

Heart Transplant Recipient and Caregiver Manual Book 2

Heart Transplant Surgery: From Hospital Admission to Discharge



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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

Office Hours: Monday-Friday 8:00am - 4:00pm

Mailing address:

Heart Transplant Assessment Program
Toronto General Hospital - UHN
585 University Ave
11 PMB- 136/ G-20
Toronto, ON M5G 2N2

Post-Transplant Office (after transplant)

Location: 12th Floor, Peter Munk Assessment Centre

Phone (EasyCall): 416 351 0793

Office Hours: Monday-Friday 8:00am - 4:00pm

Mailing address:

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

Follow-up Care in the Transplant Clinic

Location: 12th Floor, Peter Munk Building

Clinic hours: Wednesday Afternoon and Thursday Morning

Phone:

EasyCall: 416 351 0793

Clinic Reception: 416 340 4800 extension 4113
(Monday to Friday, 8:00am to 4:00pm)

Mailing address:

Follow-Up Care
Toronto General Hospital - UHN
12 PMB 100
585 University Avenue
Toronto, ON M5G 2N2

The Transplant Hospital Stay

The transplant hospital stay includes Steps 6 to 10 which match the locations where you receive care.

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Who will care for me during the transplant?

Some people on your transplant team include:

Health Care Provider	Role Description	My Provider's Name/Contact Is:
Post-Transplant Team	The post-transplant team will care for you after your transplant. The post-transplant team includes all our transplant cardiologists, nurses, other transplant providers and your pre-transplant cardiologist.	Post-Transplant Team
Registered Nurses on the Inpatient units	During your hospital stay, your nurse coordinates your care with other team members. They make sure everyone on your team is informed about your care during your hospital stay. They help prepare you when it is time for you to leave the hospital.	

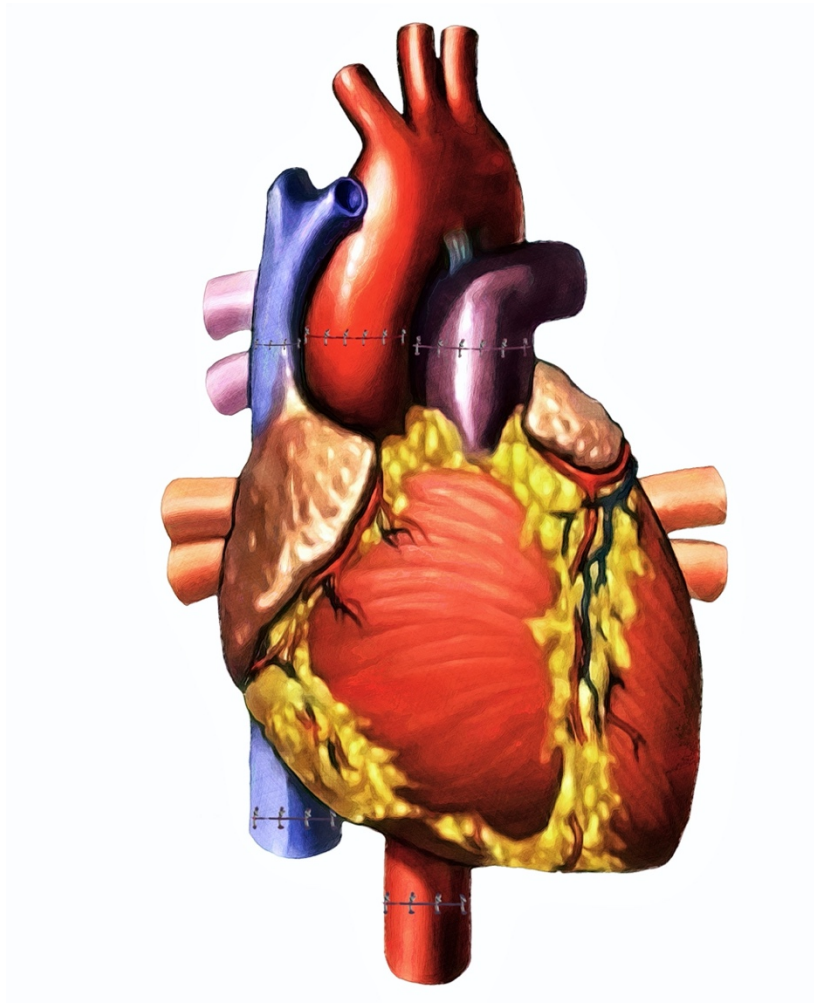
Health Care Provider	Role Description	My Provider's Name/Contact Is:
Pharmacist	Pharmacists teach you about the medications and medication routines you use after transplant. The Multi-Organ Transplant Program has its own transplant pharmacy called the Transplant Outpatient Pharmacy (TOP). TOP is located on the 12 th floor Peter Munk Wing. You may choose to have all of your medications managed through TOP. They can give you your medication in blister packs to help you stay organized.	
Drug Reimbursement Specialist	The medications you need to take after a transplant can be expensive. The drug reimbursement specialist helps you understand your drug coverage options. They can help you with provincial drug coverage through the Trillium Drug Program, private insurers, co-pay options, or enrolling in patient assistance programs when applicable.	
Inpatient Transplant Rehabilitation Team	The rehabilitation team includes physiotherapists, occupational therapists, speech-language therapists and social workers. They help build your strength, mobility and independence after the transplant. If you need rehabilitation after you leave the hospital, the social worker helps you apply to a rehabilitation center.	
Inpatient Discharge Coordinator	The inpatient discharge coordinator is a registered nurse who ensures you are ready to leave (be discharged from) the hospital. They help make sure things go smoothly when you are ready to leave the hospital.	

