

Heart Transplant

Please bring this pamphlet with you to the Halifax Infirmary, QE II.

My name: _____

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Heart Transplant

This pamphlet will help you and your loved ones during the transplant process. As you read through it, write down your questions so you can review them with your health care team later.

The transplant team

The transplant team will work with you and your loved ones to help you return to an active life after your transplant. Both the transplant team and your loved ones will be involved in your care.

My transplant team's contact information

Heart Transplant Clinic

Hours: 7 a.m. to 3 p.m., Monday to Friday

Appointments:

› Phone: 902-473-8597

Clinic nurse

› Phone: 902-473- 5511

VG pharmacy:

› Phone: 902-473-7986

	Name	Phone	Email
Heart transplant coordinator			
Heart transplant clinic clerk			
Social worker			
Psychologist			
Dietitian			
VAD coordinators			

The transplant team includes:

- › Cardiologists (heart doctors)
- › Heart surgeons
- › Heart transplant coordinator
- › Social worker
- › Dietitian
- › Psychologist
- › Specialists
- › Ventricular Assist Device (VAD) coordinators

Social worker

- The social worker can help you with:
 - › disability pensions and financial (money) information.
 - › community resources and services to support lifestyle changes.
 - › medication benefit plans.

Dietitian

- The dietitian will go over your eating plan with you and help you learn more about healthy food choices for your heart condition.

Psychologist

- A psychologist may talk with you about how you are feeling about your health, and help you work through any worries or concerns you may have. They help determine if you have the support and mental health resources to go through a transplant.

Specialists

- Specialists in other areas may be consulted during your evaluation, if needed. The information from these tests and consultations is given to the transplant team.

The team will review your medical history, test results, social history (lifestyle), and any input from other doctors. They will then decide if you will be able to survive the heart transplant procedure and manage the ongoing care needed to live a long and healthy life after your transplant.

Once they decide, your cardiologist will share the results with you.

- › If the team decides that a heart transplant will not help you, your cardiologist will continue seeing you for regular check-ups.
- › If the team decides that a heart transplant could help you, they will explain the process to you and your loved ones.

Why do I need a heart transplant?

- Your doctor feels that your heart failure symptoms are getting worse. They may no longer be well managed with medication or a less-invasive surgery (like a pacemaker).
- Heart failure may happen because of:
 - › Coronary artery disease (blocked arteries)
 - › Hereditary condition (passed from parents to their children)
 - › Congenital heart disease
 - › Hypertension (high blood pressure)
 - › Viral infection
 - › Side effects of medication
 - › History of alcohol use
 - › Pregnancy
 - › Idiopathic (exact cause is not known)

Workup

- You have been referred for a heart transplant workup by your doctor. You will have a number of tests to see if you are eligible for a heart transplant. We will check if you:
 - › Have a medical condition that a heart transplant would help
 - › Would be helped more by other treatment options
 - › Have heart disease that is not severe (bad) enough to need a transplant now
 - › Are too sick for the surgery and post-transplant treatments
 - › Have any conditions that would not let you have a transplant
 - › Have a social habit (like smoking, drinking and/or drug use) that you need to quit before you are eligible for a transplant
 - › Are willing to follow the steps needed after a heart transplant (like many follow-up appointments, blood work, tests, and medication schedule)
 - › Have the emotional strength and social support to deal with waiting for a donor heart and recovery after the transplant
- Sometimes the workup can be done while you are admitted to the hospital (inpatient), but it is usually done outside of the hospital. The workup can take 1 week (7 days) to a couple of months, depending on the tests needed and/or specialist consults.

Tests

- You may have some or all of these tests:
 - › **Blood work**
 - › **Urine (pee) and stool (poop) samples**
 - › **Chest X-ray**
 - › **Electrocardiogram (heart ultrasound)**

You may also need other tests. These will be explained to you. They may include:

- **Echocardiogram**
 - › This ultrasound shows the 4 chambers of the heart, and how well the valves and right and left ventricles are working. It can also show any clots, which sometimes happen with heart failure.
 - › You **do not** need to do anything to get ready for this test. You will be asked to take off your shirt and put on a gown. Electrodes will be attached to your chest. The technician will ask you to lie on your left side. A gel will be put on your chest, and pictures of your heart will be taken with an ultrasound probe.
- **Right heart catheterization**
 - › This test measures the pressure in your heart and lung vessels, and shows how well your heart is working.
 - › The tip of a catheter (thin, hollow tube) is inserted (put in) into a vein in your neck or leg. The catheter is then moved into your heart, around inside your heart, and into the blood vessels going to your lungs. This test usually takes about 30 minutes (half an hour). If the catheter is inserted through your leg, you will need bed rest for up to 3 hours after the test. You will not be asleep for the test, but we can give you medication to help you relax (Ativan®).
- **Left heart catheterization**
 - › This test measures the pressure in your heart and lung vessels, and shows how well your heart is working.
 - › A catheter is inserted into your groin and then moved up to your heart. A dye is injected to show how well the blood is flowing through the coronary arteries and if there are any blockages. This takes a little longer than a right heart catheterization. You will need bed rest for about 4 hours after the test if it is done through the groin.

