

Heart Transplant Recipient and Caregiver Manual Book 1

Before the Surgery: The Heart Transplant Wait List



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Welcome from our Heart Transplant Recipients

Dear patient and family,

As fellow heart transplant recipients we'd like to welcome you to the Toronto General Hospital Heart Transplant Manual. We understand how incredibly overwhelming this experience is so, we wrote this heart transplant manual to reflect real lived experience.

There are many ups and downs and everyone's transplant experience is different. But we share our experience because it can help to hear from those who have been through it.

Throughout the manual you will find quotes from patients and caregivers that look like this. These were our experiences during and after the transplant. They reflect our individual transplant journey!

We encourage you and your caregivers to read through this manual and watch the suggested video links. Take your time and ask your transplant team questions along the way.

We want you to feel comfortable and know that you are surrounded by support through your transplant journey. Please take care of yourself.

Sincerely,

Kim, Suzy, and Kelly

Main Contact Information

Pre-Transplant Office (before transplant)

Location: 11th Floor, Peter Munk Building

Mailing address:

The Heart Transplant Assessment Program
Toronto General Hospital - UHN
585 University Ave
11 PMB- 136/ G-20
Toronto, ON M5G 2N2
416 340 4800 extension 6195 or extension 8495
Hours: Monday-Friday 8:00am - 4:00pm

Post-Transplant Office (after transplant)

Mailing Address:

Heart Transplant Program
Toronto General Hospital
12 PMB
585 University Avenue
Toronto Ontario M5G 2N2
Location: 12th Floor
Phone (EasyCall): 416 351 0793
Hours: Monday-Friday 8:00am - 4:00pm

Follow-up Care

Transplant Clinic

Clinic Hours: Wednesday Afternoon and Thursday Morning.

Clinic Location: 12th Floor, Munk Building, Toronto General Hospital. (Take the MUNK elevators).

Clinic Phone: Easy Call: 416 351 0793

Reception: 416 340 4800 extension 4113

About the Heart Transplant Program at UHN

What is the Heart Transplant Program?

The Heart Transplant program at University Health Network (UHN) is a team of health professionals who take care of patients before, during and after a heart transplant.

Who is a part of the Heart Transplant team?

The UHN Heart Transplant team are world leaders in transplant and transplant research. We do 30 to 40 heart transplants each year. We do approximately 1 in every 6 heart transplants that happen in Canada each year.

Some people on your transplant team include:

Health Care Provider	Role Description	My Provider's Name/Contact Is:
Caregiver & family support team	Your caregiver and family are important members of the transplant team. You must have a support person or caregiver helping you throughout the transplant process. This is a person or a group of people who supports you and cares for you at home, at appointments, and in the hospital. They help coordinate your care before and after your transplant. They can be family members or friends.	
Heart Function Cardiologist (before the transplant)	The heart function cardiologist is the doctor who diagnoses and treat heart disease, specifically heart failure. The heart function cardiologist provides cares for you throughout the entire pre-transplant process.	
Heart Function Team	The heart function team are the health professionals that help provide the care you need before the transplant.	

Health Care Provider	Role Description	My Provider's Name/Contact Is:
Transplant Team (after the transplant)	At UHN we provide post-transplant care using a team model. The post-transplant team is made up of all of our transplant cardiologists, nurses and other transplant providers. Your heart function cardiologist is a part of this team.	
Surgeon	The heart transplant surgeon helps to evaluate if a heart transplant is the right treatment and safe for you. The surgeon performs the transplant operation and manages your post-operative recovery with your transplant team. They manage any problems related to the surgery during your recovery.	
Transplant assessment coordinator	The transplant assessment coordinator is a registered nurse or nurse practitioner who teaches you about the transplant while you prepare for it. They coordinate the tests you need to determine if a heart transplant is safe for you. They keep track of your health while you are on the transplant wait list and are your main contact before the transplant surgery.	
Transplant coordinator	The transplant coordinator is a registered nurse or nurse practitioner that coordinates your care after your transplant. They are your main contact after transplant. They communicate information between you and other clinicians, and find answers to your questions. Your transplant coordinator makes sure you have the care you need and are managing your health to stay well.	
Multi-organ transplant coordinator	The multi-organ transplant coordinator is the person who calls you when a donor heart becomes available.	

Health Care Provider	Role Description	My Provider's Name/Contact Is:
Transplant administrator	The transplant administrator coordinates all of your pre- and post-transplant appointments. They will share any health care concerns you have with the transplant coordinator.	
Social worker	The social worker meets with all transplant patients and their families. They discuss your family supports and financial situation, provide support and counselling, and help you make arrangements with other agencies before and after your transplant.	
Psychosocial support psychiatry	A psychiatrist or psychosocial nurse may see you during your transplant evaluation. They help patients and their families cope before and after a heart transplant. They may suggest strategies to help you during this stressful time.	
Pharmacist	Pharmacists help you learn about the medications you take and how to take them after transplant. The Multi Organ Transplant Program has its own transplant pharmacy called Transplant Outpatient Pharmacy (TOP). They are located on the 12 th floor Peter Munk Wing. You may choose to have all of your medications managed through TOP. They can also give you your medication in blister packs to help you keep your medications organized.	
Family physician	All patients need a family physician. They are necessary to help you with any health issues you have that are not related to the heart transplant. Make a follow-up appointment with your family physician within 3 months after you go home from having a heart transplant. Your transplant team keeps your family physician informed about your care during the transplant process.	

