

# Kidney Transplant Handbook



*Exceptional care. Healthy community.  
One patient at a time.*

## BEGIN YOUR TRANPLANT JOURNEY

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## GRH- Renal Program

*A Kidney Transplant Referral Centre*

**GRAND RIVER  
HOSPITAL**

Advancing Exceptional Care

[www.grhosp.on.ca](http://www.grhosp.on.ca)

# Introduction to Kidney Transplant

**Kidney transplantation** is a desirable treatment for many people with kidney failure. It allows you to live your life free from dialysis and without many of the restrictions that accompany other treatment options. A kidney transplant can provide better health and a new lease on life.

There are many things to learn when deciding if kidney transplantation is right for you. This handbook is available to help answer your questions and guide you through the initial steps of referral and testing. **Please bring this handbook, along with any questions and concerns, to your transplant education session.** You will probably have many more questions as you travel through your transplant journey; feel free to talk to your health care professionals or use the resources listed at the end of this book.

## Benefits of a Kidney Transplant

- Prolongs survival in many patients
- Improves quality of life
  - ⇒ Enjoy freedom from dialysis and reduced health problems related to years on dialysis
  - ⇒ Experience fewer symptoms related to kidney failure

## What are the **different types** of kidney transplants?

- **Living Donor Transplant** — In this case, a loved one's family member may choose to donate one of their own kidneys (referred to as "living related") or, a close friend may choose to give this gift as well (living unrelated or sometimes called "emotionally related donation"). Patients can avoid dialysis and the long wait by receiving a living donor kidney transplant.
- **Deceased Donor Transplant** — The kidneys donated come from someone who has died suddenly and the family generously wishes to donate their organs. Patients wait years for a deceased donor kidney and are usually on dialysis while waiting. The average wait time from starting dialysis to receiving a deceased donor transplant in Ontario is 3 to 6 years depending on blood type and antibody levels.