Health Care Provider	Role Description	My Provider's Name/Contact Is:
Spiritual Care Provider	The Spiritual Care provider offers spiritual and religious care for patients and families. Spirituality is part of your health and well-being. Spirituality can help you explore the impact a transplant has on you and your family. If you would like to speak to a Spiritual Care provider, please ask you nurse or any transplant team member.	
Transitional Diabetes clinic	The transitional diabetes clinic offers care to transplant patients who develop diabetes after their heart transplants or need help managing their blood sugar.	

Step 6: The Heart Transplant Surgery

The Heart Transplant Surgery

The surgery will last from four to six hours depending on your condition. The operation may take longer if you have had heart surgery in the past or have a mechanical heart device.



Art by: T. Dorje

There are two types of heart transplant surgeries. One is called “biatrial” and the other “bicaval.” For the biatrial technique, the back portions of the right and left atria with a portion of the pulmonary artery and aorta are left intact to serve as connections for the new heart.

For the bicaval technique, only the back portion of the left atrium along with a portion of the pulmonary artery, aorta and both vena cava (superior and inferior) are left intact to serve as connections for the new heart. The recipient right atrium is replaced with the donor right atrium.

What can my family expect while I am in surgery?

We bring your family to the waiting room when you go to surgery. The wait is about 4 to 6 hours. It can seem like a very long time. Make sure they bring something to do to help pass the time.

- Someone from the surgery team will speak with your family if there are complications or delays. They will explain what is happening and how much longer your family can expect to wait.

The surgeon comes to talk to your family when the surgery is done and you are in the Cardiovascular Intensive Care Unit (CVICU). Waiting room volunteers bring your family to the CVICU waiting room on the 2nd floor, Eaton Wing. The CVICU nurse will let your family see you when you have been admitted.

“During surgery, we went to a comfortable waiting room on the second floor. There were volunteers there who were in contact with the surgical team and kept us updated on the progress of the surgery. We were there for about 8 hours when advised that the surgery was over and that my daughter was being moved to CVICU. It was another 2 hours before we could see her in CVICU”.

How long am I in the hospital?

Expect to stay in the hospital for 2 weeks after your surgery. Some patients may need to stay longer if there are any complications.

You stay in different inpatient units depending on the stage of your care:

- immediately after your transplant surgery you stay in the Cardiovascular Intensive Care Unit (CVICU) (Step 7)
- when you are starting to recover from surgery you stay in the Multi-Organ Transplant Step-Down Unit (Step 8)
- when you are completing your recovery and hospital stay you stay in the Multi-Organ Transplant Inpatient Unit (Step 9)

Step 7: The Cardiovascular Intensive Care Unit (CVICU)

What to expect after surgery

Immediately after your transplant surgery you are brought to the Cardiovascular Intensive Care Unit (CVICU).