Health Care Provider	Role Description	My Provider's Name/Contact Is:
Palliative care medicine	Palliative Care improves the quality of life for patients with life-threatening illness and their families. The Palliative Care team works with you, your family physician and your transplant team to ensure you are comfortable, and to provide physical, emotional and spiritual support.	
Transplant infectious disease medicine	All patients considering a heart transplant must see a transplant infectious disease specialist. They will review your vaccine history. Your vaccines should be up to date before the transplant. Vaccines protect your body from getting certain infections. The transplant infectious disease doctor may also check your immunity to certain infections with a blood test.	

Working Together at UHN

UHN values patient-centered care. Working with patients and their caregivers leads to the best possible health outcomes. We invite you to participate in care decisions and tell us about your needs.

The Multi-Organ Transplant Program philosophy

- Our work is possible because of the generosity of organ donors. We must honour these remarkable gifts from donors and their families.
- Respect, dignity, integrity and empathy guide care and support relationships. We expect courtesy and consideration in every interaction.
- The goal of the Multi-Organ Transplant Program is to work in partnership with patients, families and the community so patients at all stages of the transplant have the best health and quality of life possible.
- All members of the health care team contribute important and valuable information to the plan of care. Each member of the team is a dedicated professional who has knowledge and experience in organ transplantation.
- People achieve their best health by working with the health care team. All people are unique, with their own needs, goals and abilities.
- Information and education provide patients with knowledge to exercise their rights and responsibilities to make informed decisions about their health care.
- The best possible care is based on patient needs, available resources, and ethical principles.
- All services must be provided in a safe environment that supports the patient's health goals and ensures care is delivered with comfort and efficiency.

Emotional (Psychosocial) Support

Whether you are beginning your transplant journey, or you are currently living with a transplant, it is important to remember that recovery is a lifelong journey. The Transplant Psychosocial team at UHN is made up of psychiatrists, social workers, mental health nurses and psychiatric nurse practitioners. The team supports patients who are being assessed or waiting for or recovering from a transplant.

This journey can be difficult for patients and their caregivers. The team can help support caregivers by finding local supports to help caregivers of transplant patients.

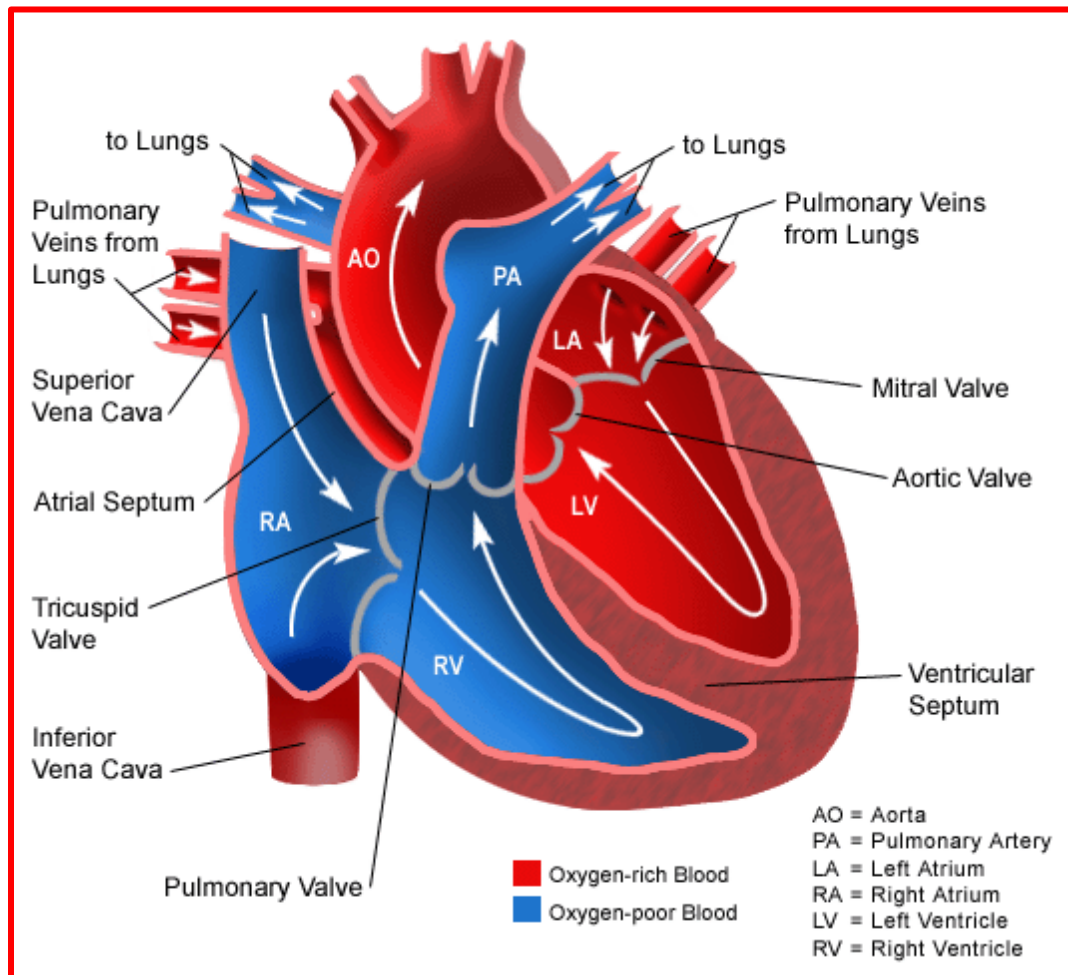
The Transplant Psychosocial team have developed resources to help you through this journey. Read the "Coping with a Transplant" brochure for resources:

https://www.uhn.ca/PatientsFamilies/Health_Information/Health_Topics/Documents/Coping_with_a_Transplant.pdf

Speak with your transplant coordinator if you need different or more support.

How the Heart Works

Parts of the heart



- The heart consists of 4 chambers:
 - 2 upper chambers ("atrium")
 - 2 lower chambers ("ventricle")
- A muscular wall ("septum") divides the heart into right and left sides.

- The right side is made up of the right atrium and the right ventricle.
- The left side is made up of the left atrium and the left ventricle.
- 4 valves control how blood flows through the chambers of the heart.
- 2 large veins come into the right atrium. The veins bring blood into the heart.
 - The “superior vena cava” brings blood from the upper body.
 - The “inferior vena cava” brings blood from the lower body.
- An artery called the “pulmonary artery” connects the right ventricle to the lungs.
- A vein called the “pulmonary vein” connects the lungs to the left atrium.
- The left ventricle is connected to a large artery called the “aorta”.

How does the heart work?

The heart pumps blood around your body. Your blood carries oxygen your body needs to stay healthy.

1. Blood from the body comes into the right atrium through the superior vena cava and inferior vena cava. The blood coming into the heart carries more carbon dioxide than oxygen.
2. The blood moves from the right atrium through a valve and into the right ventricle.
3. The blood goes from the right ventricle, through the pulmonary arteries and to the lungs.
4. The blood picks up the oxygen you breathe into your lungs and leaves the carbon dioxide for your lungs to breathe out. The blood is now “oxygen rich”.
5. The oxygen rich blood leaves the lungs through the pulmonary veins and goes into the left atrium.
6. The oxygen rich blood moves from the left atrium through a valve and into the left ventricle.

7. The left ventricle pumps the oxygen rich blood through your aorta and to all your parts of your body.

The heart repeats this cycle approximately 60 to 80 times per minute. This is what you know as your heart beat.

What is Heart Failure?

Heart failure happens when the heart is no longer able to pump enough oxygen-rich blood to meet the body's needs.

What causes heart failure?

Common causes of heart failure include:

- coronary artery disease (the arteries that bring oxygen rich blood to the heart are partly blocked)
- heart attacks (the arteries that bring oxygen rich blood to the heart are fully blocked)
- heart defects at birth
- hereditary (passed from parent to child) conditions
- high blood pressure
- infections
- side effects of medication
- history of alcohol use
- pregnancy
- sleep apnea
- diabetes

What is advanced heart failure?

Patients with advanced heart failure keep having the symptoms of heart failure even after taking the highest dose of heart failure medication and getting an implantable device such as a pacemaker or defibrillator.

What are the symptoms of advanced heart failure?

Patients with advanced heart failure may experience some of the symptoms below, even when they are taking their medications:

- shortness of breath (feeling like you can't get enough air)
- fatigue (feeling tired)
- swelling of the feet, ankles, legs or other body parts
- pain
- nausea and change in appetite
- confusion (having trouble understanding what's happening)
- anxiety or depression
- more shocks from the defibrillator than usual
- many hospitalizations related to heart failure
- serious problems with the kidneys or liver

Although every case is a bit different, having advanced heart failure usually means having a shorter life expectancy (not living as long based on statistics).

How is advanced heart failure treated?

Some patients may be eligible for life-saving treatments such as a heart transplant or mechanical circulatory support devices. This would include mechanical heart pumps, such as the Left Ventricular Assist Device or LVAD.

To see if you are eligible to have a heart transplant, you need to have a heart transplant assessment.

An Overview of Heart Transplant at UHN

What is a heart transplant?

A heart transplant is a surgical procedure that removes a failing heart and replaces it with a healthier donor heart.