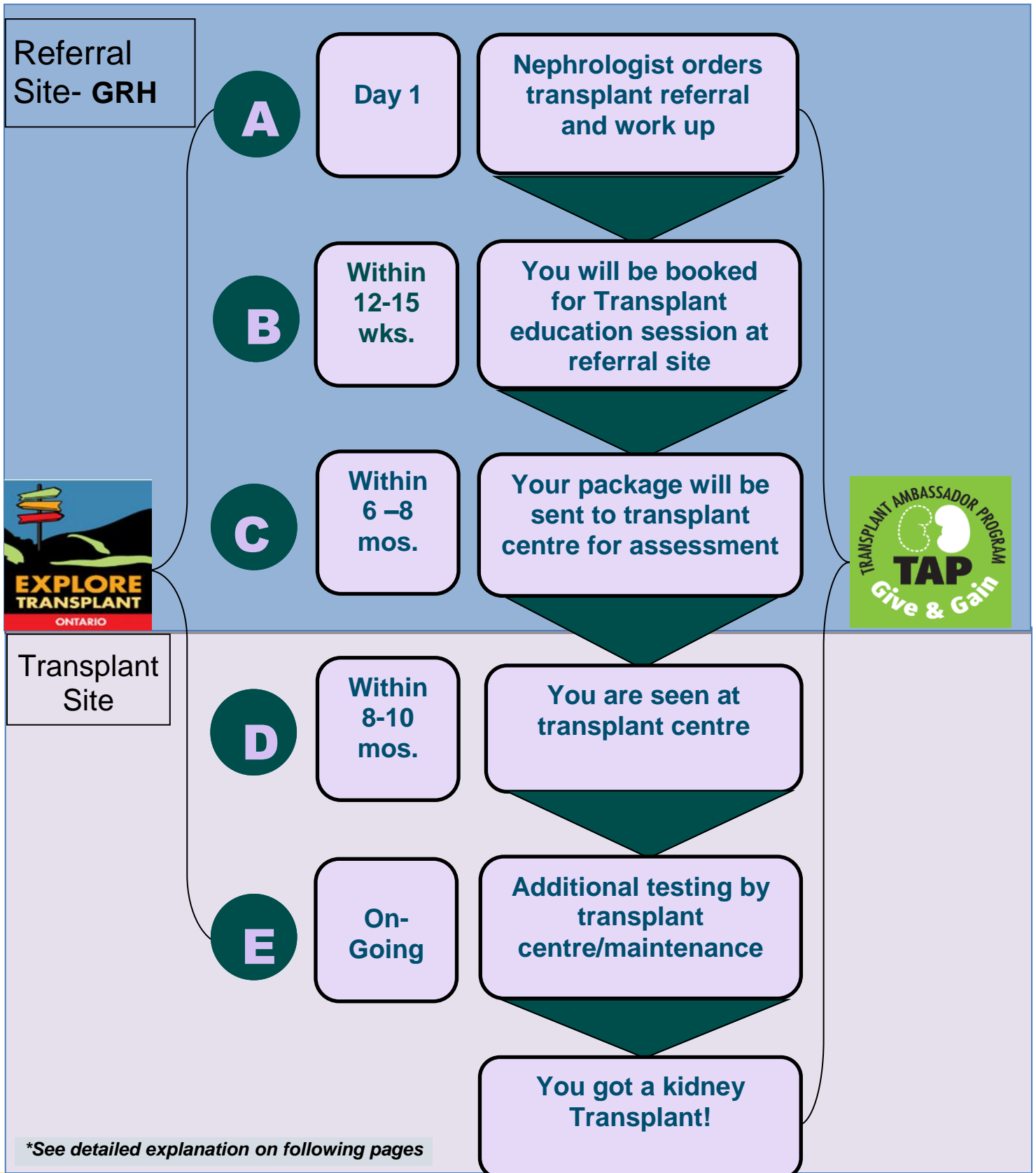
# Benefits of Living Donations

A kidney transplant from a living donor has a number of advantages over a deceased donation.

- A living donor organ is in excellent condition (not having suffered any trauma from a sudden death situation) and therefore, it **usually functions immediately**.
- In case of related donors, there is **less chance of rejection** of the transplanted organ and often less anti-rejection medication is needed due to the donated kidney being a **better genetic match**.
- The **wait time is shorter**. (Approximately 1 to 2 years for a living donor transplant as compared to 3 to 6 years for a deceased donor).
- Living donor transplant surgeries are scheduled **which may lessen the stress**.
- Both the 1 year and long term **success rates are higher** with living donor kidneys. If received at same time; the 3 years survival rate is **96%** with living donor kidneys vs **94%** with deceased donor.
- Kidney transplants are possible before needing dialysis if you have a living donor. This is called a **pre-emptive transplant**.



# Your Care Map to Transplantation



# A Transplant Work-Up

Once you have decided to proceed with a kidney transplant a number of tests are required before your referral is processed further. These tests are based on standard testing parameters, as well as testing specific to your health history.

## They will be arranged by your Transplant Coordinator.

A few of the standard tests necessary are:

- **Blood tests** — A number of blood tests are necessary including your blood group. This test determines your blood type (either A, B, AB or O).
- **Abdominal Ultrasound** — An ultrasound is performed using sound waves to create a picture. It is painless and determines if there are any problems in your abdomen. You may not eat or drink for 12 hours prior to this test. It is completed in the Medical Imaging department.
- **Chest X-ray** — A chest X-ray checks your heart and lungs. It is completed in the Medical Imaging department and no appointment is needed.
- **2D Echocardiogram** — This test checks the function of your heart using sound waves. It is completed in the Special Testing department, or through your cardiologist's office. An appointment will be arranged for you.
- **Electrocardiogram (ECG)** — This test checks the pattern of your heartbeat. Small sticky pads are placed on your chest, arms and legs and connected by wires to a monitor. Your heart rhythm is then recorded. This test is painless and takes approximately 15 minutes.
- **TB Skin Test (Tuberculosis Screening)** — Before transplant, it is important to identify if you have come in contact with the bacteria that causes tuberculosis. Tuberculosis is an infectious disease usually involving the lungs. It is both curable and preventable. Post- transplant, you must take medications that weaken your immune system and make you vulnerable to disease and infections. If your skin test is positive, preventative therapy will be initiated before you are eligible for transplant.



# Living Donor Process

**Grand River Hospital is not a transplant hospital;** therefore, any potential living donors must contact the transplant centre themselves to initiate the process.

If you have a donor who is interested in starting the process, they can expect to have many of the same tests done as yourself.

If your donor is living outside of Canada, some of the initial testing will be done in their own country, which may result in out-of-pocket expenses. However, their medical appointments and tests done in Canada that are associated with kidney donation are covered under OHIP, including the surgery itself.