What care do I get in the CVICU?

Specially trained nurses look after you. You have several lines and machines attached to you.

- You are on a ventilator (a machine that helps you breathe) until you wake up and breathe on your own.
- You are connected to a heart monitor and blood pressure machine.
- You have an intravenous (IV) line attached to a pump. The IV gives you medications into your vein.

Most patients can talk, eat and sit up in a chair a few hours after surgery. Most patients can walk a few days after surgery. It may take longer if you have complications.

How long am I in the CVICU?

Most heart transplant patients stay in the CVICU for 3 or 4 days.

Can I have visitors?

You can have visitors for short periods of time. The nurse taking care of you tells you how long your visitors can stay. Sometimes visitors may be asked to leave for us to provide medical care.

Step 8: The Multi-Organ Transplant Step-Down Unit

When you are ready to leave the CVICU, you may need to go to the Step-Down Unit on the Multi-Organ Transplant Unit (10th Floor, Peter Munk Building).

What care do I get?

We closely monitor you for several days using some of the same equipment that the CVICU uses.

- You are no longer on a ventilator.
- You are still connected to a heart monitor and blood pressure machine.
- You still have an IV line attached to a pump. The IV gives you medications.

How long am I in the Step-Down Unit?

Most heart transplant patients stay on the Step-Down unit for 2 to 3 days. Some patients may need to stay longer if there are complications.

Can I have visitors?

Yes. We encourage you to have visitors. The nurse taking care of you tells you how many visitors you can have and how long they can stay. This depends on your condition and may change each day.

While you are in the Multi-Organ Transplant Step-Down Unit you start to learn about what to do when you go home. It is helpful to have the people you live with visit so they can learn about your needs too.

Step 9: The Multi-Organ Transplant Inpatient Unit

Once you are ready to leave the Step-Down Unit, you are transferred to the Multi-Organ Transplant (MOT) inpatient unit (7th floor, Munk Building). The MOT inpatient unit is in the wings 7A and 7B. Each wing has private and semi-private rooms.

When you are transferred to the MOT inpatient unit have your caregiver bring:

1. This manual
2. Your drug card or insurance card, if you have one
3. A credit card to pay for medications at time of discharge
4. Your cane or walker if you use one
5. A small overnight bag with:
 - unscented soap and shampoo
 - comb or hair brush
 - toothbrush, toothpaste and mouthwash
 - lip and skin moisturizer. The air in the hospital is very dry
 - Kleenex
 - a bathrobe that opens all the way down the front
 - slippers with a closed heel and rubber soles or running shoes
 - a book or magazine for entertainment

You may also want them to bring:

- your own pillow, for example if you use a special neck pillow
- a set of loose, comfortable clothing
- a cellphone, tablet or laptop and headphones to contact family and friends during your stay. Patient rooms do not have phones or TVs. UHN has free guest Wi-Fi.
Note: You are responsible for keeping your cellphone, tablet or laptop safe. UHN is not responsible for any loss of personal belongings.

Do not bring:

- any valuables such as rings, watches, jewelry.
- large amounts of cash. We can lock up a maximum of \$20 on the unit. Hospital security must lock up any more cash you bring in the hospital vault.
- any large electrical equipment that needs to be plugged in. You may bring an electric razor or hair dryer.

“I found it difficult to concentrate on a book. I brought my computer with a USB stick full of movies and a good headset. The WiFi is not so great so streaming is not really an option without your own data. I also had a notebook to write any questions I had for my doctors.”

What care do I get?

The nurses help you do your personal care, sit in a chair and get up to walk until you can do it yourself.

The heart transplant team visits you every day to check on your recovery. They let you know when you are almost ready to leave the hospital.

You and your caregiver learn how to care for your new heart, about the different medications you need to take and the procedures you need to have to make sure your heart is working well.

Being in the MOT inpatient unit can be a very emotional time for patients. Some of the medications you are taking can also make it difficult to manage your emotions. Patients describe it as a rollercoaster. It is normal to feel happy one minute and to cry the next. Talk to the nurses and the transplant team about what you are feeling.

How long am I in the MOT inpatient unit?

Most heart transplant patients stay on the MOT inpatient unit for about 1 week. Some patients may need to stay longer if they experience complications.