Watch this online video about the transplant process. It explains what happens during the transplant, what to expect when recovering in hospital, and the life changes you'll make when you go home. <http://pie.med.utoronto.ca/PatientTeaching/projects/heart-transplantation-a-treatment-for-heart-failure/>

Why does my doctor think I may need a heart transplant?

Getting a heart transplant can save, lengthen or improve the quality of life (general wellbeing) of patients with advanced heart failure.

When is the right time to consider a heart transplant?

It's not always easy to know when it is the 'right time' to think about heart transplant.

- You need to consider getting a heart transplant before you are too sick to handle the surgery and recovery.
- Your symptoms must be strong and serious enough that they cannot be managed with a less intensive treatment.

If you are considering a heart transplant:

Your transplant assessment coordinator starts a complete check of your health, called a "Heart Transplant Assessment" (Step 1). Your transplant team uses the results of your heart transplant assessment to determine if a heart transplant is the right treatment for you.

Before the transplant

Many things need to happen before you have a heart transplant (pre-transplant process). The pre-transplant process follows 5 steps that are explained in the next sections of this manual.

Step 1: The Heart Transplant Assessment	Page 19
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Step 1: The Heart Transplant Assessment

What is a heart transplant assessment?

You have tests and meetings (consultations) with our team to see if heart transplant is safe and right for you. We want to be sure your body and organs are healthy enough for the surgery.

How long does the heart transplant assessment take?

The heart transplant assessment can take weeks or months.

Important: Tell your pre-transplant cardiologist or the transplant assessment coordinator if you get sicker during your heart transplant assessment. You may need to stay in the hospital.

What tests do I need to do?

You have many tests to check your health. We give you an appointment schedule and tell you how to prepare for each test.

Blood Tests

We take blood to check your kidney and liver function, check for viruses (including HIV and hepatitis), and find out your blood group and tissue typing to determine if you have specific antibodies in your blood.

How do I get my blood and test results?

We will call you if we have any concerns about your blood or diagnostic test results.

You can view the results of your blood and test results on myUHN Patient Portal. myUHN Patient Portal is a secure website to see your UHN appointments and results. You can access your personal health records anywhere, anytime, on a computer, smartphone or tablet.

Find more information and sign up for myUHN at <https://www.uhn.ca/PatientsFamilies/myUHN>.

Note: Not all of your appointments appear in myUHN. Please keep a record of all appointments you are told about when using EasyCall.

Leave a message on EasyCall if you have any questions or concerns about your tests. Your transplant coordinator will call you back.

ECG (Electrocardiogram)

This test shows the pattern of electrical activity in your heart. Small adhesive (sticky) tabs with wires are placed on your chest and legs for a short time to record the electrical pattern. This test does not cause any discomfort.

Cardiopulmonary Study (Cardiopulmonary Stress Test)

This test involves both pulmonary function (how well your lungs work) tests and exercising on a bike or a treadmill while you wear electrocardiogram (ECG) wires. The results show how your heart and lungs respond to exercise.

RHC (Right Heart Catheterization)

The right heart catheterization estimates pressures in the heart chambers and lungs. A catheter is inserted into your heart through the groin or neck to check the pressures in all parts of your heart chambers.

It is extremely important to measure the pressures in the lungs. If the pressure in the lungs is abnormally high, it may increase your risk to your health if you were to have a transplant, or it may prevent you from having a transplant at that time.

LHC (Left Heart Catheterization)

The left heart catheterization shows if you have any coronary artery disease. It may be requested if you have not done one in the past couple of years. It is done similar to the RHC but with the help of an x-ray equipment. A dye is injected to show how well the blood flows through your coronary arteries.

Echocardiogram

An echocardiogram uses sound waves to record the position and motion of your heart walls and the internal structures of the heart, such as your heart valves.

Doppler Ultrasounds of the Carotid and Femoral Arteries

A Doppler ultrasound checks how the blood is flowing into your head and into your legs and feet through your arteries. We do this test to check for a buildup of calcium (called calcification) or cholesterol that cause narrowing of the arteries in your neck (carotid artery) or your legs (femoral artery).

If you have narrowing of your arteries, also called atherosclerosis, you are at risk for stroke or other complications during and after your transplant surgery. Atherosclerosis may prevent you from being eligible to have a heart transplant.

Abdominal Ultrasound

An abdominal ultrasound gives us a picture of the major abdominal organs.

Pulmonary Function Test

This test shows how well your lungs are working. During this test, you breathe through a mouthpiece that is connected to an instrument called a spirometer.

Chest CT Scan

This test uses a special x-ray equipment to take detailed pictures of the organs and tissues of the chest including the blood vessels.

Other Tests

You may need other tests such as:

- a PAP test
- a colonoscopy
- a Prostate Specific Antigen (PSA) blood test
- a mammogram

For patients with diabetes:

You need to do these extra tests:

- **Ophthalmology Consult:** to check the eyes for any damage from diabetes
- **24-hour Urine Test:** to check kidney function
- **Hemoglobin A1C:** to check blood sugar control

What consultations do I need to have?

