Heart Transplant Recipient and Caregiver Manual Book 3

After the Surgery: Living with a Transplanted Heart

UHN Soham & Shaila Ajmera Family Transplant Centre

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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 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

Phone: 416 340 4800 extension 6195 or extension 8495

Hours: Monday to Friday, 8:00am to 4:00pm

Mailing address:
The Heart Transplant Assessment Program
Toronto General Hospital - UHN
585 University Avenue
11 PMB- 136/ G-20
Toronto, ON M5G 2N2

Post-Transplant Office (after transplant)

Location: 12th Floor

Phone: EasyCall 416 351 0793

Hours: Monday to Friday, 8:00am to 4:00pm

Mailing address:
Heart Transplant Program
Toronto General Hospital - UHN
12 PMB 100
585 University Avenue
Toronto, ON M5G 2N2

Transplant Clinic

Location: 12th Floor, Munk Building, Toronto General Hospital (take the Munk elevators)

Phone:
Easy Call: 416 351 0793
Reception: 416 340 4800 extension 4113

Hours: Wednesday afternoon and Thursday morning

When to get medical help

If you…	What to do
• feel chest pain • suddenly find it very difficult to breathe • have excessive bleeding from the surgical wound or bleeding that does not stop • cannot take your immunosuppressive medications for more than 1 day because you are vomiting (throwing up) or have diarrhea (loose, watery poo) for a few hours or days • suddenly feel confused, have changes to your ability to think and be aware of what's around you, or have trouble staying awake when you are rested • faint or pass out • have a fast or irregular heart beat	**These are signs of an emergency.** Call 911 or go to your nearest Emergency Department right away. Use EasyCall to leave a message for your transplant coordinator.
• have a fever over 38 °C (100.4 °F), with or without chills • have a sore throat • suddenly feel very bad back pain you haven't felt before • feel pain or a burning sensation when you pee • get a new rash • cough up mucus that is brown, yellow or green • feel sinus pain (pain around the eyes), with or without coughing up green or yellow mucus • see fluid around your surgery wound • have a fast or irregular heart beat	**These are signs you need urgent medical care.** Call your transplant coordinator and see your primary care provider as soon as possible.

If you…	What to do
• have the symptoms of the flu, such as sudden aches, pains and increased tiredness • see redness or swelling or have pain around your surgery wound • have a fever between 37.5 °C and 38 °C (99.5 °F and 100.4 °F) • have constipation (difficulty going poo) or diarrhea (loose, watery poo)	Use EasyCall to contact your transplant coordinator the next working day.
• get any medical care from a health care provider not at UHN, including from another Emergency Department	Use EasyCall to leave a message for your transplant coordinator.

If you go to an Emergency Department

If you go to the Toronto General or Toronto Western Emergency Departments: You do not need to bring us a copy of the discharge summary from UHN. The information will be in your electronic medical record. You can also get this information from the myUHN Patient Portal if you need it when you see your primary care provider or another medical professional.

If you go to a different Emergency Department: Ask for a copy of your discharge summary when you leave. Bring it to clinic with you so we can review the information.

Follow-up Care

Follow-up test and visits

The schedule for follow-up tests and visits changes over time.

- At the beginning there are lots of follow-up tests and visits. The tests are to check on the function of your new heart and monitor for any signs of organ rejection.
- There are a lot of clinic visits during the first year of your transplant. These visits are important to monitor your heart health and to ensure you do not have rejection or other complications. Try not to cancel them.
- The heart transplant team decides how often you visit the Clinic after the first year based on the results of your heart biopsies and tests.
- If at any time the tests show signs of organ rejection, you will have tests more often until those signs go away.

Time after surgery	**What tests and visits you have**
Month 1 (the first month after your transplant)	• a biopsy every 1 week • a clinic visit every 1 week • an Echo every 2 weeks • 1 chest x-ray and ECG • 1 chest CT scan • fasting blood work: glucose, electrolytes, liver enzymes, CK, CBC, drug levels, cholesterol profile, HbA1C • bloodwork with biopsies as needed
Month 2	• a biopsy every 2 weeks • a clinic visit every 2 weeks • an Echo every 2 weeks • 1 chest CT scan • bloodwork with biopsies as needed

Time after surgery	**What tests and visits you have**
Month 3	• 1 biopsy • 1 clinic visit • 1 Echo • 1 chest x-ray and ECG • 1 chest CT scan • fasting blood work: glucose, electrolytes, liver enzymes, CK, CBC, drug levels, cholesterol profile, HbA1C • bloodwork with biopsies as needed
Month 4	• 1 biopsy • bloodwork with biopsies as needed
Month 5	• 1 biopsy • bloodwork with biopsies as needed
Month 6	• 1 biopsy • 1 clinic visit • 1 Echo • 1 chest x ray and ECG • fasting blood work: glucose, electrolytes, liver enzymes, CK, CBC, drug levels, cholesterol profile, HbA1C • bloodwork with biopsies as needed
Month 7	• 1 biopsy • 1 chest x-ray and ECG • bloodwork
Month 8	• 1 biopsy • bloodwork
Month 9	• 1 Echo • 1 chest x-ray and ECG • fasting blood work: glucose, electrolytes, liver enzymes, CK, CBC, drug levels, cholesterol profile, HbA1C