- **Cardiopulmonary stress test**

- › A cardiopulmonary stress test measures how well your lungs work and shows how well your heart pumps blood to your muscles while you exercise. It also assesses (checks) the electrical activity of your heart.
- › An electrocardiogram (ECG) is done while you exercise on a treadmill or a stationary bike.
- › During the test, you will be hooked up to electrodes that record your heart rhythm. You will breathe into a breath analyzer, which measures the gas exchange in your lungs. A clip will be put on your finger to measure the level of oxygen in your blood. Your blood pressure and pulse will be taken regularly. **It is very important to give all of your effort on this test.**

- **CT scan**

- › A CT (Computerized Tomography) scan will be done on your chest and/or stomach area. You may be given a contrast dye before the test. During the test, you will lie on a motorized table that moves you through the CT scanner. The CT scanner is shaped like a large doughnut.

- **Carotid Doppler ultrasound**

- › This test checks to make sure there are no severe blockages of the arteries in your neck.
- › A gel is put on your neck and pictures are taken with a special ultrasound probe.

- **Arterial blood flow study**

- › An arterial blood flow study is a test done on your legs to make sure there are no blockages in your arteries.
- › Cuffs (like a blood pressure cuff) will be wrapped around each leg. The cuffs will be inflated (made bigger) and deflated (made smaller) to measure the blood flow through your arteries.

- **Pulmonary function test**

- › This test measures how well your lungs work.
- › You will be asked to blow into a mouthpiece before and after using an inhaler.

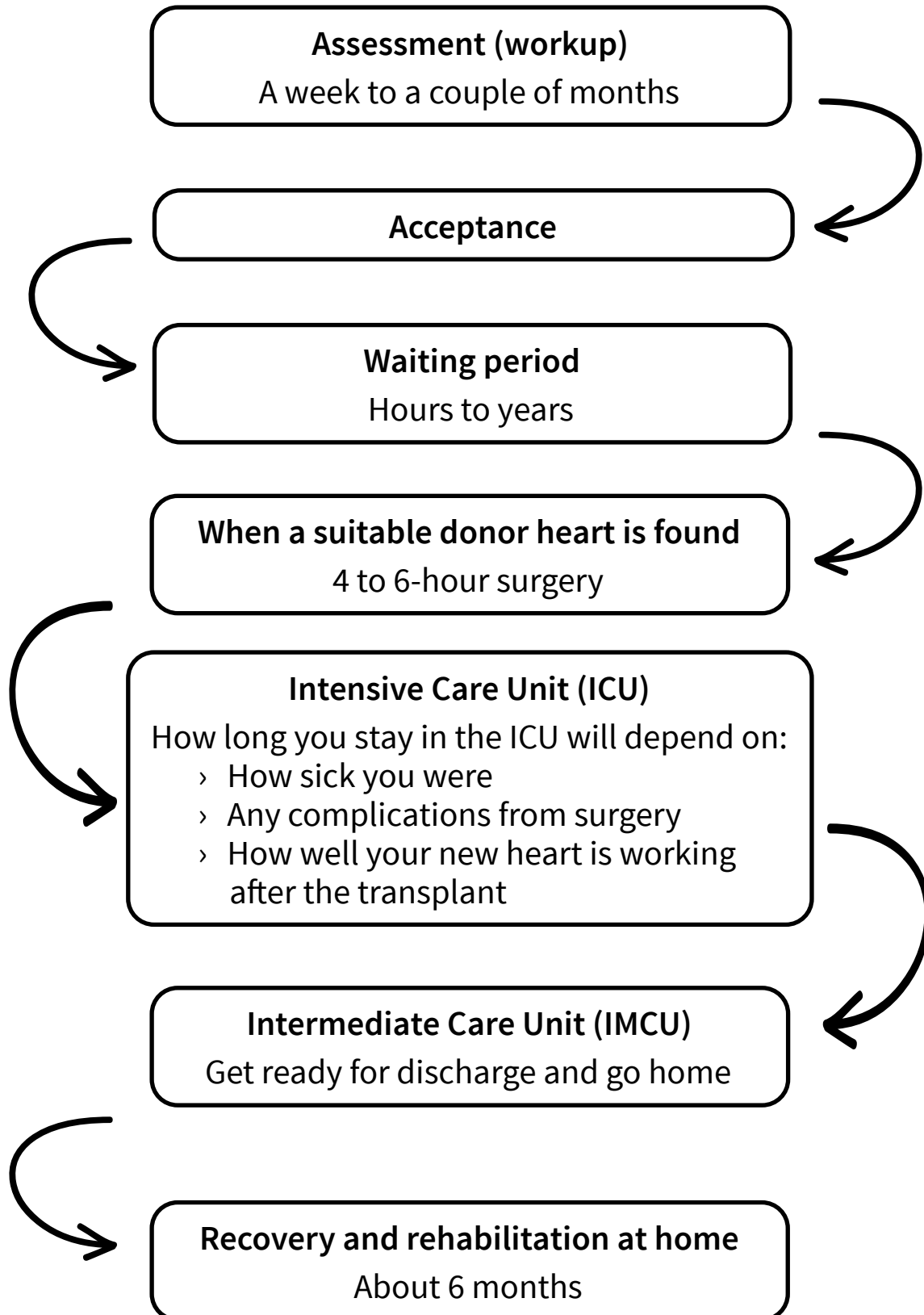
- **Bone mineral density test**
 - › This test measures the density of minerals (like calcium) in your bones using a special X-ray. As we get older, we do not build up calcium in our bones as fast as when we were younger. Immunosuppressive medications (medications that lower your immune system) can lower bone density, so it is important to check your bone health before starting these medications.
- **Tuberculin skin test**
 - › This test is to see if you have ever been exposed to tuberculosis (TB).
- **Consultations**
 - › During your workup, you will be referred to different health care providers for consultations. They may see you:
 - › while a transplant is being considered.
 - › after the transplant team has completed their assessment.
 - › while you are waiting for a transplant.
 - › after you have received a transplant.

