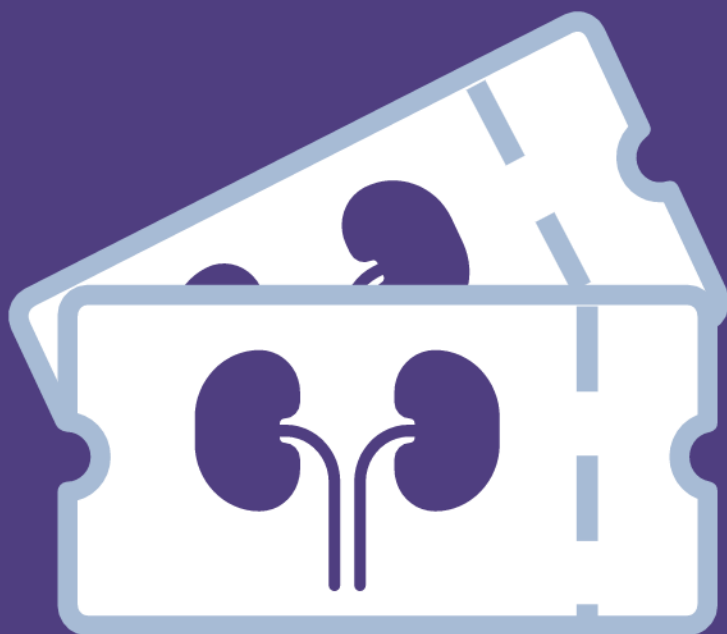




ST. MICHAEL'S
UNITY HEALTH TORONTO

Ticket to Transplant



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**Are you thinking
about having a
kidney transplant?**



A kidney transplant is a surgery that places a kidney from someone else inside your body. It is a great treatment option if your kidneys are failing.

There are many benefits to having a kidney transplant but there are risks too. Most transplants are successful and last for many years, but a transplant does not cure your kidney disease. How long the transplant will last is different for everyone.

What are the benefits of having a kidney transplant?

There are many reasons why some people decide to have a kidney transplant. Some of the most common reasons are:

- Better quality of life
- Being able to live longer
- No longer needing dialysis
- Being free to travel
- Having fewer limits on what you can eat and drink

What are the risks of having a kidney transplant?



There are risks when you have any type of surgery. All surgeries can cause complications like reactions to the anesthesia, infection, and blood clots.

The medicines you must take after your transplant also have risks. These medicines help keep your kidneys safe, but they can also cause harmful side effects like:

- Greater risk of getting cancer
- Infections
- Frail bones
- Diabetes

Every person will react differently to these medicines. If you are concerned about how post-transplant medicines might affect you, please talk to your healthcare team.

What do I have to do to get a transplant?

To decide if it is safe for you to have a transplant, you need to have a “work-up”. During your work-up, you will have a number of tests, procedures and

meetings. If the work-up shows that it is safe for you to have a transplant, your name will go on the transplant list. The process has three main steps:

1. Referral tests with hemodialysis or home dialysis team
2. Work-up with transplant team, including additional testing
3. Waiting for a transplant

What is a deceased donor transplant?

A deceased donor transplant is when a healthy kidney is donated by someone who has died.

What is living donation?

A living donor transplant is when a healthy kidney is donated to you by someone who is still alive. It is a better option than deceased donor because living donation lasts longer and has a shorter wait time. Living donors must also go through a work-up, which can take 6 to 12 months. For more information on living donation, speak to your healthcare team.

What is the transplant list?



The transplant list is called the Deceased Donor List. It is a list of all the patients in Ontario who are waiting for a kidney from someone who has died.

The Ontario transplant list is managed by the Trillium Gift of Life Network (TGLN).

When someone dies and donates their kidney, TGLN's computer system matches kidneys to patients on the list.

Special lists

There are two other specialized lists which **some** eligible patients can be placed on:

- **Extended Criteria Donor List** - This is a list of patients who have agreed to receive a kidney from an older deceased person.
- **Highly Sensitized Registry (HSP)** - This is a list of all Canadian patients who have high cPRA values. The HSP gives patients with a high cPRA a better chance at getting matched since the donors have the same cPRA values. If you have a cPRA value between 95-100%, you are automatically placed on the Highly Sensitized Registry.

How long will I wait for a transplant?



It's important to remember that wait times vary from person to person. Each person's wait time is for a different reason. Generally, your wait time will depend on:

- Your blood type
- Your antibody levels
- How long you have been on dialysis

How does my blood type affect my wait time?



Patients can only receive a kidney from someone with the same blood type. Some blood types have a lot of patients who are waiting for transplants, so the wait time is longer. The chart below gives you an idea of how long people with different blood types usually wait for a kidney.