You meet with different health care providers who assess your health. For example, you may meet with:

- social worker
- surgery (heart surgeon)
- transplant assessment coordinator
- psychiatry, if needed
- dentist for a dental assessment
- palliative care medicine
- infectious disease medicine

You may meet more health care providers based on your current health and heart transplant assessment results. Your transplant assessment coordinator tells you when you need these meetings.

Dental assessment

Your oral health is very important for your heart health. You must see a dentist for an assessment before your transplant surgery. We recommend you see your dentist regularly.

Transplant Infectious Disease Specialist and Pre-Transplant Vaccines consultation

Vaccines protect your body from getting certain infections.

Your vaccines should be up to date before the transplant. The most common vaccines are:

- measles
- varicella (chicken pox)
- diphtheria
- pertussis
- pneumonia
- hepatitis A
- tetanus
- annual influenza (“the flu”) vaccine
- hepatitis B
- shingles

The infectious disease specialist or your heart transplant team may recommend other vaccines or extra doses of certain vaccines. The infectious disease specialist may check your immunity against infectious diseases with a blood test.

It is important to update your vaccines before your heart transplant because:

1. Patients with heart failure are at a high risk for getting very sick if they get the flu pneumonia.
2. In rare cases, viruses such as hepatitis B can be passed on through blood transfusions or by transplanted organs. Patients who have been vaccinated against hepatitis B are less likely to get hepatitis B.
3. You take immunosuppressive medications after your heart transplant. These medications make it harder for your body to protect itself from infections.

4. The immunosuppressive medications you take after transplant can make it harder for vaccines to work well. Getting the vaccines before your transplant gives the vaccines their best chance to protect you.
5. Live virus vaccines can cause infections if you get them after your heart transplant. You should be up to date on your vaccines before your heart transplant surgery.

Step 2: Heart Transplant Case Conference

When your heart transplant assessment is done, your case is presented to the transplant team. The transplant cardiologists, surgeons, social workers and nurses review the results of your assessment to decide if it is safe for you to have a heart transplant.

What is a case conference?

The transplant team reviews all the results of your heart transplant assessment (Step 1). They meet to decide if:

- a heart transplant is the best option for you, or if another treatment option may be better.
- you are too healthy or too sick for a heart transplant.
- you have a condition that makes it unsafe for you to have a heart transplant.
- you have a social habit or addiction that needs to be managed or stopped, such as smoking, drinking alcohol, or using drugs.
- you can handle the stress of waiting for a donor heart and recovering from surgery.
- you have the social support you need to help you before and after a heart transplant.
- you are ready and willing to follow the steps required after a heart transplant. Steps required after a heart transplant can include having tests and appointments frequently and taking many medications.

What happens after the case conference?

If we think transplant is the best treatment for you: we tell you that you are a candidate for transplant. You decide if you want to have a transplant and we put your name on the heart transplant wait list.

If the risk of transplant is too high: we offer to arrange a second opinion. We tell you about other treatment options and continue to treat your heart failure with medications until the heart stops and death occurs.

Step 3: Deciding to Have a Heart Transplant

Making a decision to have a heart transplant can be very stressful and emotional for you and your caregivers. We are here to support you. Please let your transplant assessment coordinator know if there is anything you need during the transplant process. We have mental health counseling as well as psychiatric support to offer you at any time.

Please speak to your doctor or transplant assessment coordinator for more information or if you have questions. We want to make sure you have all the information you need when deciding to have a heart transplant.

“Making an informed decision for me was about information gathering. I asked as many questions to my cardiologist as I could think of. I kept a running list of questions in between appointments. I also had the opportunity to speak with other heart transplant recipients.”

What are the survival rates?

For every 100 patients who have a heart transplant:

- 95 survive the surgery and go home.
- 88 live for 1 year or more after the surgery.
- 81 live for 5 years or more after the surgery.
- 70 live for 10 years or more after the surgery.

How much can having a heart transplant extend my life?

It is different for everyone. The average life expectancy for patients after heart transplant is about 10 to 15 years.

What are the benefits of having a heart transplant?

Having a heart transplant is an effective treatment for most people with advanced heart failure. It can:

- save or lengthen your life
- improve your symptoms
- improve your quality of life (your general well-being)
- improve your overall health

Having a heart transplant is a treatment for heart failure. It is not a cure. Getting a heart transplant means making permanent changes to your life, such as changing what you eat and your habits, coming to the hospital for regular clinic appointments and taking medication every day.

What are the risks?

There are risks you need to think about before deciding to have a transplant.

- Your body may reject the organ (your immune system attacks your new heart).
- You need to take medication for the rest of your life to prevent rejection. These medications may have side effects.
- You get heart biopsies on a regular basis. These biopsies help us see if your body is rejecting the donor heart.
- You have appointments at the transplant clinic for the rest of your life.
- Having a heart transplant puts you at risk for other health issues such as:
 - infections
 - cancer
 - kidney failure
 - osteoporosis
 - diabetes

- coronary artery disease
- hypertension

During your assessment we will discuss the risks that are specific to you. You can read more about these risks in the *After the Surgery: Living with a Transplanted Heart* manual (book 3).