Time after surgery	**What tests and visits you have**
Month 10	• 1 biopsy • bloodwork
Month 11	• fasting blood work: glucose, electrolytes, liver enzymes, CK, CBC, drug levels, cholesterol profile, HbA1C
Month 12 (1 year after transplant)	• 1 biopsy • 1 clinic visit • 1 Echo • 1 stress echo • 1 chest x-ray and ECG • 1 chest CT scan • 1 angiogram • bloodwork
After 1 year	• fasting bloodwork every 3 months • an Echo every 6 months • a clinic visit every 6 to 12 months • a stress Echo every 1 year • a chest x-ray and ECG every 1 year • an angiogram at year 5 and year 10 after the transplant • biopsy as needed • bloodwork as needed • chest CT scan as needed

> “The UHN is very accommodating when scheduling appointments. Although it can be difficult to schedule all appointments on the same day, it is important to inform your transplant coordinator of your schedule and personal preference so they can be taken into consideration. Sometimes appointments can creep up unexpectedly, so I recommend keeping a schedule of your appointments or frequently checking your myUHN account. If you have any questions regarding your appointments whether it is scheduling, times, or reason for appointment, please do not hesitate to reach out to your transplant coordinator in order to get the details and answers.”

What to expect during your clinic visit

The Heart transplant clinic is located at Toronto General Hospital, Peter Munk Building 12th floor.

1. When you arrive, check in at the reception desk of the transplant clinic.
2. You go for bloodwork before your clinic visit. There is a blood lab on the 12th floor.
3. A member of the clinical team brings you to a clinic room.

Your clinic visit may be delayed depending on the volume and complexity of patients we are seeing that day. Let the reception desk know if you have more appointments scheduled on the same day as your clinic visit.

> "My biggest piece of advice is to make the most of your appointments! At appointments, do not be scared to ask questions if you are unsure of any results or information that was given. If comfortable, engage in conversation with your health care providers! This really helps in building a trusting, therapeutic relationship and can make the appointments more enjoyable for you and your health care providers!"

What to bring to your Clinic Visit

- Your OHIP card.
- A list of all medications you are taking. This includes prescription medications, over-the-counter medications, vitamin or mineral supplements and herbal remedies.
- A list of all of your prescriptions that require refills.
- Bring any medications you normally take during the day. Appointments can take several hours.
- A record of your daily weight, temperature and blood pressure.
- Any notes about changes in your condition that you've noticed since your last visit. Share these with your transplant team.

- Bring a list of questions to your appointment to help you remember everything you want to ask.
- A family member or friend. They can give you emotional support and can help you make good choices. They can also help you gather information, take notes and ask questions.
- Bring any forms you need us to fill out for work, disability benefits or insurance.

Insurance Forms

Insurance forms require information from both your transplant coordinator and your transplant physician. It may take up to 30 days to complete these forms. Please make sure that you have completed your portion of the documents. You must also sign the consent form, which allows your transplant team to give out the requested medical information about you.

> “Although UHN staff try their best to keep appointments running on time, sometimes wait times can be long and the experience can be tedious and boring. To ensure that you are kept entertained during your wait, I recommend bringing your phone or any other device that you can use while you wait. It may also be helpful to bring any work or homework that you have catching up to do. With keeping this in mind, beware that sometimes the hospital Wi-Fi can go in and out so if you have mobile data or hotspot, then this may be useful!”

"In between appointments I kept a running list of questions or concerns that had come up since my last visit. I couldn't always remember all my questions during my appointment so it was always helpful to have. My visit to the Transplant Clinic were often filled with new information and that notebook was my recording device during my visits as well."

"Bringing a list of questions to your clinic appointments is very useful. Once your concerns are addressed at clinic, you'll have a better understanding of your recovery process. I usually start my list a few days ahead of time as questions or concerns come to mind. There will be a lot of information to retain during your clinic visits, especially in the beginning, so take notes and ask a family member or friend to join you.

You will have many questions post-transplant about how you are feeling; don't shy away from asking. Some of my questions and concerns were about: fatigue and weakness, medication doses and side effects, rejection and infection, over the counter medication, activities and diet. As time goes on your questions change and the number of questions will decrease.

While at clinic, pick up any medication refills at the Transplant Outpatient Pharmacy. You can call the TOP in advance and they will have it ready for you when you get to clinic. Occasionally you'll have other tests booked on the same day so may want to bring water, snacks and a book."

Transferring from SickKids

Some of our transplant patients make the transition from having appointments at SickKids to UHN. They have a unique set of challenges. Here is what one of our patients has to say:

> “The transition from SickKids can be difficult. As appointments and treatments may be done differently, it may be hard to adjust to these new changes. As you transition across the street to TGH, it’s okay to feel nervous, overwhelmed, and emotional. These feelings are normal and are nothing to be ashamed of! During this transition it is important to talk to your new health care team about your emotions regarding the transition. Be sure to ask about how the policies and procedures regarding appointments and treatments differ from those at SickKids and ask questions on any information you are unsure of or confused about. Most importantly, strive to make therapeutic, trusting relationships with your new health care team. They are there to not only care for you but are there to support you and your family during this time. These relationships will help to make both you and your family more comfortable surrounding your transition and will help to ease some emotions. The transition across the street can be difficult and emotional, but always remember that you are surrounded by a health care team that truly cares for you and will support you and your family throughout your transition, and transplant journey.”