What are your questions?

Please ask a member of your health care team. We are here to help you.

How long is the heart transplant process?

This is an estimate of how long the process can take. Each person's experience is different.



Waiting period

- Once you have been accepted for a transplant, an active search for a donor heart will start. Your time on the waiting list will be determined by:
 - › Your blood type
 - › Your body size
 - › How sick you are (this determines your status on the waiting list)
 - › Antibodies in your blood that could make organ rejection a concern

Blood type

- The donor heart must match your blood type.
 - › Patients who are type O tend to wait longer because they can receive only type O hearts.

Your body size

- The donor has to be close to your body size to be a good match for you.
 - › If you are taller or smaller than average, you may wait longer than someone who is of average body size.

This pamphlet is just a guide. If you have questions, please talk to your health care provider. We are here to help you.

Status on the waiting list

Your status on the waiting list is based on:

Status 1	<ul style="list-style-type: none">• Patients who are waiting at home
Status 2	<ul style="list-style-type: none">• Patients who are admitted to the hospital because their heart failure is not well controlled• Stable patients who have a left ventricular assist device (LVAD)• Stable patients who have cardiomyopathy• Stable patients waiting for a combined heart-kidney transplant
Status 3	<ul style="list-style-type: none">• Patients in the ICU who are on intravenous (I.V.) medications for their heart failure• LVAD patients who are admitted to the hospital• Patients with complex congenital heart disease• Patients waiting for a combined heart-lung or heart-liver transplant
Status 3.5	<ul style="list-style-type: none">• Patients in the ICU on high doses of I.V. medications for their heart failure or arrhythmias• Patients who would not do well with an LVAD
Status 4	<ul style="list-style-type: none">• Patients who are in the ICU on life support
Status S (1S, 2S, 2S, 4S)	<ul style="list-style-type: none">• Patients with lots of antibodies in their blood that make it hard to find a donor

Antibodies

- You will have blood tests during your workup to check for antibodies in your blood. Your body makes antibodies when it is exposed to things like viruses, blood transfusions, previous transplants, and, for some people, past pregnancies.
- When a suitable donor heart is found, your antibodies are compared to the donor antigens. If the donor heart has any antigens that match your antibodies, the donor heart cannot be accepted. This can cause your wait to be longer.

While you wait (for patients active on the waiting list only)

- If you are admitted to the hospital for any reason, it is important to tell us as soon as possible, even if it is not related to your heart condition.
- If you have a new health concern or diagnosis, you should also tell the transplant coordinator as soon as possible.
 - › For example, your doctor finds that you have low thyroid function (how well your thyroid works) and this is new for you. It is possible that you may have to be placed on hold on the waiting list because of this new health problem. This is mandatory (must be done) if the new condition may increase your risk of dying during transplant surgery. If you are on hold, you will not lose the time you already spent on the waiting list.

Advance care planning

- Advance care planning includes documents like advance directives and living wills.
- There may be a time in the future when you are not able to make decisions about your medical care and treatment.
 - › This may be temporary or permanent.
 - › It could happen suddenly or over time.
- Advance care planning helps to make it clear how you wish to be cared for and gives someone you trust the authority to act on your wishes.
 - › This person is known as a **Substitute Decision Maker (SDM)**. This is the person we would ask to make decisions, in the event that you are not able to do so.
- If you are not able to make decisions for yourself, there are 2 important things we need to know:
 1. What are your specific wishes for your health care?
 2. Who would you want to make decisions for you?
- It is important to answer these questions now, while you are capable of making decisions. **This helps to make sure that your wishes guide your care.** Please talk about your wishes with your loved ones, your SDM, and anyone else who might make decisions for you in the future. We are always happy to answer any questions you may have.

Powers of attorney

- It is important to think about your situation and make plans for your powers of attorney. Powers of attorney can have a big impact on your care and finances. It is a good idea to get legal advice to set up your powers of attorney.
- There are 2 basic forms of powers of attorney:
 - › Powers of attorney for personal care
 - › Powers of attorney for finances

Power of attorney for personal care

- A power of attorney (POA) for personal care is a person you choose to make decisions about your care when you are not able to make them yourself. This person is also called your SDM. To appoint a POA for personal care, you need to create a legal document.
- If you do not assign a POA for your personal care, the law states who may make these decisions on your behalf, in the following order:
 - › Spouse
 - › Adult children
 - › Parents
 - › Siblings
 - › Extended family members
- Sometimes people choose a POA for personal care who is different from their usual SDM.
 - › If this applies to you, make sure this is clearly stated in your POA document. Give copies of your POA document to your transplant team, the person named as your POA, and the hospital before you have your transplant.
- If there is no one to make decisions for you, and you cannot identify anyone to be your POA for personal care, the law can appoint a public guardian to make these decisions. This can be a long process. It is recommended you find a person to act as your POA for personal care to avoid delays.

Power of attorney for finances

- Your POA for finances is a person you choose to make decisions about your finances when you are not able to make them yourself. This person is called a power of attorney for finances. To appoint a POA for finances, you need to create a legal document. This document states who will be responsible for making your financial decisions or any payments.