Your blood type	Your estimated wait time
O	5 to 7 years
A	2 to 5 years
B	6 to 8 years
AB	2 to 5 years



Patients who have a living donor with a blood type that is different than theirs may still be able to get a transplant. For more information, speak to your health care team.

What else could affect my wait time?

Calculated Panel Reactive Antibodies (cPRA) value

When you are listed for a transplant, your blood will be tested to measure your Calculated Panel Reactive Antibodies (cPRA) value. Your cPRA value will be somewhere from 0 to 100 and is written as a percentage. Your cPRA value gives us an idea how hard it will be to find a kidney that will be a good match for you. Your cPRA value can change, so you will be retested every 3 months.

Your cPRA values may increase if you have:

- Been pregnant
- Had blood transfusions
- Had previous transplants

Patients with a cPRA higher than 95% are called **highly sensitized patients**. They have a harder time finding a match and generally wait longer for a kidney. To help sensitized patients find a match, they can be added to another waiting list called the Highly Sensitized Patient (HSP) program. This list increases the potential donors as it considers deceased donors from across Canada.



Wait times are only estimates and are not guaranteed

How does being on dialysis affect my wait time?

The longer you have been on dialysis, the higher up you are placed on the transplant list.

Point system

The Trillium Gift of Life Network (TGLN) uses a **point system** to allocate a kidney to you. The more points you have, the higher your chance of getting a transplant. This is how TGLN calculates your points:

- For every 30 days you have been on dialysis, you get 0.1 points. That means your total number of months on dialysis is multiplied by 0.1
- The cPRA value on your blood test result is divided by 100. This number is then multiplied by 4
- These two sets of numbers are then added together, giving you your allocation points

- Remember that each person has a different cPRA value. Even if another person has been on dialysis for the same amount of time as you, their CPRA value may give them a different number of points.

How much do transplant medicines cost?



After your transplant, you must take transplant medicines every day or your kidney will stop working. The transplant medicines help to prevent your body from rejecting the transplanted kidney.

These medicines are very expensive. The hospital will not pay for your medicines after you go home. Your medicines can cost you anywhere from \$1,200 to \$3,000 each month. The transplant social worker can help you apply for drug coverage.

Make sure you keep your drug coverage active while waiting for a transplant.



You will not be approved for a transplant if you do not have a plan to pay for your medicines

How will my life change after my transplant?

After your transplant, it will take some time to recover from your surgery but most people report feeling better and returning to their normal activities 3 months after the surgery. Other benefits of having a transplant include freedom from dialysis, a less restrictive diet and freedom to travel. However, a transplant does not cure other health conditions.

You will need to come back to the hospital often for follow-up appointments and blood tests. You will also need to take your transplant or anti-rejection medicines for the rest of your life. It is very important to take these medicines to make sure your donated kidney keeps working. If you think you will have trouble taking your medicines, let us know. We can help find a solution.

**Welcome to your
transplant work-up**



We are excited that you have made the decision to get a transplant. We will be here to support you every step of the way! Here are a few things you can expect during your transplant work-up:

Tests and procedures

There are standard tests and procedures that the Trillium Gift of Life Network requires all patients to have as part of the transplant work-up referral. Some include:

- An echocardiogram
- An ECG
- A CT Scan
- An Iliac Doppler
- An ultrasound

These tests and procedures are important. They help your healthcare team understand your overall health. They also help your team find other health problems that might put you at risk during your transplant surgery.



Get the tests done as quickly as you can, as the tests expire in 1 year

Blood tests



Blood tests also very important for the work-up referral. Most of the blood tests can be done during your dialysis session. You do not have to book a separate appointment.

Other appointments



We know you spend a lot of time in the hospital and that it can be hard to come in for other appointments. But, your tests and appointments are very important. It's best to get them done as quickly as possible. You may have a lot of different appointments during your work-up referral, but it will only be for a short time.

We will do our best to make your doctor's appointments on the same days as your dialysis treatments, but this is not always possible. If you are having trouble making it to your appointments, let us know. We are here to help.

What tests and appointments do I need?

Tests

Standard imaging tests	Abdominal ultrasound Chest x-ray CT scan of your abdomen and pelvis ECG Echocardiogram Iliac Dopplers Mammogram (women aged 50-74) Stress test
Tests done by your family doctor	Pap smear (for women who are or have been sexually active)
Standard blood tests	Albumin total Bilirubin Blood typing Calcium Complete Blood Count (CBC) Electrolytes Fecal Immunochemistry Test (FIT) – for people over age 50 HbA1C INR Lipid profile Liver function tests Oral Glucose Tolerance Test (OGTT) Phosphate

	Protein PSA (for men over age 50) PTH PTT Sickle Cell Urea creatinine
Standard blood tests - infectious disease/virology testing	CMV IgG EBV IgG HIV serology HTVLI/HTVLII Hepatitis C Hepatitis B core antibody Hepatitis B surface antigen Hepatitis B surface antibody Measles, mumps, rubella Syphilis Tuberculosis skin test Varicella zoster

Appointment with your social worker

Your social worker will meet with you as part of your work-up. Together you will discuss your income, housing and any support you have from family and friends. This is to make sure you have everything you need after transplant.