Organ rejection

What is organ rejection?

Organ rejection happens when your immune system recognizes the donor heart came from someone else and tries to get it out of your body.

Organ rejection is common after having an organ transplant. Most heart transplant patients experience organ rejection 1 or more times.

Important: Experiencing organ rejection does **not** mean that you will lose your heart or that it will be permanently damaged.

It is important to treat organ rejection as soon as possible. Know the signs of organ rejection and tell your transplant team right away if you notice them.

What are the signs of organ rejection?

Your transplant team checks you for signs of organ rejection and teaches you what to look for while you are in the hospital. You need to watch for these signs when you leave the hospital.

Some signs of organ rejection are:

- fever of 37.5°C (99.5 °F) or more
- fatigue
- finding it difficult to breathe
- sudden weight gain
- getting tired faster or more easily from your regular activities

Tell your transplant team right away if you have any of these signs of organ rejection. They will give you instructions on what to do next. Sometimes these signs may be caused by another condition.

Important: Sometimes you may not have any of these signs when experiencing organ rejection. This is why it is important to notice and make notes about your fatigue and what activities you can normally do.

How is organ rejection treated?

We may treat organ rejection by giving you more IV medication or adjusting your current immunosuppressive medications.

You will need more frequent biopsies to check if the treatment is working. This means having heart biopsies more often than the usual schedule.

Heart biopsy

What is a heart (cardiac) biopsy?

A heart biopsy (cardiac biopsy) is a test to diagnose organ rejection. The doctor takes tiny pieces of tissue from the heart using a catheter that is inserted into a blood vessel in your neck. They examine the tissue to test how healthy it is. The results tell your transplant team if your medications need to be changed or adjusted.

How often do I have a heart biopsy?

You have a heart biopsy:

- before you go home from hospital
- 1 time each week for 2 to 3 months after your transplant

You have heart biopsies more often if you have signs of organ rejection. Your transplant team will decide on your schedule.

What happens during a biopsy?

1. You go to the Catheterization Lab at the Toronto General Hospital.
2. We give you local anesthetic (freezing) to the catheter site. The procedure takes about 30 minutes.
3. The doctor doing the test puts a biopsy instrument (called a bioptome) through a small incision in the skin on the right side of your neck and into the large vein (jugular vein). If they cannot get the jugular vein, the doctor will use the large vein in your groin (femoral vein).
4. The doctor uses fluoroscopy (a special x-ray) to move the bioptome through your vein into the right ventricle of your heart.
5. Your doctor takes 4 or 5 small pieces of tissue from your heart and sends them to the lab. The pathologist examines the tissue under a microscope to look for signs of organ rejection in the cells.
6. After the procedure, you rest for about 30 minutes.

7. We send you home when your blood pressure is normal and there are no signs of bleeding.

When do I get my biopsy results?

Your biopsy results are available the same week. We will call you if there is a problem or if you need to change your medications.

Are there alternatives to having a heart biopsy?

If it is difficult to do regular heart biopsies, we may recommend you have AlloMap tests instead starting 1 year after your transplant. Your transplant coordinator will talk to you about having AlloMap tests if it is a good option for your care.

The AlloMap test uses a blood sample to rule out cellular rejection (signs of organ rejection from the cells in your body). We measure how much of a specific gene is in your blood using a scale from 0 to 40. Higher numbers may indicate cellular rejection. You need a heart biopsy to confirm organ rejection if the AlloMap sore is above 34. a certain number.

Ongoing health monitoring after the transplant

After the transplant you are at risk for other health conditions such as:

- cancer
- osteoporosis
- diabetes
- coronary artery vasculopathy (CAV)
- high blood pressure (hypertension)
- high cholesterol
- kidney failure

Cancer

What is cancer?

Cancer is the uncontrolled growth of abnormal cells in the body. Cancer develops when the body's normal control mechanisms stop working.

What causes it?

After heart transplant you have a greater risk of getting certain cancers because of the immunosuppressive medication you have to take. These cancers are:

- **lymphoma or post transplant lymphoproliferative disease (PTLD)**. Lymphoma is a type of cancer that affects white blood cells. It is sometimes related to the Epstein Barr Virus. Lymphoma may occur at any time after your transplant but is most common during the first 2 to 3 years after the transplant. It is sometimes associated with the use of immunosuppressive medications. The treatment may involve chemotherapy or reducing your immunosuppressive medications.
- **skin cancer.** The most common skin cancers after having an organ transplant are squamous cell and basal cell carcinoma. These lesions (wounds) usually begin to appear 3 to 5 years after the transplant. Check your skin and tell your primary care provider if you see a mole or mark that looks unusual. Protect your skin when you are outside to reduce your risk of skin cancer. Wear a hat, use a sunscreen with a sun protection factor (SPF) of 30 or higher and avoid the sun between 11:00 a.m. and 3:00 p.m.

- **If you had cancer before having a heart transplant** (such as breast or prostate cancer), you may be at risk for getting this cancer again after your transplant.

How is it monitored?