Transplant process

When a suitable heart becomes available

- Your new heart will come from someone who has been declared brain dead and whose family consents to the donation of their organs.
 - › Brain death is a permanent condition that usually results from a head trauma or bleeding into the brain.
 - › Organ donation is an anonymous gift — you will not know who donated the heart.
- When a matching heart becomes available, the organ recipient coordinator or the heart transplant doctor on call will call or page you.
 - › **Do not eat or drink anything from that time on.**
- You will be asked how long it will take for you to get to the hospital. The organ recipient coordinator will tell you where to go at the Halifax Infirmary.

Important

- You must come to the hospital **safely** as soon as possible after the organ recipient coordinator contacts you.
- **Do not** rush or break any speed limits.

Testing the donor heart

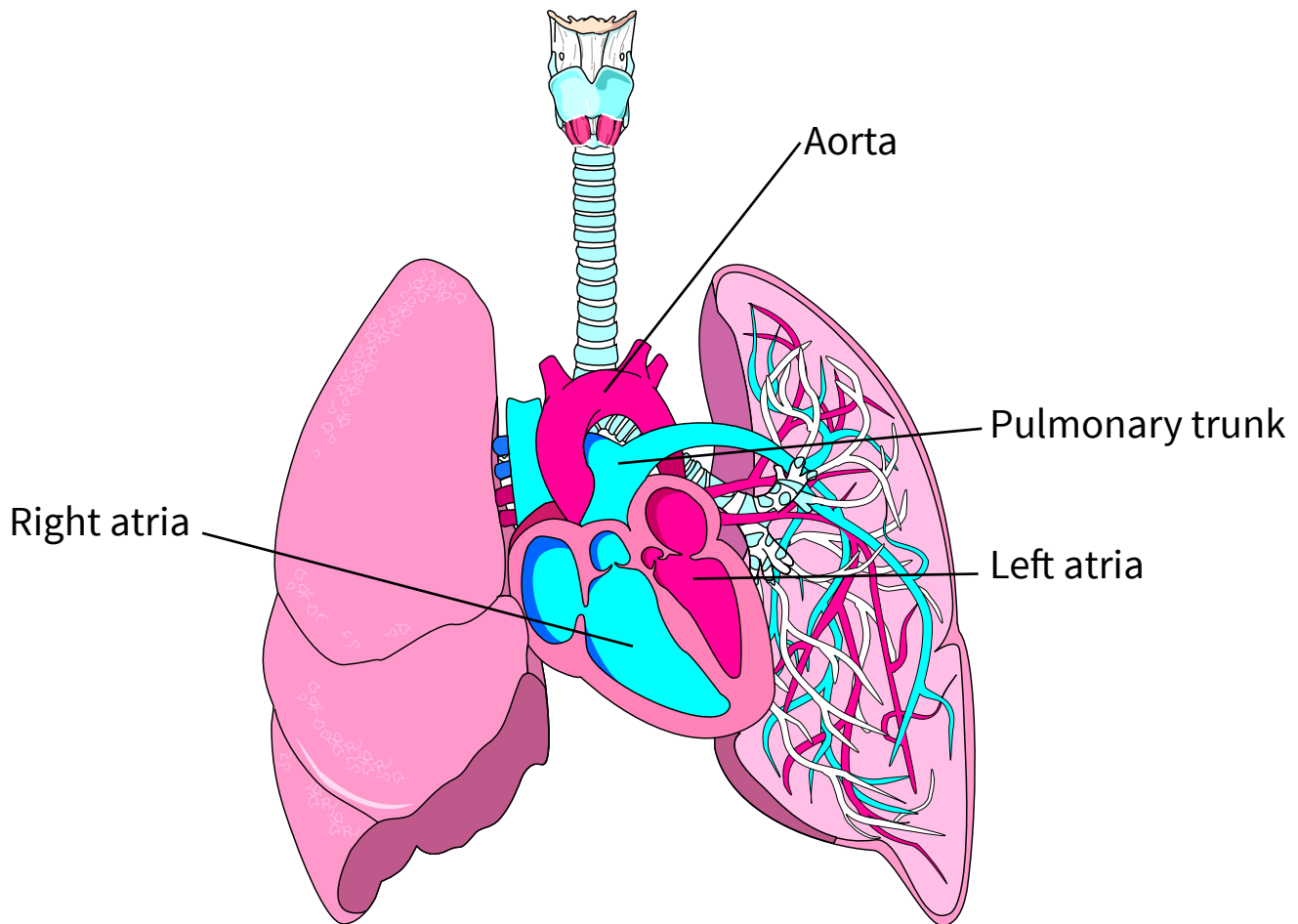
- Donors have a number of blood tests to make sure their organs are safe for donation.
 - › Two (2) of these blood tests are for cytomegalovirus (CMV) and toxoplasmosis.
 - › Even if a donor tests positive for CMV and/or toxoplasmosis, this does not mean that the donor heart is unsafe. This will depend on your immunity and your risk of getting a disease from the virus.