What are the side effects?

Side effects of a heart transplant may include:

- infection
- stroke
- diabetes
- kidney or liver failure
- rejection (your body rejects the new organ)
- side effects of transplant medications
- cancer

How long will I wait on the transplant list?

It is too hard to predict your wait time because there are many factors involved. You may wait less than a day or you may wait over a year. Your position on the list depends on how serious your condition is and it can change over time.

Learn more about the heart transplant wait list in Step 4 and what happens when you get a heart offer in Step 5.

Am I guaranteed to get a heart transplant if I'm on the transplant wait list?

There is no guarantee that a suitable donor will be found for you. Some patients do not survive long enough for a suitable transplant to become available.

Step 4: Waiting for a Heart Transplant Donor Heart

Who manages the heart transplant wait list?

Trillium Gift of Life Network (TGLN) is an Ontario government program that manages organ donations in Ontario. TGLN arranges the organ donation and determines which patient on the wait list will get offered the organ based on their listing status and time on the wait list.

About organ donors

Organ donors are people who have recently died from a severe injury, such as a car accident, trauma, bleeding in the brain or drug overdose. The family decides to donate the person's organs after the person has been declared "brain dead".

How is the heart transplant wait list managed?

The wait list is organized by current health condition ("status"). Your status can change as you wait for transplant.

Your heart transplant status is considered when the TGLN is allocating donor organs. The table below gives you a summary of statuses and related health conditions. These statuses are reviewed and updated every year by the Canadian Cardiac Transplant Network, a group of transplant specialists, to ensure that they reflect how seriously ill a transplant recipient is.

Status	Health Condition
0	On hold
1	At home

2	In hospital or at home on inotropes (potent intravenous heart medication)
3.0	LVAD (mechanical heart pump), staying in Cardiac Care Unit (CCU) or cardiology floor and on inotropes
3.5	Staying in CCU and on inotropes or Staying on cardiology floor but not an LVAD candidate
4	On life support or intra-aortic balloon pump
4s	Highly sensitized, PRA >80% (high antibody counts)

Important: You or your caregiver must tell us if you are admitted to another hospital so we can update your status on the heart transplant wait list.

What does my care look like while I’m on the wait list?

You visit your heart failure cardiologist and the heart function team every 4 to 8 weeks. We do regular tests such as blood work, echocardiogram and electrocardiogram to monitor your health. The team decides if you need changes to your medications and what routine tests you need to have during your visit.

It is important that you do not miss your appointments.

Tell the heart function team about any changes to your health, such as:

- if you have a cold, flu, fever or other infections
- if you received blood transfusions
- if you have been admitted to the hospital
- increasing signs and symptoms of heart failure:

- changes in your weight
- decrease in your activity level
- increased shortness of breath
- swelling in your ankles and legs
- peeing less

“My life while waiting for transplant continued as usual. My daily routines remained the same and I continued to follow my current treatment and diet. Emotionally I was fine. I was born with congenital heart disease and for many years I have been aware that my heart would most likely fail. I understood that a heart transplant was the only option, and I accepted it.”

How long will I wait for a donor heart?

How long you wait depends on:

- your blood group
- your body size
- your medical status
- organ availability

Your wait could be as little as a few hours to more than a year. As the number of patients requiring transplant increases, so does the wait time.

What if I get sicker while I'm waiting?

We may be able to offer a mechanical heart pump called a left ventricular assist device (LVAD) to improve your health while you wait for a donor heart.

Here is a video link about the LVAD:

<http://pie.med.utoronto.ca/PatientTeaching/projects/left-ventricular-assist-devices/>

Although uncommon, you may no longer be eligible for a transplant if you become too sick while waiting. We tell you when there are changes to your transplant status. If transplant is no longer the best possible treatment for you, we meet with you and your family to discuss other options.

What are my responsibilities while I wait?

Be ready to come to Toronto General Hospital at any time

You could receive a heart transplant offer at any time when you are on the wait list. The transplant must happen as soon as possible when a donor heart is available.

You need to be available and within 4 hours driving distance from Toronto General Hospital at all times. If you are too far away or unavailable when you get an offer we may need to offer the heart to the next suitable patient.

Plan ahead for your surgery

It is difficult to think clearly when you get a heart transplant offer. You will feel excitement and fear. Plan ahead so you are prepared when you get the call.

- Who will take you to the hospital?
- How you will get to the hospital?
- What do you need to bring to hospital?
- Who do you need to notify?
- What are your goals and wishes?

Make sure we have up-to-date contact information at all times

Tell us right away if your phone number or address changes.