It is important to detect cancers as early as possible.

- Pay attention to and look for changes in your bodies that could suggest a problem.
- Follow Ontario's cancer screening guidelines and get screened when it is time.

Osteoporosis

What is osteoporosis?

Osteoporosis is a disease that weakens the structure and strength of bones. This may increase your risk of fractures (broken bones).

What causes it?

Your age, heredity and having gone through menopause make you more likely to develop osteoporosis. You have a higher risk of developing osteoporosis because you take prednisone (a common immunosuppressive drug) after the heart transplant.

How do I prevent it?

Decrease your risk of developing osteoporosis by:

- doing weight bearing exercise such as walking
- eating food that contains calcium every day.
    - Your doctor or dietician may recommend you take calcium pills and vitamin D supplements. **Do not** start taking these supplements before speaking with your doctor.

Your transplant team will choose the most appropriate therapy for you. Your doctor may prescribe medication if exercise and supplements are not effective.

How is it monitored?

A special X-ray called a bone density DEXA scan detects osteoporosis. Ask your primary care provider to set up routine bone density scans.

We refer you to a specialist for therapy if the bone density scan shows weakness in your bones.

You may get a bone density scan before your transplant so we can see changes in your bone density over time.

Diabetes

What is diabetes?

Diabetes is a condition where blood sugar levels are higher than normal. Your body controls your blood sugar by releasing a hormone called insulin. Your cells use the insulin to absorb sugar from the blood. Blood sugar levels rise either because:

- the pancreas cannot produce enough insulin

or

- the insulin is not able to work effectively

When you have diabetes your blood vessels are more likely to collect plaque and become narrow. This affects the small blood vessels in the body, most commonly in the kidney, heart, eyes, fingers and toes. People with diabetes have a higher risk of developing kidney and heart problems. It is important to follow your treatment plan and control your blood sugar levels to reduce the risk of developing complications. Many patients fear diabetes because of these complications, but know that diabetes is manageable.

What causes it?

Some transplant patients have diabetes before their transplant. Some patients may develop diabetes after the transplant because of the immunosuppressive medications they take, such as Prednisone and Prograf (Tacrolimus).

You are more likely to develop diabetes after having a heart transplant if:

- your blood sugar has been high before
- you have family members who have diabetes

How is it treated?

Diabetes can be a temporary condition that improves with medication or it may be an ongoing condition that needs regular treatment.

The treatment you get depends on how serious it is.

- If your blood sugar is a little high, you may be able to manage it by controlling what you eat or taking pills to help your body manage.
- If your blood sugar is higher, you may have to manage it by using insulin therapy and controlling what you eat.

If needed, we may refer you to a diabetes specialist when you leave the hospital after your transplant.

Coronary Artery Vasculopathy (CAV)

What is coronary artery vasculopathy?

Having a heart transplant is a treatment. It does not cure heart failure. Arteries of the new heart may start to narrow (a condition called atherosclerosis) after some time. This is called transplant coronary artery disease or coronary artery vasculopathy (CAV).

CAV is different from the artery disease you may have had before the transplant

How do I prevent it?

Follow a healthy heart diet that is low in sodium. Do not add salt to your food. We recommend following the Canadian Guidelines for Heart Healthy Eating.

Other strategies that can help prevent CAV include maintaining a healthy weight, doing regular exercise, and quitting/reducing cigarettes.

How is it monitored?

We do regular angiograms and stress tests to check if you are developing CAV.

How is it treated?

If we find signs of CAV we may:

- adjust your medications
- perform an angioplasty (use a thin, flexible tube and balloon to open a blocked artery)
- recommend other medical treatment

High blood pressure (hypertension)

What is high blood pressure?

High blood pressure develops when your heart pumps more often and your arteries get narrower. It makes blood push harder against the walls of your arteries. It develops over time.

High blood pressure is a very common complication after having a heart transplant.

What causes it?

Changes in your blood pressure can be caused by:

- some medications that can strain your kidneys.
- eating extra salt. Eating extra salt causes your body to keep extra water and that may increase your blood pressure.
- some immunosuppressive medications you may be taking after the transplant, such as Cyclosporine, Tacrolimus and Prednisone
- individual factors such as your age and family history

How do I prevent it?

You can help control your blood pressure naturally by keeping track of your weight, avoiding salty foods and by exercising.

How is it monitored?

Check your blood pressure once per day. Your blood pressure gives us information about how hard your heart is pumping and how much work it takes to push the blood through your blood vessels.

We may ask you to keep track of your blood pressure when you go home. Ask us for information on getting a blood pressure monitor at home. Tell us if your blood pressure is >130/75 or <100/70.

We may have asked you to start checking your blood pressure before your transplant surgery. Our goal is to have you in the best possible condition before your surgery so that you have a speedy recovery.

How is it treated?

It is important to treat high blood pressure with blood pressure medication to get it within a normal range. If left untreated, high blood pressure can damage your heart, kidneys and the blood vessels in your brain.

Blood pressure medication may have side effects. Your transplant team will adjust and change the dose or medication to find the right treatment for you. Tell your transplant doctor if you have side effects from your blood pressure medication. **Do not** stop or change your blood pressure medication on your own.

High cholesterol

What is high cholesterol?