Start thinking about how you are going to get home when you are ready to leave hospital. Let the nurses and your transplant team know if you need to arrange air bus or train travel. It's easier to help you plan when we know how you are getting home.

Can I have visitors?

Yes. Your caregiver should be at the hospital every day to help you learn about your recovery, medications and procedures.

You can have visitors. Consider other patients and visitors in the unit. Try to limit visitors to 1 to 2 people at a time between 10:00 am and 8:00 pm.

How do I manage my pain?

Taking pain medication regularly helps to stop the pain from getting too intense. The nurses and doctors work with you to help manage your pain.

You do not need to worry about becoming addicted to the pain medication because you will only be on pain medication for a short time.

Below is a list of ways that we can give you pain medication. Please talk to your doctor or nurse if you have any questions.

Types of pain medication

1. Patient-Controlled Analgesia IV

Patient-Controlled Analgesia (PCA) is IV pain medication attached to a pump that **you** control. When you feel you need pain relief, you press the PCA button and the PCA pump gives you pain medication through your IV.

The pump gives you a small dose of pain medication each time you push the button. There are safety features to stop you from getting too much medication.

Push the PCA button when you are:

- starting to feel pain

- moving around in bed
- getting ready to do your deep breathing and coughing exercises
- starting any activity that causes you pain

2. IV Medication (as needed)

The nurse gives you pain medication through your IV. Tell your nurse when you have pain and if the medication is working for you.

3. Pills

Once you can drink fluids, we give you pills at regular times to help control your pain. Pills take longer than IV medication. This means that it is important to tell your nurse when you are feeling uncomfortable. Do not wait until your pain is strong or overwhelming.

What are the side effects of pain medications?

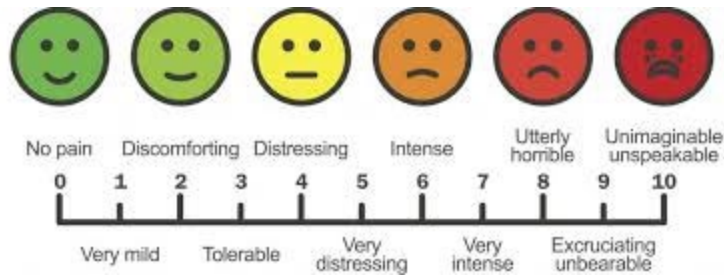
Some patients have side effects from pain medication. Common side effects are:

- nausea
- constipation
- itching
- vomiting
- sleepiness

Talk to the nurse if you have any of these side effects or if you have questions about your pain medication.

How do I talk to my care team about my pain?

We use a pain scale. It looks like this:



On this scale 0 means no pain. 10 means the worst pain you could ever imagine.

You may also find it helpful to describe the pain with words, such as mild, moderate or severe.

What else can I do to manage my pain?

Some tips to help you manage your pain while you are taking pain medication are:

- **Do relaxation breathing exercises.** Relaxation breathing directs your attention away from your pain because you are focusing on your breathing. You take slow deep breaths, in through your nose and out through your mouth.
- **Visualize yourself without pain.** Start by closing your eyes. Imagine yourself in a place or time that brought you happiness, such as being on a beach, at the cottage or on a mountaintop. Try to remember the sounds, smells and other details of the experience.
- **Massage your body.** Gently rub your shoulders, back or arms to ease tension. You can do it yourself or you can ask someone else to do it for you.

MedicAlert

Get a MedicAlert bracelet after your transplant or update the information if you already have one.

MedicAlert bracelets give important health information about you when you are unable to tell people yourself. MedicAlert bracelets can save your life in an emergency.

It takes 6 to 8 weeks for your MedicAlert bracelet to arrive at your home. Fill out the form while you are in the hospital so it will arrive shortly after you get home.

Speak with your health care team if you have questions around getting a MedicAlert bracelet or visit the MedicAlert website (<https://www.medicalert.ca>).

Step 10: Going Home

Everyone has a different experience during their transition from hospital to home. Please see the “Coping with a Transplant” brochure on possible feelings you may encounter as you adjust to life after transplant.

