw vegetables
Skin of fruit (peaches, pears, grapes)	

If you need additional nutrition information, please contact your dietitian or transplant coordinator.

## **APPENDIX 7 - Sample One-Day Menu Post-Intestinal Transplant**

(This is only an *example*)

### **Breakfast:**

- Carrot Muffin with margarine
  - Cheerios with lactose-free, skim or 1 % milk
  - Fat-free, sugar-free vanilla yogourt
- OR
- 1 slice of white or brown bread with margarine
  - Cheerios with lactose-free, skim or 1 % milk
  - Boiled egg

### **Lunch:**

- ½ egg salad sandwich
  - Diced peaches (skinless)
  - Broth or sugar-free jello
- OR
- Baked chicken breast
  - Mashed potatoes
  - Unsweetened applesauce

### **Dinner:**

- White or brown dinner roll
- Lean roast beef with light gravy
- Steamed rice
- Cauliflower
- Diced pears (skinless)

### **Snacks:** (morning, afternoon and evening)

- ½ sandwich (e.g. egg, salmon, tuna) or filling alone in cup
- Light cheddar cheese or peanut butter with crackers, melba toast, bread slice
- Low-fat cottage cheese with fruit
- Yogourt (plain or low-fat, low-sugar/ sugar-free) with low-sugar cookies
- Unsweetened applesauce and Cheerios
- banana

### **Drinks:**

Water, tea, coffee (in moderate amounts), sugar-free beverages, broth.