Getting ready for surgery

- Once you arrive at the Halifax Infirmary, you will get ready for surgery:
 - › You will have blood tests.
 - › You will have a chest X-ray (if a recent one is not available).
 - › Your chest hair will be clipped.
 - › The nurses will use a special product to clean your skin.
 - › The surgeon and anesthesiologist (a doctor who puts you to sleep for your surgery) will visit you.
- Two (2) surgeons will be involved in your surgery.
 - › One (1) will get the new heart and one will get you ready to accept the heart.
 - › They will work together to decide when to move you to the operating room.
 - › They will also do a final check to be sure the donor heart is in good shape for your transplant.
- Sometimes the heart must be refused (turned down) at the last minute because it is no longer suitable.
 - › If this happens, your transplant surgery will be cancelled. Try not to be discouraged.
- If the heart is accepted and you are taken to the operating room, send all of your personal belongings home with your loved ones.
 - › Make sure to keep your dentures, glasses, and hearing aids, if you have them.

Heart transplant surgery

- The surgery will last many hours. It may take longer if:
 - › You had heart surgery in the past
 - › You are taking warfarin
 - › You have a mechanical heart device
- During the transplant surgery, your own heart is removed.
 - › The back parts of the right and left atria and part of the pulmonary artery and aorta are left in place to connect to the new heart.
 - › The donor heart is removed and sutured (stitched) in place to replace your heart.



- The right and left atria of the donor heart are joined to the back part of your right and left atria.
- Your pulmonary artery and aorta are then attached to the donor heart.

What should my designated contact person/family members expect?

On the day of surgery

- Your family can stay with you before you go to the operating room.
- Once you leave to go to the operating room, your family should take all of your belongings from your room, since we do not know how long you will stay in the ICU.
- Your designated contact person/family member will be responsible for keeping your other family members informed of your progress.

During your surgery

- Your designated contact person/family members are welcome to wait in the family lounge on the floor.

After your surgery

- Once the surgery is complete, the surgeon will meet with your designated contact person if they are waiting in the family lounge.
 - › If your designated contact person chooses not to wait in the family lounge during your surgery, they should tell the nursing coordinator. The surgeon will call them at the number you have provided.
- You will get daily updates from the heart transplant team after your surgery.
- Staff on each unit will give your designated contact person/family member information about the unit where you will be staying.
 - › Unit staff will be able to answer any questions they may have.

Please note: Our privacy policy only lets us share information with the people you have specifically designated as contacts.

Donor information

- Both the donor and the recipient (person who receives the heart) are to stay anonymous. Details will **not** be shared between the donor and the recipient. This is the current policy in all of Canada, including Nova Scotia Health.
- You can write a letter to the donor family if you wish.
 - › In this letter, you can express your appreciation for the gift you have received and what it means to you.
 - › **Do not** give your name or identify yourself in the letter.
 - › **Do not** seal the letter.
 - › Give the letter to the transplant coordinator. They will forward it to the transplant organization coordinator who arranged for your new heart, who will review it and then give it to the donor family. Some donor families find it helps to get a letter from the recipient. On the other hand, some donor families may not want to get any information. This is why the transplant organization coordinator makes the connection between the 2 parties.

After your surgery

Cardiovascular Intensive Care Unit (CVICU)

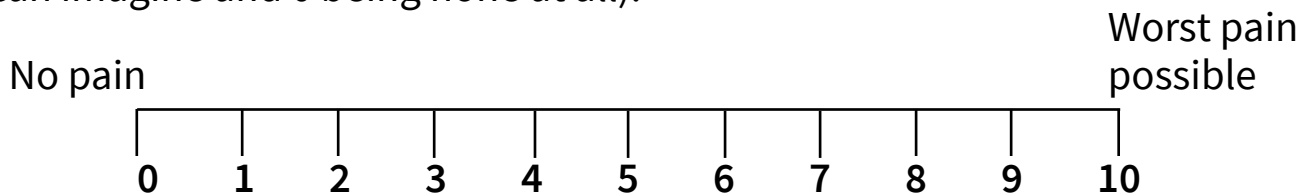
- After your surgery, you will be cared for in the CVICU. The number of days you may stay in this unit is different for each person. It is often more than 1 week.
- You will have many tubes attached to you after surgery. This table explains what these tubes are for and when they will be taken out:

Type of tube	Description
Breathing tube	<ul style="list-style-type: none">• Tube that passes between your vocal cords and is connected to a ventilator (breathing machine)• Talking is not possible with this tube in place• Use your hands to communicate with the nurse – if you are having pain near your incision (cut), rub your chest with your hand• Removed once your vital signs and blood work are stable, and when you are strong/awake enough to breathe on your own
Chest tubes	<ul style="list-style-type: none">• Drain blood from around your heart and lungs• Exit your body near the bottom of your chest• Removed when they are no longer draining fluid

Type of tube	Description
Arterial line in your wrist	<ul style="list-style-type: none"> Measures your blood pressure Removed when your vital signs (like heart rate, blood pressure, breathing) are stable
Catheter in your neck	<ul style="list-style-type: none"> Measures pressure inside your heart Removed when your vital signs are stable
Wires near the bottom of your chest	<ul style="list-style-type: none"> Used to pace your heart, if needed Removed the day before you are discharged home
Catheter in your bladder	<ul style="list-style-type: none"> Drains urine from your bladder Makes some people feel like they have to urinate (pee) Removed once you are more active

Pain

- **It is important to tell your nurse if you are in pain.** They have no other way of knowing.
- Your chest incision pain can be controlled with pain medication. This pain should not stop you from moving or breathing well. Moving will help you heal.
- Please describe your pain on a scale from 0 to 10 (10 being the worst pain you can imagine and 0 being none at all):



Coronary Care Unit (CCU)

- When you leave the CVICU, you will be cared for in the CCU. The number of days people stay on this unit is different for each person.
- You may still have some tubes attached from your surgery. This is different for each person.
 - › Tubes will be removed as they are no longer needed.
 - › The team will keep monitoring you closely and will make adjustments to your care plan as needed.
- You may still need some medications to support your heart function and blood pressure.
- Your stay in the CCU will focus on lowering the supports your body needs as you heal and recover from your surgery.