Follow the medical recommendations we give you

Stay as healthy as possible to have the best chances of having a successful transplant. Follow all of the medical recommendations we and your other health care providers give you. Tell the transplant assessment coordinator if you:

- are not feeling well
- have a cold, flu or fever
- have a sore throat or diarrhea
- had surgery or blood transfusions in the last month
- have an infection or are taking antibiotics

These situations may change the risk of getting a heart transplant.

Avoid travelling

You cannot leave the country, go to remote areas or travel long distances if you are on the wait list. We cannot wait for you to arrive if a heart donor becomes available and you are too far from the hospital. The heart will be offered to the next person on the wait list.

Tell your transplant team about your travel plans and dates if you must travel while you are on the waitlist. If you are on vacation and more than 4 hours away from Toronto you are put on hold on the heart transplant wait list during this time.

Talk to your transplant assessment coordinator about your travel plans if you have any questions.

Take care of your emotional and mental needs

The wait time can be stressful for you and your family. Patients and families describe waiting for a transplant as putting their lives on hold. These are natural feelings. Talk about your feelings with your partner, a friend or a health care worker. The social worker or your transplant assessment coordinator can also help you cope with these feelings.

Arrange your Powers of Attorney

Powers of Attorney are legal documents where you choose a person or organization to make decisions for you when you are unable to make them yourself. The person or organization you choose is called “substitute decision maker”.

Important: Powers of Attorney are powerful documents. They affect your care and finances. Get legal advice to set up your Power of Attorneys.

There are 2 basic types of Powers of Attorney:

1. the Power of Attorney for Personal Care names a substitute decision maker for your personal and medical care.
2. the Power of Attorney for Finances names a substitute decision maker for your money and finances.

The law states who your substitute decision maker is if you do not have Powers of Attorney documents. In order of priority, your substitute decision maker is your:

1. spouse
2. adult children
3. parents
4. siblings
5. extended family members
6. a public official if there is no one to make decisions for you

Some patients have a substitute decision maker for health care who is different from the substitute decision maker for personal care. For example, they may choose to name an adult child rather than their spouse. If you would like your substitute decision maker for health care decisions to be different from your substitute decision maker for personal care, make sure it is clearly stated in your Power of Attorney document.

You and the social worker talk about Powers of Attorney and substitute decision makers during your heart transplant assessment.

Give a copy of your Power of Attorney document to:

- the transplant assessment coordinator. They will put a copy in your electronic medical record.
- the nurse in the CICU (Cardiac Intensive Care Unit) when you are admitted for your transplant.

You can find more information about Powers of Attorney in Ontario online:

<https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>

Advance Care Planning

Advance Care Planning helps you think about the care and treatments you want or don't want. Advance Care Planning helps make it clear to your substitute decision maker and health care team what medical treatment and care you would and wouldn't want.

Talk to your substitute decision makers or write out instructions about your preferences, values and wishes. It is important your substitute decision makers know your preferences, values and wishes so they feel they are making the decisions you want.

Ask your care team for a copy of the "Speak Up" Advance Care Planning booklet or visit the Peter & Melanie Munk Patient & Family Learning Centre & Library on the 1st floor of the Norman Urquhart Building to get a copy. You can also find the guide online:

www.myspeakupplan.ca.

For patients who live outside of Toronto:

We recommend staying in or near Toronto so you can get to the hospital within 4 hours of getting a call for the transplant. The heart may be offered to the next person on the transplant wait list if you cannot get to the hospital in time. You keep the same place on the wait list.

Important: You do not need to relocate to Toronto if you live a long distance from Toronto General Hospital. Your transplant assessment coordinator and social worker will talk with you about your options if you decide to stay at home while you wait.

Research studies

We may ask you to participate in research studies. You do not need to participate. You can choose not to participate and it will not affect your care.

Step 5: When a Donor Heart Becomes Available

What happens when a donor heart is available?

The organ donor is tested to make sure the organs are suitable for transplant. These tests include blood tests, virus tests (such as HIV, hepatitis B and hepatitis C), x-rays and ultrasounds of the organs.

The organs are offered to patients on the transplant wait list after the tests are done. A specialized team of surgeons carefully remove the donor organs and send them to the transplant hospitals.

How does TGLN decide who gets offered a donor heart?

TGLN uses a matching system to determine which patient on the wait list will get offered a donor heart. TGLN uses specific factors to make sure the decision is fair and equal (equitable), such as:

- if the donor heart is a good match for the recipient
- how long the recipient been on the wait list

How does the TGLN decide if the donor heart is a good match?

TGLN checks the donor heart against the recipient's information to make sure it is a good match.

- ✓ The donor heart must not have heart disease.
- ✓ The donor heart must not be injured.
- ✓ The donor and recipient must have a similar body size (height and weight).
- ✓ The donor must have a blood type that the recipient can receive.

- ✓ Sometimes the donor's lifestyle, behaviours or travel history are also considered. They may put some recipients at a higher risk for complications after the transplant.

Understanding blood types

People are identified as blood type A, B, AB, or type O.