**PRELOD (Program for Reimbursing Expenses of Living Organ Donors)** is a resource available to your donor to help with some of the expenses they incur through the donation process, such as loss of wages, travel and accommodations. It is run through the Trillium Gift of Life Network and is available to anyone in Ontario, out-of-province or out-of-country who donates or intends to donate to an Ontario resident. The transplant hospital will help your donor through this process.

If your potential donor does not have a matching blood type to you, there are several options that can be considered for them to still donate on your behalf. The “**kidney paired donation**” through the Canadian Blood Services is a process that enables other NON matching donors to be matched up with other recipients. The transplant centre will help your donor with this process if necessary.

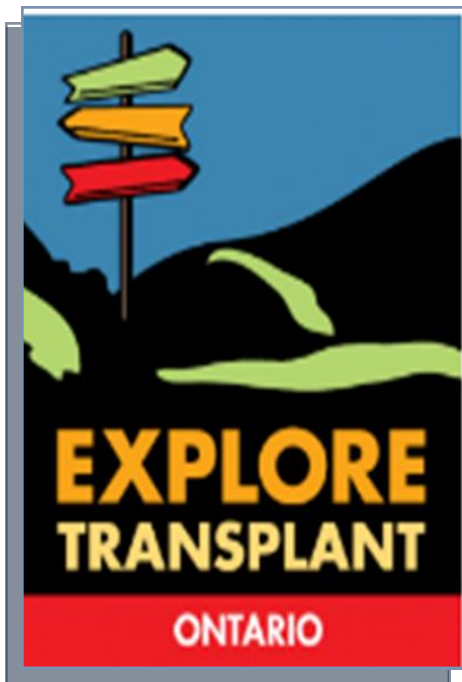


- Susan McKenzie and her donor Marian Reich



# B Transplant Education Session

During this testing period, you will receive an appointment to meet with your Transplant Coordinator and a social worker for a **Transplant Education Session**. During this session, you will learn more about the “basics” of kidney transplantation, and have questions or concerns answered. The social worker will do an assessment of your motivation for transplant and your ability to adhere to the rigors of the transplant process and will provide information and guidance on obtaining drug coverage. Please feel free to bring family, friends, and/or potential donors with you. We have provided “note pages” at the end of this handbook to write down anything you want to discuss during your Education Session.



**Explore Transplant Ontario** is an education program designed for Ontarians with kidney disease, along with their families, friends, potential living donors and healthcare providers. Its purpose is to explain the available kidney transplant options so that those living with kidney failure can make well-informed decisions about their treatment. We hope that **Explore Transplant Ontario** will help patients, family members and friends, potential living donors, healthcare providers and the general public learn more about kidney disease, dialysis and transplant.

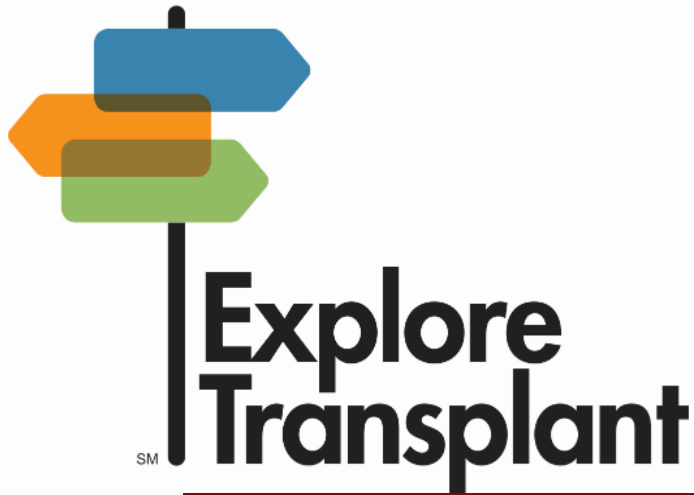
**Website:** <https://etontario.org/>



Explore Transplant Ontario has been adapted from the Explore Transplant program developed by **Dr. Amy Waterman**, which has been used successfully to educate more than 28,000 kidney patients in the United States.