Transfer to the Cardiology Intermediate Care Unit (IMCU)

- You will be transferred to the Cardiology IMCU when your vital signs are stable, most of the tubes have been removed, and you can move around with the help of 1 person. When you are transferred to the IMCU, you will still have an I.V., pacer wires, and a heart monitor.
- The goal for your care in the IMCU is to increase your independence by:
 - › Improving your strength, mobility (movement), and coordination
 - › Taking medication on your own
 - › Getting you and your loved ones ready for your discharge home
 - › Continuing to watch for changes in your condition
- **It is important to get up and move as soon as possible after your surgery.** This will prevent you from having complications like pneumonia (lung infection), clots in your legs, and constipation (not being able to poop).
 - › **When you move, it is important to remember not to use your arms. Using your arms will cause the bones in your chest to rub together and get inflamed (irritated and swollen). This inflammation can lead to an infection that is very dangerous for heart transplant patients.**
- Your length of stay in the hospital will depend on your condition. You will be discharged once you:
 - Have stable vital signs and your incisions are healing well.
 - Have no infections and your blood work is stable (blood, kidney).
 - Are mobile and independent.
 - Can safely take your own medications.
 - Have home care and other services ready, if needed.
 - Had 1 biopsy showing no signs of rejection.
- Before you are discharged home, your health care team will review information with you and your family about:
 - › your new medications, including anti-rejection medications.
 - › how to self-monitor.

Discharge instructions

When you are discharged, make sure you have:

- Someone to help you at home for the first 2 weeks. **If you do not have someone to help you once you are discharged, please tell the social worker.** Arrangements will be made for you.
- A list of your medications.
- A follow-up appointment with the transplant team.
- Appointments for your next biopsy and blood work.
- Requisition forms for your blood work.
- Follow-up appointments with other services you were followed by (infectious disease, endocrinology), if needed.

Exercise

- **Exercise is very important to your physical and mental health.** Before you leave the hospital, your nurses and physiotherapists will work with you to:
 - › Improve your mobility and coordination
 - › Build your strength and endurance
- By the time you are ready for discharge, you will likely be able to walk around the Cardiology IMCU and climb 2 flights of stairs.
- After being discharged, you will slowly be able to go back to your usual activities.
 - › **It is important to follow an exercise program and walk every day.**
 - › Walk a bit more each day until you are walking 20 minutes in the morning and 20 minutes in the afternoon.

For the first 3 months after your transplant, **do not** lift anything over 5 pounds. This includes children, pets, and heavy shopping bags.

Sex

- Early on in your recovery, you may feel too tired to think about sex. This is common.
 - › Sex uses about the same amount of energy as climbing 2 flights of stairs. If you can climb 2 flights of stairs without shortness of breath or chest discomfort, you can go back to having sex.
- As you start to feel better, plan to have sex at a time when you are feeling rested and comfortable.
 - › Wait a few hours after you have had a large meal before having sex.
 - › During sex, use a position where you do not need to hold yourself up with your arms until your sternum (breastbone) has healed (at least 3 months).
 - › Find a position that is comfortable for you and your partner.
- If you are not in a monogamous (with only 1 person) relationship, always use latex condoms during sex to avoid being exposed to sexually transmitted infections (STIs).
 - › Avoid unprotected exposure to feces during sex.

Pregnancy

- Pregnancy is not recommended when taking medications needed after a heart transplant.
 - › Some of the medications have been shown to be linked with a higher risk of miscarriage and birth defects.
 - › Other medications have no information about how the medication affects a human fetus.
- Pregnancy after a heart transplant is possible, but it carries a higher risk for the pregnant person and the baby, including cardiac rejection and death of the pregnant person. If you have questions, please talk with your transplant cardiologist.
- **It is recommended that you use 2 forms of birth control when taking these medications.**
 - › A condom is the only method that protects against sexually transmitted infections (STIs).

Adjusting to life after your transplant

- You should expect the first 3 to 6 months after your transplant to be a time of major adjustment.
 - › During these months, the fear of infection, rejection, and medication side effects will slowly go away. It will be at least 6 months before you feel like your old self. Try not to get discouraged with your progress.
- After the excitement of having surgery, comes the realization of lifelong monitoring, taking care of your body, staying in shape, and possible changes to your career or activities.
 - › The support of your loved ones is very important during this time. Remember that the first year after your transplant is usually the hardest. After this, things usually get easier.

Weight

- Weight control can be hard for some post-transplant patients. Some medications may make you feel hungrier.
 - › Try to eat 3 meals a day and drink low-calorie drinks (like water and skim milk).
 - › If you drink soft drinks, drink the diet versions.
 - › Try to avoid sweets and high-calorie foods.
- Your weight will be checked at your outpatient clinic visits.
 - › We recommend keeping your own daily weight record to help you stay on track.