- Type O is the most common blood type.
- Type A is the second most common blood type.
- Only a small percentage of the population have type B or type AB blood.

The table below shows who can give you a heart based on the blood type:

A person with this blood type	can receive a heart from a donor with blood type	can donate to a person with blood type
O	O	O, A, B, AB
A	A, O	A, AB
B	B, O	B, AB
AB	O, A, B, AB	AB

What happens when I get a heart offer?

The multi-organ transplant coordinator calls you. If you do not answer the phone, they leave a message with a return phone number. The message asks you to call them back. **If we do not hear from you in 1 hour we must offer the heart to the next suitable patient.**

You must tell the multi-organ transplant coordinator if you:

- are not feeling well

- have a cold, flu or fever
- have a sore throat or diarrhea
- had surgery or blood transfusions in the last month
- have an infection or are taking antibiotics

These situations may change your risk when getting a transplant. The multi-organ transplant coordinator discusses your situation with the transplant team to decide if it is safe to go forward with the transplant.

“I received the call at 10:05pm on a Friday, only 9 days after being listed. I was shocked! I wasn’t expecting the call so soon. I was asked how I was feeling and if I had a cold or flu. I was told not to eat or drink anything and then advised to go directly to emergency at Toronto General Hospital where they would be expecting me. I told my husband that I just got the call. He said “what call?” I said “THE CALL!” He was equally surprised, as were my parents and sister. I then changed into yoga pants and a sweatshirt, packed a small bag and we were on our way. While in the car I made a few other calls to family and friends. Upon arrival in emergency I was calm yet at times quietly anxious. My memory from this point is a little hazy. I vaguely remember getting an x-ray in emergency, then going to admitting, then upstairs to CCU. The experience was surreal.”

“I received the call at 4:30pm on a Tuesday. I was driving and just pulling into my Mom's driveway and was unable to answer my phone. I had my 7 yr old niece in the car with me and quickly got her out of the car and raced indoors so I could get to my messages. The transplant office had already called my backup person, my sister. By the time I got in the door my phone was ringing again and my mom was on the phone with my sister. They knew before I did. We told my niece what was happening and she started cheering, clapping, and jumping up and down. She was very excited that I was getting a new heart. What a way to lighten a situation. I was on the list for 2 years, 4 months and 8 days. I got to the hospital by 5:30pm and was in surgery by 10:00pm. Those 4 1/2 hours were so full of meeting doctors, surgeons, nurses, procedures, and letting loved ones know. It went by very quickly.”

What do I do when I get the call?

When you get the call:

- ✓ **Do not** eat or drink anything. It is important for your safety that you have an empty stomach for the surgery.
- ✓ Notify your designated driver and come to the hospital right away. **Do not** drive yourself.
- ✓ Bring all your medications with you.
- ✓ Bring all of your personal items for your hospital stay.

What should I bring to the hospital?

Bring only what you need. You need:

1. this manual
2. your OHIP, extended medical benefits and drug card (if you have one)

3. a small overnight bag with your toiletry items such as soap, shampoo, comb or brush, toothbrush, lip and skin moisturizer (The air in the hospital is very dry)
4. a book, magazine or other things to help you pass the time

Do not bring:

- any valuables such as rings, watches, jewelry. You must take them off before your surgery.
- large amounts of cash.
- any large electrical equipment that needs to be stored after you are moved into the operating room.

Where do I go when I arrive?

Go to the admitting department on the Ground floor, Eaton Wing at Toronto General Hospital. Tell them you have been called in for a heart transplant. They complete the required paperwork and tell you how to get to the Coronary Intensive Care Unit (CICU).

If the admitting department is closed go to the Emergency Room and tell them you have been called in for a heart transplant.

What to expect when you arrive

When you are admitted to the CICU:

- We put a heart monitor on you.
- We check your heart rate and blood pressure when you arrive and every 2 to 4 hours while you wait.
- Your nurse gives you medications.
- We put intravenous lines (IV) to a vein in your arm. We use the IV line to do blood tests and give you some medications before surgery.
- You have a chest x-ray.

- We check how much your heart pumps and the blood pressure in your heart and lungs, called a “right heart catheterization” test.
- The transplant surgeon, anesthesiologist and transplant cardiologist speak with you.
- We ask you to shower with a special soap. We may also shave your chest.

How long you wait in the CICU before your surgery depends on what tests we need to do on you and your donor. You go to the operating room when the tests are complete and we are ready to start the surgery.

False alarms

The donor heart goes through many tests before it gets to the transplant hospital. The transplant surgery team looks at the heart to make sure the heart is in good condition. Sometimes the heart does not pass this final check and the transplant surgery is cancelled, called a “false alarm”.

If your transplant surgery is cancelled, you stay on the heart transplant list in the same position. You do not lose time on the list.

It is normal to feel shock, disappointment and sadness. Talk to your transplant assessment coordinator or transplant team if you or your family are having difficulty coping with the false alarm. They refer you to someone on the transplant team who can help you deal with your feelings.