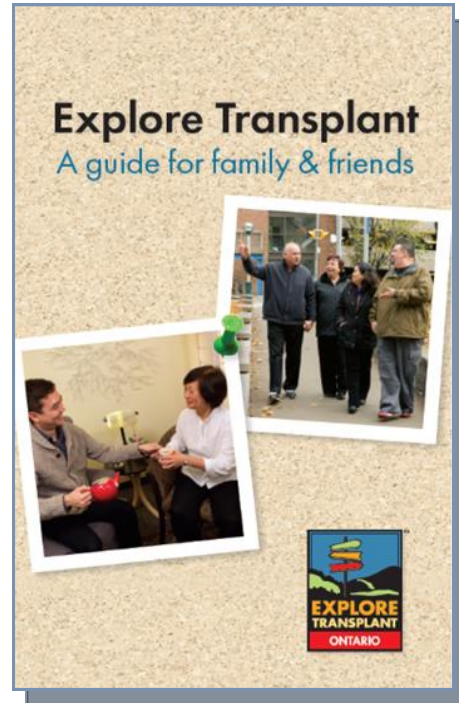
# Explore Transplant Ontario



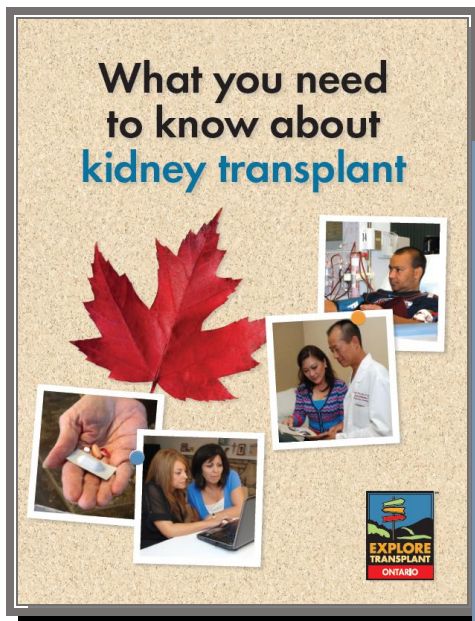
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**ONTARIO**

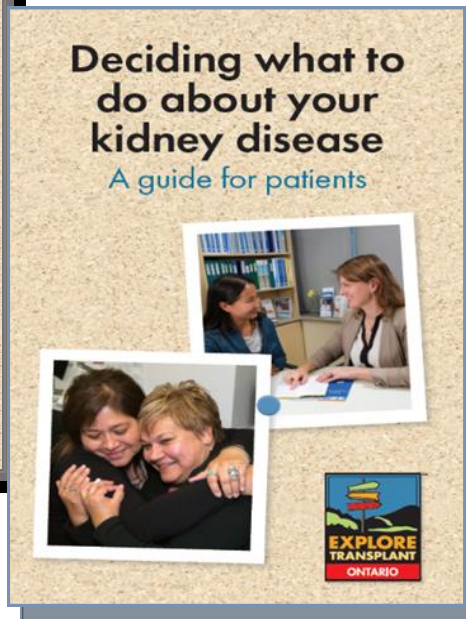
Website: <https://etontario.org/>



**Explore Transplant**  
A guide for family & friends



**What you need to know about kidney transplant**



**Deciding what to do about your kidney disease**  
A guide for patients



**Why people donate their kidneys**



- Ask your Nurse or Transplant Ambassador how you can access this information.
- These educational materials may also help spark thoughtful conversation.





# The Big Tell

**How** do I ask someone for a **kidney**?

Consider the **BIG TELL!**

For most recipients, the road to receiving the gift of a living donor kidney does not involve the BIG ASK.

For many recipients it was more about the **BIG TELL**. Share with the people in your circle what you are going through at all stages. Some people may not know how serious your situation is or how they can help. You may be amazed at the support you receive and the people who want to help!

Some people have appealed for a kidney through social media. Ambassadors can assist you in this if you would like support. Many of our Ambassadors have received a living donor transplant and are happy to share their stories. We are here to share!



# Transplant Ambassador Program (TAP)

The **Transplant Ambassador Program (TAP)** has been created by living kidney donors, recipients, and family members who are passionate about supporting patients living with chronic kidney disease (CKD) and their family members in **learning more about kidney transplantation and living kidney donation.**

The Ambassadors are people who have received a kidney transplant or have donated a kidney. They are volunteers who are passionate about kidney transplantation and want to share their personal experience to those who are interested in hearing their perspective. They will be visible and recognizable in the renal clinics and dialysis units as they wear a special vest or sash. They can also make arrangements to communicate by email or meet patients and family/friends in the community.