Smoking

- **Do not smoke.** Smoking will damage your new heart. It constricts (makes smaller) blood vessels and takes oxygen away from your heart by replacing oxygen with carbon monoxide in your blood.
- Smoking will also harm your lung tissue. It can lead to lung infections and many types of cancer. Because you are taking immunosuppressive medications, you are already at risk for developing infections and cancer. Smoking will greatly increase these risks.
- Second-hand smoke is just as bad.
 - › Avoid places where others are smoking.
 - › People who live with you should not smoke in the house or in the car when you are there.



Driving

- The sternum is usually healed enough for you to drive 6 to 8 weeks after your surgery.
- Before you can drive, your transplant cardiologist must assess you to determine your fitness to drive.
 - › They may decide to do more tests to see if it is safe for you to drive. Your transplant cardiologist will talk about this with you during one of your clinic visits.
- **If you have a commercial driver's license** (like a taxi driver), you cannot drive for 6 months after your transplant.

Sun protection

- The medications you are taking put you at a higher risk for skin cancer from the sun.
- Try to stay out of direct sunlight. **You must use sunscreen with a sun protection factor (SPF) of at least 30 before going out in the sun.** This will give you 97% protection from the sun's rays.
- You must put sunscreen on again every 2 hours, or after swimming or a lot of sweating. Wear a wide-brimmed sun hat and lightweight, long-sleeved shirts and pants when possible to protect your skin from the sun.

Going back to work

- The goal of your heart transplant is to help you go back to work or to your pre-transplant activities.
- When and if you go back to work will depend on how well you are recovering and the type of work you do.

Dental care

- **After your transplant, because you are taking immunosuppressive medications, it is more important than ever to keep your mouth and teeth very clean. Bacteria in your mouth can get into your bloodstream through your gums and infect your heart.**
- You can prevent dental complications by:
 - › Brushing 2 times each day
 - › Using dental floss at least once a day
 - › Cleaning dentures or prostheses after every meal
- It also helps to have regular dental checkups, every 6 to 12 months.
- We recommend taking a preventive dose (amount) of antibiotic 30 to 60 minutes before any dental work involving gingival mucosa manipulation (working on the gums).
 - › This can be prescribed by your transplant team.

MedicAlert® bracelet

- In an emergency, this bracelet will tell health care providers that you are a heart transplant recipient and are on immunosuppressive medications.
- The following should be engraved on your bracelet:
 - Heart transplant
 - Immunosuppressive medications
 - Any medication allergies



Follow-up schedule

Blood work

- You will need blood work at each clinic visit.
 - › The heart transplant coordinator will tell you when blood work is needed between visits. This may be done often until your immunosuppressive medication levels are stable. Then it will be done less often.
 - › If you are having a biopsy, you can do the blood work on the same day as your biopsy.
- Remember to leave 12 hours between your evening dose of anti-rejection medications and your morning blood work.
- **Do not** take your morning medications until after your blood work is done.

Clinic visits

- During your clinic visits, the cardiologist will assess you, review your lab work and medications, and tell you of any changes.
 - › You will need frequent clinic visits for the first 6 to 12 months after your transplant.
 - › Once your medications are stable, you will be seen 1 or 2 times a year.

Cardiac biopsy schedule

- You will have at least 1 heart biopsy before you leave the hospital. After discharge, your biopsy schedule will be:
 - › Each week for the first month
 - › Every 2 weeks for the second month
 - › At 3 months, 6 months, 9 months, 1 year, 18 months, and 2 years
 - › 2 weeks after any episode of rejection needing treatment
- This schedule may change depending on your condition, or if there is a major change in your immunosuppressive medication.

Diagnostic tests

- You will need several diagnostic tests at different times. The heart transplant coordinator will arrange for these.

Rehabilitation (rehab)

- Once you are discharged, we recommend that you join a rehab program to help you get your health on track. This will depend on whether there is a cardiac rehab program where you live.
- You may also be able to work on rehab at home. Talk with your physiotherapist about this.

Immune response

- Your immune system is made up of cells, tissues, and organs. It protects your body from infections caused by foreign organisms and substances (like bacteria and viruses).
- Your immune response is the steps your immune system takes to attack these organisms and viruses so that they do not cause disease.
- The cells in the donor heart carry markers that identify them as not belonging to your body. Your immune system sees these cells as a threat and triggers an immune response. This causes your immune system to attack the donor heart. This is called **rejection**. Immunosuppressive medications stop this immune response to the transplanted heart.
- Your immune system will be very active right after your heart transplant. You will take higher doses of immunosuppressive medications during this time. Over time, your immune system will be less active and your medication doses will change. Because your immune system remembers these cell markers, **you will need to take these medications for the rest of your life.**

Acute rejection

- You may still have a rejection episode, even with the right care and medications. Acute rejection is most likely to happen within the first year after your transplant, but may also happen at any time. Most rejection episodes are mild and are usually treated well with medications while you are at home.
- You may not know that rejection is happening. It is often found during a regular follow-up biopsy and routine clinic visits. **This is why it is important for you to go to all of your appointments and not miss a biopsy.**
- **Know the signs and symptoms of rejection and tell your transplant team right away.** Treatment works better if rejection is caught early.

