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Kidney Transplant Handbook: Beginning your transplant journey

Waterloo Regional Health Network Renal Program

A kidney transplant referral centre

Inside this handbook

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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 3-6 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

This is a short snapshot of the kidney transplant journey. Continue reading this booklet for more information about each step.

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Day one: [Before your transplant](#) – Nephrologist orders transplant referral and work up

Within 3 – 4 months: You will be booked for a [Transplant Education Session](#)

Within 6 – 8 months: Your completed Transplant Package (containing all tests, doctor's notes, and other medical information) is sent to the transplant centre for assessment

At the Kidney Transplant Centre

Within 8 – 10 months: Your first visit at the Kidney Transplant Centre

Timelines vary depending on the patient's needs and type of kidney transplant:

- Additional testing and assessment at the Kidney Transplant Centre, depending on your needs.
- **TRANSPLANT DAY! You get a new kidney!**

Before your transplant

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 Echo cardiogram:** This test checks the function of your heart using sound waves. It is completed in Cardio Respiratory and Electrodiagnostic Services (CRES), 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

WRHN 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.

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.

Explore Transplant Ontario

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://eontario.org/>

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

Learn more:

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

Email: connect@transplantambassadors.ca

Results Sent to Transplant Centre

Your test results are collected by the WRHN 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.

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.

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 Deceased Donor 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:
 - a. Does my plan cover 100% drug costs?
 - b. Is there an annual maximum?
 - c. 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)

Cash Paying: You **MUST** apply for the Trillium program. Trillium application forms can be obtained online at <https://www.ontario.ca>, or by calling 1-811-575-5386 (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 WRHN, support is available through the Kidney Connect Support Group. This group is created by patients for patients. Ask your renal social worker for details

There are a number of other things you can do to ensure you are ready for transplant surgery.

- 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

@WRHN

WRHN Renal Program Transplant Coordinator: 519-749-4300 x 2462

To speak or meet with a WRHN Social Worker: 519-749-4300 x 2428

Transplant Ambassador Program

1-833-274-3740 | connect@transplantambassadors.ca

www.transplantambassadors.ca

Transplant Centres:

London Health Sciences Centre Renal Pre-Transplant Office Living Donation Program

339 Windmere Road London, ON

www.lhsc.on.ca | 519-685-8500 x 33552

St. Joseph's Healthcare Hamilton Renal Pre-Transplant Office

50 Charlton Avenue East Hamilton, ON

www.stjoes.ca | 905-522-1155

Toronto General Hospital Renal Pre-Transplant Office

200 Elizabeth Street, Toronto, ON

www.uhn.ca | 416-340-4800

Other organizations that support kidney patients

Kidney Foundation of Canada - Ontario Branch

www.kidney.ca/ontario

Region of Waterloo Public Health Tuberculosis (TB) Control Program

99 Regina Street South, Waterloo, ON | 519-575-4400

Trillium Gift of Life

www.giftoflife.on.ca

Ontario Renal Network

www.renalnetwork.on.ca

Transplant Checklist

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