“Transitioning home was both terrifying and victorious. Leaving the hospital meant I was well enough to be without 24 hour monitoring. It also meant I was giving up the security of having the nurses help with medications and seemingly simple things like getting bathed and dressed, as well as someone to ask those questions that I hadn't yet thought of. This is where my support team (family and friends) was so helpful. I was attached to my meds schedule for the first few months. The list you get on discharge has doses and times and can't be regenerated. I suggest making a few photocopies. Your doses and medications will more than likely change a lot over the first few months. I would use correction tape and right in my new doses and add new meds at the bottom.

The first few months I was back and forth to and from the hospital 2 and 3 times a week sometimes. It seems overwhelming but it's all a part of the healing process and the Transplant Clinic was with me every step of the way.”

“Leaving the hospital to go home was wonderful. It felt good to be in the comfort of my home and be with my family. I was fortunate to have my mother stay with us for the first few weeks. She was a big help with my care and routine tasks. Initially I spent most of my time in bed resting. I did some reading, binge watched my favorite shows and putzed around the house when I felt up to it. During this time, I experienced fatigue, some pain, numbness in my right chest, muscle weakness (especially in my legs), nausea, diarrhea, insomnia and headaches.

Medication was not new to me but the volume had increased and the multiple scheduled times for doses was new. The pharmacy medication spreadsheet was very helpful, but I couldn't copy it so I designed my own. I also set up an alarm on my cell phone to remind me when it was time to take my medication. To this day I'm still using a spreadsheet and the alarm on my cell phone.

For my first few months at home, I had to inhale an infection medication and inject a blood thinner medication into my stomach. A nurse came by each day to administer these medications and teach me how to do them on my own. The inhalation wasn't that bad but I dreaded the injections. At times my stomach was very bruised. I was so relieved when both were done.

It was tough at times. I had good days and bad days. If I did too much one day, I could be very tired the next two days. So, I tried not to overdo it. Gradually I started to feel better and was able to do more things with confidence.”

When will I be discharged (sent home) from the hospital?

Hospital discharge happens before 11:00 am.

- Gather all of your belongings, instructions and important information the night before you are discharged.

We give you a discharge letter and prescriptions for your medications the morning you are discharged. The discharge letter tells you when your next appointment is scheduled in the transplant ambulatory (outpatient) clinic. It may also have information on your next biopsy appointment.

What do I need to do to travel home safely?

If you are travelling by car: Ask a family member, partner or friend to help you carry your belongings to the hospital entrance. Have the driver wait for you at the entrance.

- Stop every 1 to 2 hours to get out and walk around the car if you are driving a long distance. This helps prevent stiffness and pain from getting too bad.

If you are travelling by air, bus or train: Ask a family member, partner or friend to travel with you and help you carry your belongings, and to help you on and off the vehicle.

What should I do the day I get home?

You may have some pain and or discomfort when you get home. Plan to rest the day you get home. Try not to have visitors from outside your home.

When to call 911

Call 911 right away if you feel:

- sudden shortness of breath
- chest pain

The ambulance takes you to the nearest hospital emergency department. Tell the emergency doctor that you had a heart transplant at Toronto General Hospital. Call your

transplant coordinator using EasyCall (See Pg. 20) when you are sent home or admitted to the hospital.

What can I do while I heal?

You are recovering from major surgery. It will take time to feel normal after your transplant.

The incision (surgery wound) will be painful. It may feel stiff or achy when you are active and still healing. You may need your caregiver to help you with daily activities.

It can take up to 3 months for your incision and sternum (chest bone) to heal, which is longer than you may expect. It takes longer to heal because of the steroid medications you take. For 3 months after your surgery:

- Do not lift anything over 4.5 kilograms (10 pounds), such as a bag of potatoes or a laundry basket full of towels
- Do not do abdominal exercises such as sit ups
- Do not do upper body exercises such as push-ups, pull-ups, pushing or pulling heavy objects
- Avoid:
 - vacuuming
 - shoveling snow
 - swimming
 - playing tennis
 - gardening

What happens to my body weight?

Expect to slowly gain more weight after surgery. This is a sign you are regaining your muscles and strength. Your weight will stop changing when you have recovered.

Important: Call the transplant clinic if you gain 0.5 kilograms (1 pound) or more each day for 3 days in a row. This may be a sign of fluid retention.

What precautions do I need to take around pets and animals?

You are at higher risk of getting an infection or disease from animals because you take immunosuppressive medications.