What can I expect when I am referred to the Transplant Office?

- **Transplant education class** – This class will cover topics like what to expect during your surgery, life after transplant and drug coverage.
- **Transplant nephrologist** – Your transplant nephrologist is a doctor who will look at all the blood work, tests and procedures you did during your work-up referral. It is their job to decide if you are eligible for a transplant. The nephrologist will also discuss the risks and benefits of transplant with you.
- **Transplant surgeon (urologist)** – Your transplant surgeon, also called a urologist, will look at your tests and talk to you about transplant surgery. Your urologist will also decide if it is safe for you to have transplant surgery.



The transplant nephrologist may refer you to see other specialists or to have more tests

- **Transplant nurse** – Your transplant nurse will help you understand all of your transplant options and guide you through the listing process. They work with your transplant nephrologist and surgeon.
- **Social worker** – The transplant social worker will help with you find resources to help pay for your medicines. They can help you arrange ways to get to your follow-up appointments too. As part of your visit, they will also ask questions to see how you are managing your stress and what your motivation for wanting a transplant is.
- **Pre-anesthesia Assessment and Testing Clinic (PATC) appointment** – This appointment can take up to 4 hours. You will see many health professionals during this time. A nurse will do a physical assessment and blood work, and talk to you about transplant surgery. A pharmacist will discuss your medicines with you. You will also see an anesthesiologist. This is a doctor who specializes in planning and caring for you during your surgery. They will review your test results and decide if the surgery anesthetic is safe for you.



The transplant office will mail you a letter to let you know when you have been listed for transplant. Completing the work-up referral does not mean that you are automatically on the transplant list.

Waiting for your transplant



While we hope that you do not have a long wait for a kidney, sometimes patients are on the transplant list for many years. At times you may feel frustrated, sad or angry. We have a great team of people who are here to help you work through those feelings. Please let us know if you are having trouble coping.

What tests will I need while I'm on the transplant list?

cPRA sample

Once you have been placed on the transplant list, you will need to have a cPRA (Calculated Panel Reactive Antibody) test done every 3 months. This can be done during your dialysis session. If you do not complete this test every three months, your transplant status will be changed from “listed” to “on hold”. For more information, please speak to your nephrologist or nurse practitioner.

Repeat tests

Every year the transplant office will tell you and your dialysis team which tests and procedures you need to repeat to keep your file up-to-date. This may include blood tests and other tests and procedures that you may have done during your work-up.

Staying healthy while waiting for a transplant

It is important that you stay healthy while waiting for your transplant. Below are a few tips for maintaining your health:

- Exercise every day
- Eat healthy foods
- Take your medicines as prescribed
- Manage your stress
- Ask for help if you have anxiety and/or depression



If you have any questions or are having trouble staying healthy, please ask us! We are here for you and want you to be happy, healthy and informed!

Your status may change from “listed” to “on hold”

If your health changes while you are waiting for a kidney, you may be placed **on hold**. You could be placed on hold if you have had:

- A hospital admission
- A major change to your health – for example, a heart attack or stroke
- An existing health problem that has gotten worse
- An infection
- An open wound or broken bone
- Your cPRA test was done more than 3 months ago



You will **not** be called for transplant while you are on hold but you will still gain points. Your transplant nephrologist will decide when to change your status back to “listed”.

Things to keep in mind

The process of completing a transplant referral is different for everyone. Try not to compare your path to others and stay positive! Here are a few things to keep in mind:

- Some people may need certain tests that others don't. Ask your medical team if there's anything you don't understand.
- Someone's wait time for a kidney will be different than yours. Try not to let it upset you. Please ask your medical team to explain reasons for your wait time.
- It's normal to discuss your experiences with your peers. However, information can sometimes get twisted and become incorrect. If you are concerned about something you've heard about transplant, please talk to your medical team.

We are here to help support you during this process. Let us know if you have any questions or concerns. We are proud that you've made it this far. Well done!

Glossary of tests



Below is a list of tests you may have done as part of your work-up referral.