Cholesterol is a fat-like substance produced by the body and stored in the blood. Having high levels of cholesterol increase your risk of CAV because the cholesterol can block your arteries.

What causes it?

Some people develop high cholesterol levels after having the transplant. Some people who had high cholesterol before transplant find their cholesterol gets higher after having the transplant.

High cholesterol may be caused by taking Prednisone, Cyclosporine, Tacrolimus or Sirolimus. It can also be caused by hereditary conditions (a condition passed on from parent to child), what you eat and other medical conditions such as diabetes.

How do I prevent it?

You are prescribed cholesterol-lowering medication after the heart transplant to prevent problems related to high cholesterol.

How is it monitored?

Your cholesterol levels are monitored after transplant. You will have your cholesterol checked every 3-4 months.

How is it treated?

You have an appointment with the dietitian if we find high levels of cholesterol in your blood. The dietitian reviews the foods you eat to see what may be causing your high cholesterol levels.

We may also prescribe medication to help lower your cholesterol or refer you to an endocrinologist to help you manage your cholesterol.

Kidney Failure

What is kidney failure?

Kidney failure happens when your kidneys no longer filter waste from your blood as well as they should.

What causes it?

There are some people who develop issues with their kidney function before or after their heart transplant. It may be related to your health before the transplant, the medications you take before or after surgery, the surgery or the recovery after your heart transplant.

How do I prevent it?

We help prevent kidney failure by regularly checking your kidney function and adjusting your medications when needed.

How is it monitored?

We will watch you closely for signs of kidney failure, such as:

- decrease in urine output
- swelling in your legs, ankles, or feet
- shortness of breath
- fatigue and weakness
- confusion

How is it treated?

Kidney failure is treated with dialysis, a procedure that filters waste and extra water from your blood. You may need dialysis at some point during the transplant process.

Kidney failure can be a temporary condition that improves with treatment, or it can be an ongoing condition that needs regular treatment.

If you have signs of kidney failure we share your treatment plan with you and your caregivers.

Returning to Usual Activities

Most heart transplant patients can eventually return to a normal life that includes work, sports, social and sexual activities. How long it takes for you will depend on how you are recovering, your level of pain and how your sternum is healing. Try to do a little more activity each day and follow your transplant team recommendations. It usually takes about 1 year for heart transplant patients to fully recover.

Return to Work or School

> "Everyone's recovery is so different. I returned to work full time 2 years after transplant. That's when I was ready."

How long will I be off work or school?

Expect to be off work or school for 1 year after having your transplant. This gives you time to recover from your surgery and adjust to your transplant.

It is important to wait at least 6 months after the transplant before returning to work or school. During these 6 months:

- you are at high risk for organ rejection or getting an infection
- you have many hospital appointments that would mean a lot of time away from work or school

What happens when I'm ready to return to work or school?

Your transplant doctor checks your health before you can go back to work or school. We consider:

- how active and physical your work or school is
- how stressful your work or school is
- if your workplace or school can adapt to your needs or limits

- how work or school will affect your rehab schedule

When your transplant doctor says it is safe to do so, speak with the Human Resources Department at your work/school and ask them for a return-to-work/school plan. We will need to review and approve the plan before you return to work or school.

Returning to work if you are on disability benefits

Be sure you are physically and mentally ready to return to work if you are on disability benefits. Your disability benefits may stop when you return to work. It may take weeks to reapply and restart your benefits if you decide to go back on disability benefits.

> When I began my post-secondary education, the transplant team was very supportive of my decision and made it very clear that whatever post-secondary option I choose to pursue was possible. They made a very strong effort to ensure that my transplant and medical status had little to no impact on my post-secondary education."

What do I eat?

Follow Canada's Food Guide (https://food-guide.canada.ca) for what to eat after your transplant.

- Eat plenty of fresh fruits and vegetables.
- Eat protein foods.
- Drink water most often.
- Eat whole grain foods.
- Continue to follow a lower sodium diet (less than 2 grams of sodium each day).

Return to Driving

Talk to the transplant team when you feel strong enough to drive again. Most patients can start to drive 8 to 12 weeks after the transplant.

- Do not drive if you feel tired, have dizzy spells, headaches or visual disturbances such as blurred vision, double vision or vision loss.
- Always wear your seatbelt when you are driving or riding in a vehicle. Put a towel under the seatbelt strap if the seatbelt is uncomfortable against your surgery wound.
- If your license was taken away before having the transplant and you would like to get it back, contact the Ministry of Transportation to get the required forms. Bring these forms to your transplant team and ask them to fill them out.

Return to Sex

When will my interest in sex come back?

Many patients lose interest in sex before their transplant because they feel unwell. Your interest in sex should return to what's normal for you after you recover from the transplant.

When can I have sex again?

You can have sex when your surgery wound and chest bone are fully healed. This may take 3 months after your surgery.

When you have fully healed and you feel ready to have sex:

- start slow and use positions that are comfortable for you.
- ask your transplant coordinator how to protect yourself from sexually transmitted infections. You are at greater risk for getting a sexually transmitted infection because you are taking immunosuppressive medication.

How can I protect myself from sexually transmitted infections?

You may get sexually transmitted infections from having sexual contact with another person. To protect yourself from sexually transmitted infections:

- **get vaccines** that protect you from HPV and hepatitis B.