Some animals put you at greater risk for infection. Stay away from:

- stray or wild animals
- animals with diarrhea
- exotic animals
- sick animals
- monkeys

You can still be around your pets but you need to take extra precautions to lower your risk of getting an infection or disease.

1. Wash your hands after touching your pet, especially before you eat.
2. Keep your pet clean and well groomed.
3. Use a flea control program for your pet.
4. Try not to touch your pet's throw up, poo, pee or drool.
 - a. Ask someone else to clean up after the pet using a disinfectant.
 - b. Do not let a pet lick your wounds or your face.
 - c. Ask someone else to clean cat litter if you own a cat.
5. Keep your pet's vaccinations up to date at all times.
6. Take your pet for an annual check-up at the vet.

7. Trim your pet's nails so that they are short.

Tell your transplant coordinator about your pets. They will give you specific information on how to protect yourself from infection for different types of pets you have.

My medical care

Who provides my care?

Talk to your primary care provider (doctor or nurse practitioner) for any minor problems or issues not related to the transplant. Call your transplant coordinator if you start taking any new medications.

How do I contact my transplant coordinator?

We tell you about the EasyCall telephone system before you are discharged home. EasyCall allows you to leave messages for your transplant coordinator and administrative assistants.

- Messages are picked up from Monday to Friday between 8:00 and 4:00pm.
- Messages left on evenings or weekends are answered the next business day.

EasyCall can be accessed from any telephone using a PIN number and password that we give you.

If you cannot attend an appointment, please leave a message on EasyCall. We call you back with a new appointment or instructions on how to rebook your appointment. We group your appointments together as much as possible.

Can I see my transplant coordinator if I don't have an appointment?

If you need to see your transplant coordinator outside of your clinic appointment, please call and leave a message on EasyCall.

- When you arrive to see the transplant coordinator, always check in with the clinic receptionist.
- Your transplant coordinator comes out to meet you.

How do I get prescription refills?

Try to tell us you need a new prescription for your regular medications when you come to an appointment at the transplant clinic.

If you must change or renew your prescription between appointments, leave a message on EasyCall. It may take up to 3 days for us to write a new prescription.

My New Medication Routine

After your heart transplant you will take many new medications. Some or all of these medications will be taken for life. This change can be difficult, but your care team is here to support you through a new routine and to answer any questions.

You should expect side effects from your new medication. Your transplant team is trained to manage these side effects. Before going home, the transplant team will try to improve your symptoms. Simple changes in medication or routine are usually all that are needed to deal with these side effects. Sometimes, other medications are added to counteract these side effects. It is important to remember never to stop or change the way you are taking any of your medications without consulting your transplant team.

You will likely take:

- immunosuppressive medication
- aspirin
- blood pressure medication
- cholesterol medication
- acid-reducing medication
- diabetes medication, if you have diabetes or are at risk of developing diabetes

Immunosuppressive medication

What is immunosuppressive medication?

The immune system protects the body from infection and disease. Immunosuppressive medication makes your immune system work less well.

Why do I need to take it?

For your body to accept your transplanted heart, it is necessary to suppress the function of your immune system.

Your immune system will reject (cause harm to) your transplanted heart if your immune system is working well. Rejection can affect how the transplanted heart functions. It is very important to prevent rejection by taking immunosuppressive medications. You need to take these medications for the rest of your life.

What is the name of the medication?

Most patients are prescribed 2 or 3 of these medications:

- Cyclosporine (Neoral®)
- Tacrolimus (Prograf® or Advagraf®)
- Prednisone
- Azathioprine (Imuran®)
- Mycophenolate mofetil (Cellcept®)
- Mycophenolate sodium (Myfortic®)
- Sirolimus (Rapamune®)

The medications you are prescribed depends on what other conditions you have and any other medications you take.

What should I remember while taking this medication?

Never change or skip your medication doses on your own. It is very important that you take these medications exactly as directed by your transplant team.

While you are taking these medications your body is less able to fight infection. We prescribe medications to help protect you from certain types of bacterial, viral and fungal infections.

What are the side effects of this medication?

It is normal to have side effects when you first start taking this medication. Your body needs time to adjust to the new organ and new medications. It also takes time to find the best dose for you.