Imaging

Test	Definition	Why it's needed
Abdominal ultrasound	Imaging of the stomach	To check the health of your organs in your abdomen
Stress test (cardiac perfusion testing, exercise ECG or MIBI)	Shows how heart works during physical activity	To check for heart disease
Chest x-ray	Imaging of the lungs	To check for lung disease
CT scan of your abdomen and pelvis	Imaging of the abdomen and pelvis	To check blood vessels where kidney will be attached
ECG	Measures the heart rhythm	To check the heart rhythm
Echocardiogram	Ultrasound of the heart	To check heart structure
Iliac Doppler	Checks blood vessels	To check blood vessels where kidney will be attached

Lab tests

Test	Definition	Why it's needed
Albumin	Blood protein	Routine screening
Bilirubin	Liver function test	Routine screening
Blood typing (group & screen)	This is your blood type	Routine screening
Calcium	Electrolyte in the blood	Routine screening
Complete Blood Count (CBC)	Overview of components of the blood (red/white blood cells, platelets, etc.)	Routine screening
Creatinine	Kidney function test	Routine screening
Electrolytes (Lytes)	Sodium, potassium and bicarbonate levels in the blood	Routine screening
Fecal Immuno-chemistry Test (FIT)	Check for blood in stool	Routine cancer screening
HbA1C	Average amount of "sugar" (glucose) attached to the hemoglobin in past 3 months	Routine screening

Test	Definition	Why it's needed
INR	Measures how long the blood takes to clot	Routine screening
Lipid profile	Cholesterol and fat in the blood	Routine screening
Liver function tests	Liver enzymes	Routine screening
Oral Glucose Tolerance Test (OGTT)	Measures sugar level in the blood	For diabetes screening
Phosphorus	Electrolyte in the blood	Routine screening
PSA	Protein Specific Antigen	For prostate cancer screening
PTH	Parathyroid Hormone level	Routine screening
PTT	Measures how long it takes for the blood to clot	Routine screening
Sickle cell	Abnormally shaped red blood cells	Screen for sickle cell trait
Total protein	Total protein level in blood	Routine screening
Urea	Waste product excreted by the kidneys	Routine screening

Infectious disease and virology

Test	Definition	Why it's needed
CMV IgG	Cytomegalovirus	Check immune status
EBV IgG	Epstein Barr virus	Check immune status
Hepatitis B core antibody	Test for past or current hepatitis B infection	Check immune status
Hepatitis B surface antibody	Test measures immunity to hepatitis B	Check immune status
Hepatitis B surface antigen	Test measures previous or current hepatitis B infection	Check immune status
Hepatitis C	Test for hepatitis C infection	Check immune status
HIV serology	Test for HIV infection	Check immune status
HTVL1 / HTVL2	Test for Human T-Lymphotropic Virus	Check immune status
MMR	Measles, Mumps, Rubella	Check immune status
Syphilis	Sexually Transmitted Infection (STI)	Check immune status

Test	Definition	Why it's needed
TB skin test	Tests if you have ever been exposed to TB	Check immune status
VZV antibody	Test for immunity to varicella zoster	Check immune status

My test and appointment checklist

Test	Date completed	Notes
Abdominal Ultrasound		
ABO		
Chest X-Ray		
CMV IgG		
CT Scan		
ECG		
Echo		
EBV IgG		
Fecal Immunochemistry Test (FIT)		
Hepatitis B Core Antibody (HBcAb)		
Hepatitis B Surface Antibody (HBsAb)		

Test	Date completed	Notes
Hepatitis B Surface Antigen (HBsAg)		
Hepatitis C antibody		
HIV serology		
HTLV1 & HTLV2		
Iliac Doppler		
Mammogram (if applicable)		
Measles, Mumps, Rubella		
Oral Glucose Tolerance Test (if applicable)		
Pap Smear (if applicable)		
PSA		
Sickle cell screening (if applicable)		
Stress Test		

Test	Date completed	Notes
Syphilis		
Tuberculosis skin test		
Varicella zoster		

Consultations	Date completed	Notes
Social work assessment		

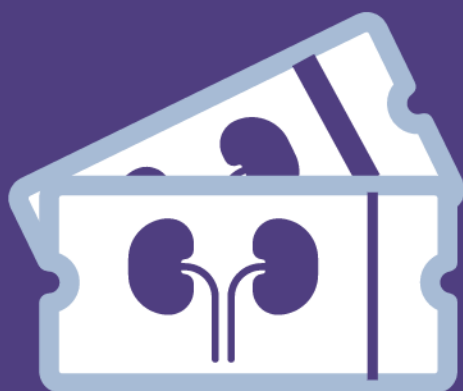
My transplant referral team

Team member	Name	Phone
Nephrologist		
Nurse practitioner		
Social worker		
Transplant admin coordinator		

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Unity Health Toronto cares about your health. For health information you can trust, visit us online at **unityhealth.to/learn**.

This information does not replace the advice you receive from your health care provider. If you have questions, ask your health care team.



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