***TAP is a grassroots, patient-directed initiative supported by the Can-SOLVE CKD Network***



INTERESTED IN LEARNING MORE:

Website: <http://transplantambassadors.ca/>

Email: [connect@transplantambassadors.ca](mailto:connect@transplantambassadors.ca)





# Results Sent to Transplant Centre

Your test results are collected by the Grand River Hospital Transplant Coordinator and sent to your transplant centre along with notes from your Nephrologist and other health specialists (i.e. Cardiologist, Gastroenterologist, Endocrinologist). An appointment is then set up for you to meet with the “team” at the transplant centre.



**London Health Sciences Centre**  
Renal Pre-Transplant Office  
339 Windermere Road  
London, ON  
[www.lhsc.on.ca](http://www.lhsc.on.ca)



**St. Joseph's Healthcare Hamilton**  
Renal Pre-Transplant Office  
50 Charlton Avenue East  
Hamilton, ON  
[www.stjoes.ca](http://www.stjoes.ca)



**Toronto General Hospital**  
Renal Pre-Transplant Office  
200 Elizabeth Street,  
Toronto, ON  
[www.uhn.ca](http://www.uhn.ca)



**At the end of this handbook, we have provided the phone numbers of each transplant centre, should you need to get a hold of your transplant team.**



# **D** At the Transplant Centre

Once you have completed this series of tests to determine your suitability for a kidney transplant, the **next step is to be assessed by the transplant centre**. Your assessment is done at the transplant centre on an outpatient basis. Depending on the centre, this may take place over two days or spread out over several appointments. **This step must be completed before you get listed on the deceased donor kidney transplant wait list.**

**You will meet the following team members during your visit:**

- Nephrologist (a doctor who specializes in kidney disease/transplantation)
- Transplant Surgeon (a doctor who performs the transplant surgery)
- Transplant Recipient Coordinator (a nurse who explains the transplant process to you, and is also your contact person during the assessment and waiting period)
- Social Worker (the social worker provides you and your family members with emotional and practical support throughout the transplant process)
- Anesthetist (a physician who will administer your anesthetic during surgery)





# Waiting for Your Transplant

## **YOU WILL BE INFORMED BY THE TRANSPLANT CENTRE ONCE YOU ARE ACCEPTED ON THE LIST.**

Once accepted on the waiting list, it is **very important** that the transplant lab receives a **monthly blood sample**. If you are on hemodialysis, arrangements will be made to draw this blood sample. Patients who are on home dialysis or not on dialysis at the time of assessment will be advised on how to have this blood sample drawn monthly. Please check with your clinic or dialysis unit to ensure this happens. Without this monthly blood sample, the transplant team will not be able to test your blood with potential donors (“crossmatch test”).

**Failure to provide this monthly sample will prolong your wait for a kidney transplant.**

The transplant waiting list is made up of patients from all across Ontario; it is managed by **Trillium Gift of Life**. Once your tests are complete and you are eligible to be placed on the list, you will receive a letter and a phone call from the transplant centre. As kidneys are now ‘matched’ with sophisticated technology, it is impossible to say exactly how long you will wait for the kidney that is ‘right’ for you. When a kidney becomes available, the computer system compiles a list of “best matches”. Priority is given both to children and patients with a difficult blood/tissue type match. The best matches are then called for transplant.

### **REMEMBER:**

- It is very important that your transplant centre to have your correct address and phone number on file.
- It is your responsibility to inform your dialysis unit and transplant team of any changes.



# Drug Coverage

Transplant medications are very expensive. Here is the process for you to follow, according to your current situation:

1) **65 years or older:** Transplant medications are covered. You will still pay any fees as per your current situation. No further action required.

2) **Ontario Works or Ontario Disability Support Program (ODSP):** Transplant medications are covered. No further action unless status changes. If status changes, follow up according to status change.

3) **Private drug insurance** (usually through employer). Important questions to ask your insurance provider immediately:

- Does my plan cover 100% drug costs? Is there an annual maximum?
- Are all transplant medications covered? (transplant coordinator will provide you with a list)

If your private insurance does not cover 100% of your transplant medications, **you MUST apply for the Trillium program** (application process described below, under the cash-paying section)

4) **Cash-paying:** You MUST apply for the Trillium program. **Trillium application forms** can be obtained online at <https://www.ontario.ca>, or by calling **1-800-575-5386 (toll-free); or request a form at your pharmacy.**

- Complete and mail application as soon as possible.
- Once the response letter is received, you should:
  - Keep a copy for your records.
  - Bring a copy of the letter to your pharmacy and ensure they are filling prescriptions under your OHIP number towards deductible.
  - Renew the application annually to remain active.