- **use condoms or dental dams** during vaginal, oral or anal sex.
- **get tested** if you or a partner may have a sexually transmitted infection.
- **limit how many sex partners you have.** Your risk of infection is higher if you have more partners.

Talk to your transplant coordinator or transplant team if you have any questions about sex or sexually transmitted infections

Return to Exercise and Sports

What do I need to know before I exercise or play sports?

Your body will react differently to exercise after having a heart transplant.. There are many nerve connections to the central nervous system. These nerves control you heart rate. During you transplant, these nerves are cut. Over time these nerves may grow back. We call this denervation. Denervation of your heart is not harmful to your heart transplant. Denervation results in:

1. A faster heart rate. Your resting heart rate will likely be around 90-110 beats per minute.
1. When you exercise it will be important for you to increase and decrease your heart rate at a slower rate. You will need to warm up and cool down when you are exercising.

How can I exercise safely?

- Do long and progressing warm up activities before exercising. Your transplanted heart needs more time to react to exercise.
- Do cool down activities for at least 10 minutes after exercising. Slowly walk or stretch until you heart rate returns to your resting level.
- Start exercising after the transplant by following the walking program below.
- Exercise at your own pace. Do not push yourself too hard.
- Slowly increase your daily activity over time. Work up to 30 minutes of exercise each day.
- Exercise indoors when the weather is extremely hot or cold.

- You can safely exercise by walking around a mall or working out in a public gym.

It takes time to build your exercise tolerance. In time you will be able to exercise at an appropriate level.

How to warm up

Start your warm up with gentle stretches. You should not feel any pain.

Hold stretches for 10 to 15 seconds. Repeat each stretch 3 to 5 times on each side. Some stretches you may want to try include:

- neck side bend
- shoulder shrugs
- ankle pumps
- hamstring stretches
- calf stretches
- marching on the spot

Then start your exercise with 10 minutes of slow walking before you begin more intense activity.

How to cool down

Walk slowly and do more stretches for 10 minutes after your exercise or until your heart rate returns to normal. The cool down helps keep your blood circulating while your heart slows down.

Stretching after exercise also helps lengthen the muscles and prevent stiffness.

Walking Program

Walking is the most important activity you can do during the day.

Start with frequent short walks and work up to longer and less frequent walks. For example, you may start with taking 5 minute walks 6 times each day and gradually work up to taking 15 minute walks 3 times each day.

1. Always warm up before and cool down after a walk. This should include slow walking and stretching.

2. Start by taking many short walks throughout the day. For example, take 5 minute walks 6 to 9 times each day.
3. Walk at a slow and relaxed pace. You are going too fast if you feel out of breath or that you are pushing yourself.
4. Try to increase your total walking time by 1 minute each day. If you find this too difficult, increase your total walking time by 1 minute every 2 to 3 days.
5. Take fewer walks as you increase the number of minutes of each walk. For example, take 7 minute walks 5 times a day.
6. Keep walking at a slow and relaxed pace until you can easily walk for 15 minutes. Then increase your pace so you feel mild to moderate effort on your walks.
7. You should be able to have a simple conversation as you exercise. Your exercise is too intense if you are having trouble talking

When to stop exercising

Stop exercising and do a cool down if you have:

- pain on the surgery wound
- trouble catching your breath (excessive shortness of breath)
- dizziness or lightheadedness
- palpitations (heart beating fast or irregular)
- excessive fatigue
- nausea (feeling like you might vomit)

Tell your transplant team if you have these symptoms when exercising. Tell your transplant team if your exercise tolerance is getting worse (less able to exercise).

Cardiac Rehabilitation Program

We refer most transplant patients to a cardiac rehabilitation program about 3 months after the transplant. The timing for your cardiac rehabilitation program referral depends on your healing.

Cardiac rehabilitation programs are supervised exercise programs that help you rebuild your strength and stamina. The program will also provide information on health and fitness. We try to refer you to a cardiac rehabilitation program near your home.

Travel

Stay close to home and avoid travelling for 1 year after your transplant. **Do not** leave the country for 1 year after your transplant.

- You have many clinic visits and tests in the first year after having a transplant.
- You are recovering from surgery.

Tips when planning a trip:

- Share your travel plans with your transplant team.
- Before travelling, ask your transplant coordinator for a **travel letter** that lists:
  - a record of your medication
  - your most recent laboratory results
  - emergency contact phone numbers
- **Travel Letters:** Call your transplant coordinator 2 weeks before travelling to request a letter. You may leave a message on EasyCall.
- Always carry your medication with you. Never check your medication with your luggage.
- Bring extra medication with you in case you are delayed returning home. Depending on the length of the trip and your destination, you may want to bring a few extra days or weeks.
- Be prepared to return home at any time if you become ill.
- If you are travelling by car, stop every 2 hours to stand up and stretch your legs.

If you are travelling outside of Canada:

- Talk to your transplant coordinator or primary care provider before planning a trip outside of Canada. Depending on your destination, you may need vaccines several weeks before your trip. You can get vaccines from a travel clinic.
- Buy travel insurance that includes:

- out-of-country health insurance in case you need medical care while on your trip
- airline cancellation insurance in case you need to cancel your trip for health reasons

Using alcohol, cannabis and drugs

Talk to your transplant team about alcohol, cannabis and other drug use. These drugs may cause problems with your medications.