For the first year after transplant surgery, it is normal to:

- be tired or confused
- have difficulty concentrating or sleeping
- have mood swings

Call the transplant team right away if you:

- Have severe or continued nausea, vomiting, or diarrhea
- Are experiencing new side effects or new symptoms from the medications
- Have been prescribed a new medication by a physician or dentist
- Chose to take over the counter medications, as some of these drugs may interact with your medications

What should I do if I miss a dose?

If you miss any doses of your immunosuppressive medications, please notify your transplant team through EasyCall as soon as possible.

Where can I find more information?

The Transplant Outpatient Pharmacy has provided information and links on specific immunosuppressive medications on the UHN website (www.uhn.ca).

Here is the link: <https://www.uhn.ca/Transplant/TOP/Pages/TMITT.aspx>

You can also go to the www.uhn.ca and search for the transplant outpatient pharmacy in the search bar. Information on immunosuppressive medications is located in the Transplant Medication Teaching Tool (TMITT) tab.

The information is also available in a separate booklet – Immunosuppressive Medications. Please tell your nurse, pharmacist or transplant coordinator if you would prefer to receive information on immunosuppressive medications in paper format.

Aspirin (ASA)

What is aspirin and why do I need to take it?

Aspirin is an anti-inflammatory and blood-thinning medication. Aspirin is prescribed to help prevent the narrowing of the coronary arteries in the transplanted heart.

The dose is either 325 mg or 81 mg (a baby aspirin tablet) daily.

What are the side effects of this medication?

The most common side effects of aspirin are stomach irritation, indigestion, and nausea.

What do I do if I miss a dose?

If you miss a dose of Aspirin, let your coordinator know. Resume your Aspirin as soon as you remember to take it.

Blood pressure medications

What are blood pressure medications (antihypertensives)?

Antihypertensives are a class of medication that lower high blood pressure.

Why do I need to take it?

Many patients have high blood pressure after a heart transplant.

What is the name of the medication?

Some of the medications used to treat high blood pressure are:

- Calcium channel blockers, such as Amlodipine or Diltiazem
- ACE inhibitors, such as Perindopril

- Diuretics such as Lasix and Hydrochlorothiazide

What do I need to do while taking this medication?

Get a blood pressure monitor and check your blood pressure every day at a random time during the day. Keep a log of these measurements.

- The top number (systolic) should be less than 135.
- The bottom number (diastolic) should be less than 90.

Tell your transplant team if your blood pressure, as a trend, is higher than this.

What are the side effects of this medication?

It is possible for your blood pressure to drop too low after starting a new blood pressure medication. Symptoms of low blood pressure can include:

- Fatigue or lack of energy
- Dizziness or light-headedness when standing up
- Fainting
- Blurred vision
- Poor concentration
- Nausea

Stand or sit up slowly to decrease the sudden drop in blood pressure you may feel if you move from lying or sitting to standing.

If this does not help decrease your symptoms, tell your transplant team at your next appointment or leave a message through EasyCall.

What do I do if I miss a dose?

If you miss a dose of your blood pressure medication, let your coordinator know. Resume your medication as soon as you remember to take it. You may need to stagger your second dose if it is a medication you take twice per day.

Cholesterol medications

What are cholesterol medications?

This group of drugs is used in combination with dietary therapy and exercise to decrease the levels of cholesterol and other fats in your blood.

Why do I need to take it?

Some immunosuppressive medications may increase your cholesterol levels after a transplant. Some patients already have high cholesterol before transplant and these levels become higher after transplant.

You may be prescribed a cholesterol medication to help manage this condition. Decreasing cholesterol levels helps prevent the coronary arteries in the transplanted heart from narrowing.

What is the name of the medication?

The most commonly prescribed cholesterol medications are called statins, although other medications may be used.

What do I need to do while taking this medication?

These medications are used in combination with a healthy diet and exercise to decrease levels of cholesterol and other fats in your blood.

The goal is to have an LDL level under 2.0.

What are the side effects of this medication?

Common side effects of cholesterol medications include muscle pain and weakness, nausea and/or vomiting, constipation and/or diarrhea, and dizziness.

What do I do if I miss a dose?

If you miss your cholesterol lowering medication, you can resume this the following day. Let your coordinator know.

Acid Reducing Medications/Medications for your stomach

What are acid-reducing medications?