## **Documentation to provide to transplant coordinator (if relevant):**

- Private drug insurance – a letter from your insurance provider confirming coverage of transplant medication
- Trillium drug program response letter



# Now What?

We all benefit from **taking an active role in our own care and now is the time to remain healthy!**

- Be committed to your dialysis schedule, follow your diet and take all medications as your doctor or pharmacist has instructed you.
- If you are a smoker, talk to your family doctor about methods to help you stop. **Smoking cessation is mandatory.**
- Attempt to achieve your ideal body weight. A renal dietitian can help you with a meal plan that can satisfy your dialysis requirements and help you achieve weight loss.
- Keep active as it promotes better health.
- Remain emotionally healthy.
  - Keep in contact with your friends and family
  - Talk about your experience with renal failure
  - If you are feeling symptoms of depression, such as feelings of hopelessness or despair, don't be afraid to let your health team know
    - A renal social worker is available for counseling or your doctor may prescribe medications to help alleviate the symptoms.
    - In conjunction with Grand River Hospital, support is available through the **Kidney Connect Support Group**. This group is created by patients for patients. Ask your renal social worker for details.

Once listed, there are a number of other things you can do to ensure you are **ready for transplant**.

- Plan ahead for things like childcare, work schedules, transportation, etc. If you are called suddenly for a transplant, it helps to have plans in place.
- Prepare a list of medications you are taking. Keep it complete and up to date.



# Contacts & Additional Information

## 1. Grand River Hospital

7A Renal Clinic/Transplant

519-749-4300 x 2189

Guelph Renal Clinic/Transplant

519-749-4300 x 3600

519-822-7664 (Guelph toll free)

### - Social Workers

KW Site

519-749-4300 x 2428

Guelph/Freeport/Palmerston Satellite

519-749-4300 x 2760

### - Transplant Ambassador Program

Transplant Ambassadors

1-833-274-3740

Email: [connect@transplantambassadors.ca](mailto:connect@transplantambassadors.ca)

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

## 2. London Health Sciences Centre

Renal Pre-Transplant Office

519-685-8500

Living Donation Program

519-685-8500 x 33552

339 Windmere Road

London, ON

[www.lhsc.on.ca](http://www.lhsc.on.ca)

## 3. St. Joseph's Healthcare Hamilton

Renal Pre-Transplant Office

905-522-1155

50 Charlton Avenue East

Hamilton, ON

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

## 4. Toronto General Hospital

Renal Pre-Transplant Office

416-340-4800

200 Elizabeth Street, Toronto, ON

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





# Contacts & Additional Information

## 1. The Kidney Foundation of Canada

Ontario Branch

1-800-387-4474

Email: [kidney@kidney.on.ca](mailto:kidney@kidney.on.ca)

[www.kidney.ca/ontario](http://www.kidney.ca/ontario)

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

## 2. Region of Waterloo Public Health

Tuberculosis (TB) Control Program

519-575-4400

99 Regina Street South,

Waterloo, ON

## 3. Trillium Gift of Life

[www.giftoflife.on.ca](http://www.giftoflife.on.ca)

## 4. Ontario Renal Network

[www.renalnetwork.on.ca](http://www.renalnetwork.on.ca)



# Transplant Checklist

Completed	To Do	Date Completed	Notes
<input type="checkbox"/>	I have spoken with a Nephrologist (kidney doctor) about kidney transplant		
<input type="checkbox"/>	I have received a call informing me of my transplant referral		
<input type="checkbox"/>	I have begun my transplant work-up		
<input type="checkbox"/>	I have an appointment for my transplant education session		
<input type="checkbox"/>	I have talked with a TAP Ambassador		
<input type="checkbox"/>	I have met with my transplant coordinator		
<input type="checkbox"/>	I have watched Explore Transplant Ontario		
<input type="checkbox"/>	I have spoken to my family/friends about kidney donation		
<input type="checkbox"/>	I have been informed that my transplant package has been sent to transplant centre for assessment		
<input type="checkbox"/>	I have an appointment at the transplant centre		
<input type="checkbox"/>	I have transportation to the transplant centre		
<input type="checkbox"/>	I have met with the transplant care team		