Can I smoke cannabis?

Tell your transplant coordinator if you use cannabis because it may affect your medication. Avoid smoking cannabis because we don’t know the risks. Use edible cannabis products instead.

Can I vape?

Avoid vaping. There is no research on the effects of vaping in heart transplant patients.

Can I smoke cigarettes?

Avoid smoking cigarettes. Smoking cigarettes will reduce your life after your transplant.

Talk to your transplant team if you are having nicotine cravings or want to start smoking again. They will help and support you through this time.

Can I use tobacco as part of my culture?

For many Indigenous people, tobacco is a sacred medicine used in ceremonial and spiritual practices. Used in a **traditional** way, tobacco is an important part of healing and wellness. This is very different from **commercial** tobacco, which is not used for spiritual reasons or wellness. Commercial tobacco is also harmful to a person’s health.

Fertility and pregnancy

Having a heart transplant does not change your fertility (ability to have a baby). It is possible to get pregnant or get someone pregnant after having a heart transplant, but there are risks.

- **If you want to get pregnant:** talk to your transplant team 1 year or more before you start trying to get pregnant, if possible. We can help you plan to reduce the risks.
- **If you do NOT want to get pregnant:** use 2 types of birth control if you have vaginal sex.

What are the risks of having a baby after a heart transplant?

- There is a higher risk of development problems (birth defects) in the baby.
- If your heart failure was caused by a hereditary condition (a condition passed on from parent to child), your baby may be at risk for the same condition. Ask your transplant team to refer you to a genetics specialist.

If you are the partner who can get pregnant:

- Your pregnancy may be complicated. You may need extra medical care such as staying in the hospital before the delivery.

How can I lower the risks of having a baby?

It is important to plan your pregnancy and talk with your transplant team to lower your chances of complications and birth defects. We can:

- review your medications and make adjustments to lower the risk of complications and birth defects.
- refer you to the high risk pregnancy program at Mount Sinai Hospital. We work closely with them to ensure you have the best and safest pregnancy experience.

How can I prevent getting pregnant?

Use 2 types of birth control when having penis-in-vagina sex. Use:

1. a long-acting method. For example, the partner who can get pregnant can use an intrauterine device (IUD) or birth control pill.

AND

2. a barrier method such as a condom. An external condom is worn on the penis. An internal condom is a soft plastic pouch inserted in the vagina.

Talk to your transplant coordinator about your birth control options. If you are the partner who can get pregnant, we may refer you to a gynecologist to make the best birth control plan for you.

If you have penis-in-vagina sex without using birth control: The partner who can get pregnant can take emergency birth control as soon as possible. Emergency birth control can be:

- pills you buy at the pharmacy (“Plan B”). You can take emergency birth control pills up to 5 days after sex.
- an IUD. You need to see a doctor to have it inserted.

Sun protection

Your immunosuppressive medications increase your risk of getting skin cancer. Take steps to protect yourself from the sun.

- Wear sunscreen with a SPF (sun protection factor) of 30 or higher.
- Wear a hat, long sleeve cotton shirts and cotton pants when you are outside.
- Avoid being in the sun between 11:00 a.m. and 3:00 p.m.

Tell your transplant doctor or coordinator right away if you notice a new skin lesion (wound) that gets larger and bleeds or a mole that has changed.

It is important that you have regular skin screening by a dermatologist after your transplant. Ask your primary care provider to refer you to a dermatologist or ask your transplant coordinator to refer you to our transplant dermatologist at Toronto General.

Vision and eye care

The general anesthetic given to you during surgery can affect your vision for a few months after the transplant. Do not change your eyeglass prescription if your vision isn’t clear right away. See your eye doctor if your vision problems last more than 3 months.

See your eye doctor for an eye exam every year. Prednisone can increase your risk of developing cataracts. If you notice any changes in your vision tell your primary care provider and make an appointment with your eye doctor.

Dental care

It is very important to take care of your mouth and teeth.

- Brush and floss your teeth 2 or more times each day. Use a toothbrush with soft bristles.
- Check the inside of your mouth for any lesions (wounds or sores) and your gums for swelling. Tell your transplant team if you find anything.
- Speak with your transplant team before you go to the dentist after your transplant. You will need to wait at least 6 months after your transplant before going to the dentist due to risk of infection.
- After 6 months, get regular dental cleaning and exams from your dentist.
    - Tell your dentist you had a heart transplant and your immune system is suppressed.
    - You need to take antibiotics before having any dental procedure, including cleaning. The antibiotics prevent you from getting an infection. Your dentist will prescribe the antibiotics.

Vaccines

It is important that you and the people you live with are up to date on your vaccines.

You are responsible for keeping a record of the vaccines you get. You must arrange to get any vaccines you need through your primary care provider. The transplant clinic does not give any vaccines.