These medications slow acid production or lessen the amount of acid your stomach makes.

Why do I need to take it?

Acid-reducing medications are often prescribed after transplant to prevent and treat problems caused by excessive stomach acid such as heartburn, acid reflux and stomach ulcers.

Acid-reducing medications can also prevent stomach irritation or heartburn which may be caused by certain immunosuppressive medications such as prednisone.

What is the name of the medication?

The medications used to protect your stomach include:

- Pantoprazole Sodium (Pantoloc)
- Pantoprazole Magnesium (Tecta)
- Omeprazole (Losec)
- Ranitidine (Zantac)

What are the side effects of this medication?

Common side effects are abdominal pain, headaches, rashes, and muscle pain.

What do I do if I miss a dose?

If you miss a dose of your acid reducing medication, you can resume your dose the following day.

Diabetes Medications

What are diabetes medications?

You may be prescribed a medication to help control your blood glucose after transplant.

Why do I need to take it?

Some of the antirejection medications increase the risk of developing diabetes, or make pre-existing diabetes more difficult to control. [text]

What is the name of the medication?

The medications used to help control blood glucose may be oral medications or insulin.

What are the side effects of this medication?

There are varying side effects of this medication depending on the type of medication you are on. Your pharmacist will review these side effects with you.

What other medical care will I receive?

If you have a new diagnosis of diabetes after transplant, we refer you to the Transitional Diabetes Clinic at Toronto General Hospital.

- They will help you learn how to manage your diabetes and high blood sugar.
- The clinic's nurse practitioner follows most patients for about 3 months and provides comprehensive diabetes care and support with blood sugar management.
- The goal is to transfer your diabetes care to your family physician after 3 months. If this is not possible, the Transitional Diabetes Clinic will refer you to an endocrinologist for ongoing diabetes management.

What do I do if I miss a dose?

If you miss a dose of your diabetes medication, it is important to report this to your coordinator or diabetes specialist ASAP.

What medications and supplements should I avoid?

Some medications and supplements may interact with your transplant medications. These interactions may increase your risk of side effects or make your transplant medications less effective.

Do not take:

- **echinacea.** Echinacea is an ingredient in many herbal remedies sold at drug stores and health food stores. It is often used to prevent colds and flu. Echinacea stimulates the immune system. This can cancel out your immunosuppressive medications. **Do not** use any products containing Echinacea.
- **herbal and natural health products,** such as herbal remedies, homeopathic medicine, Traditional medicines, vitamins and minerals, amino acids or essential fatty acids. Herbs and natural health products may interact with your immunosuppressive medications and other medications. This can cause harmful side effects such as bleeding, infection or kidney damage or can make other medical conditions such as high blood pressure or diabetes worse. They can also affect how your transplant medications work.
- **Ibuprofen** (Advil®, Motrin®) or **ASA** (aspirin) beyond of your regular daily dose. These medications may increase your risk of kidney problems, especially if you are taking the immunosuppressive medications cyclosporine or tacrolimus. These products may also cause stomach irritation or increase your risk of bleeding.

Speak to your transplant team before you take:

- products with **magnesium** (e.g., Maalox®, Milk of Magnesia®) and **iron supplements.** They can make some immunosuppressive medications less effective if taken at the same time.

If you are taking any products containing magnesium or iron, take them 2 hours or more before or after your transplant medications.

Where can I learn more about my transplant medications?

The Transplant Medication Information Teaching Tool (TMITT) is an online tool to help you learn about your transplant medications.

- You can learn at your own pace by selecting the specific medications and material you want to learn.
- The information is divided into short lessons and uses sound and visuals to help you learn.
- There are interactive quizzes to help you test your knowledge.
- You can print summaries for each medication.

Visit www.TMITT.ca or find a link to the TMITT on the Transplant Pharmacy website.

Transplant Outpatient Pharmacy

Transplant patients have a complex medication regimen. UHN's Transplant Outpatient Pharmacy is designed to meet your unique medication needs. They work closely with you and your health care team to make sure you get the maximum benefit out of your medications.

For more information on the Transplant Outpatient Pharmacy, visit <https://www.uhn.ca/Transplant/TOP>

My Medications

Name	Dose	Frequency	Notes

Name	Dose	Frequency	Notes