- Talk to your transplant team before getting any vaccines, including travel vaccines.
- Do not get any live vaccines after your transplant. Live vaccines include MMR (measles mumps rubella), yellow fever, smallpox, and Varicella (live attenuated; Varivax and Zostavax).
- Sometimes the vaccines you get after transplant do not last as long they normally would. We can check the levels (titres) of some vaccines in your blood to see if they are high enough to protect you.
- Get the influenza (flu) vaccine each fall. You are more likely to get sick from the flu because of the medications you take to prevent organ rejection.
- Wait 3 to 6 months after your transplant surgery before getting a vaccine, if possible. Your immune system will be better able to use the vaccine.

- You will need to get the pneumococcal vaccines Pneumovax and Prevnar 13. Your transplant team will tell your primary care provider when you should get these vaccines.

Primary care provider (doctor or nurse practitioner)

You must have a primary care provider before and after transplant.

We expect that you will keep your primary care provider informed of your health and see them about health issues not related to your transplant.

The transplant team will send your primary care provider information on taking care of transplant patients and regular updates from your appointments. We work in partnership with your primary care provider and are available to them if they have any questions.

Annual Checkups

It is important to have annual health exams (“checkups”) with your primary care provider. You need to take care of your whole body and not just your new heart. Every year:

- follow the Canadian guidelines for cancer screening
- get a bone density scan to check for osteoporosis

Your primary care provider may refer you to other medical specialists for other issues or routine tests.

- Keep your transplant team informed of your health. Ask medical specialists outside your transplant team to send us a copy of the consult note or plan.
- The transplant team may send you to specialists for complicated problems that are best managed at a transplant hospital.

Your primary care provider or local specialists can speak with us at any time to decide on the best health care for you.

Other lifestyle considerations

> "Everyone's transplant journey is different. Just because you had a heart transplant does not mean you are not human. You can still partake in most activities that others can, and it is important to not limit yourself from experiencing new and exciting activities! After having your transplant, live life to the fullest and make the most of every experience! Always be safe and have fun!"

Can I take herbal medications?

Talk to your transplant coordinator before taking any herbal medications. Most herbal medications cause problems with your transplant medications.

Can I get a tattoo?

You have a higher risk of getting an infection because of your immunosuppressive medication but you can still get a tattoo.

- Wait 1 year after your transplant before getting a tattoo.
- Go to a professional tattoo studio that is inspected by public health. Check the studio's inspection history with your local public health department.

Can I go in a hot tub or sauna?

You can go in a hot tub or sauna when your transplant wound is completely healed.

- Do not go in a hot tub or sauna if you have any open wounds.
- Drink plenty of water to avoid dehydration.
- Do not stay in a hot tub or sauna for more than 15 minutes.

Can I dye my hair?

Yes. You may choose to wait a few months after your transplant because the texture of your hair may be different in the first few months after your transplant. Tell your hair stylist that you have had a heart transplant and ask them to reschedule your appointment if they are sick or not feeling well.

> “I highlighted my hair about 2 months after transplant. I didn't notice any issues with my hair. However, I did notify my hair stylist in advance that I had a heart transplant and asked her to reschedule my appointment if she wasn't feeling well and had a cold.”

Can I go swimming?

You can go swimming when your transplant wound is fully healed and you have finished your rehabilitation program.

Can I get a manicure or pedicure at a salon?

Yes. You can get a manicure or pedicure as long as you do not have any other concerns of infection. Choose salons that sterilize their instruments to reduce the risk of infection.

Can I eat sushi?

We do not recommend that you eat any raw fish, meat or eggs. There may be a risk of contamination in these raw foods.

Can I get acupuncture?

We do not recommend that you get acupuncture because you may get an infection.

Can I still go out and hang out with large groups of people?

Yes, but take steps to avoid getting sick.

- Avoid people who are sick.
- Wash your hands often.
- Don’t touch your face

HeartLinks

HeartLinks is a group of transplant patients and their families. There are events throughout the year like the Valentine's Day appreciation day where heart recipients give awards of appreciation to their Doctor's. There is also an annual Craft and Bake sale run entirely by recipients and their families to raise money for transplant research and at the end of every year HeartLinks hosts a potluck lunch where pins are handed out to recipients commemorating transplant anniversaries. HeartLinks is a Fantastic way to stay in touch with other recipients. I find it very helpful to connect with others who truly understand the challenges of being a recipient.

Please contact your transplant coordinator or reach out to us via Facebook/Email to join.

Email: heartlinksgroup@yahoo.ca
Facebook Page: https://www.facebook.com/heartlinksgroup/

HeartLinks

Saying Thank You to Your Donor

Transplant recipients often wonder how to say “thank you” to their donor’s family. When your donor is an anonymous person whose organs were donated by their family at the time of their death, a “Thank You” can be difficult.

You may want to write to the donor’s family to express your thanks. Thank you letters or cards may be a comfort to donor families as they deal with their loss. There is no right or wrong time to write to the family. Some recipients feel that they want to write right away. But you might need time to recover from your surgery before you are able to write.

In Canada, the identities of the recipient, donor and their families are kept confidential out of respect for everyone’s right to personal privacy. For this reason, all correspondence is anonymous.

Some things you may want to include in your letter are:

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

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

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

If you would like more information about writing a letter to your donor family, please review the following resource from Trillium Gift of Life:

https://www.giftoflife.on.ca/resources/pdf/Writing_to_Your_Donor_Family_(EN)_Apr1918.pdf