Watch for these signs:

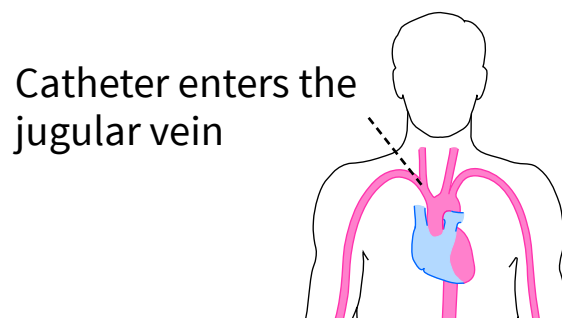
- New or increasing shortness of breath from mild exertion
- Progressive weight gain of about 2 pounds a day with ankle swelling
- Irregular or fast heartbeat
- Loss of energy and appetite
- Flu-like symptoms:
 - › Fatigue (tiredness)
 - › Chills
 - › Nausea (feeling sick to your stomach)
 - › Aches
 - › Fever (temperature above 38 °C or 100.4 °F)

Since rejection is an ongoing concern for transplant recipients, **it is extremely important for you to take your medications exactly as prescribed.**

Cardiac biopsy

Cardiac biopsy is the only reliable way to diagnose acute rejection. A biopsy can detect rejection before any permanent damage is done to your heart. You **do not** need to stay in the hospital overnight for a cardiac biopsy. During the biopsy, you will:

- Be in a special room with X-ray equipment.
- Lie on a hard table and be connected to a heart monitor.
- Have drapes around your head, neck, and chest.
- Get an injection in your neck or groin that will numb the area. Have a catheter inserted into the jugular vein in your neck or in your groin once your skin is numb.
- Have an instrument called a bioptome inserted through the catheter into your heart. The bioptome has small jaws on the end that open and close, letting it take small tissue samples of your heart. We will take 3 to 5 samples that are about 2 millimeters in size.
- Possibly feel a few extra beats of your heart. This is normal. You will also feel a slight tugging sensation, but it will not hurt.
- Have pressure and a bandage applied over the puncture site (where the catheter entered your body).



- The samples are sent to a pathologist (a doctor who looks at tissue to diagnose diseases) to be examined.
- Complications from a cardiac biopsy are very rare. If they do happen, it is during or right after the procedure. **It is important to report any:**
 - › **Chest pain**
 - › **Fast or irregular heartbeat**
 - › **Shortness of breath**
- Remove the bandage after 48 hours (2 days). **Do not** do any heavy lifting for 24 hours (1 day) after the biopsy. Before you cough or sneeze, put pressure on the puncture site with your hand. If the site starts to bleed, apply pressure for 10 minutes. **If the bleeding does not stop, go to the nearest Emergency Department right away.**

Biopsy results

- The number of rejection cells found in the biopsy samples shows the amount of rejection, called a **grade**.
 - › The grades include zero, mild (1R), moderate (2R), and severe (3R). The grade of rejection, along with other factors, helps to determine the treatment you will need.
- The biopsy results are usually available late the next day.
 - › If the biopsy shows rejection that needs treatment, the heart transplant coordinator will contact you right away with instructions.
 - › Most rejection episodes can be treated safely with oral (taken by mouth) medication at home, but sometimes I.V. medications are needed. We may ask you to come to the clinic or go to your local hospital for this.
- The oral medication used to treat rejection is prednisone.
 - › You will be given high doses of prednisone for 3 days, and then a lower dose until your next biopsy.
 - › If you have diabetes, you should monitor your blood sugar level more closely during this anti-rejection therapy. Call your diabetes doctor if your blood sugar level increases.
- Your cardiologist may decide to change the other immunosuppressive medications you are taking to better treat your rejection.

Cardiac allograft vasculopathy (CAV)

- CAV is a common complication after a heart transplant.
 - › It is caused by a thickening of the inner lining of the coronary arteries.
- About half of heart transplant patients have some CAV 10 years after their transplant.
 - › To lower the risk of this happening, you will need to take cholesterol medication and Aspirin®.
 - › We may also suggest taking a medication called sirolimus (Rapamune®), which lowers the risk of CAV getting worse.

Immunosuppressive medications

- For your body to accept your transplanted heart, your immune system must be suppressed (slowed down). This will let your new heart work properly. You will need to take this medication for the rest of your life.
- The medications used most often to suppress your immune system include tacrolimus (Prograf®), mycophenolate (CellCept®), and prednisone.
- Your transplant cardiologist will decide what doses of medication you need. This is based on the results of your blood tests, biopsies, and other factors. **Your transplant cardiologist should be the only person to change the doses of your medications.**

Important: Never change your medication doses on your own.

Take all of your medications exactly as directed. If you have any questions about your medications, ask your transplant cardiologist or your pharmacist.

Contact your transplant cardiologist if you:

- Have severe nausea, vomiting (throwing up), or diarrhea (loose, watery poop).
- Have nausea, vomiting, or diarrhea that does not go away.
- Are having possible side effects or new symptoms from your medications.
- Have been prescribed a new medication by a doctor or a dentist.
- Choose to take over-the-counter medications or natural health products, as some of these may interact with (affect) your medications.
- You should know the names of your medications, how often you take them, and what they are for.
- **It is important to bring all written prescriptions for your medications to your regularly scheduled appointments with your cardiologist.**
 - › It is your responsibility to keep track of all remaining refills on your prescriptions and to avoid running out of your medications between appointments.

Immunosuppressants – General warnings

Missed doses

- **It is very important to take all of your medications.** If you miss a dose, take it as soon as possible, then go back to your regular dosing schedule. If you do not remember until the next day, skip the missed dose.
- **Do not** take 2 doses at the same time or use any extra medication to make up a missed dose. If you vomit or have diarrhea right after taking a dose, call the heart transplant coordinator for advice.

Warnings

- **Do not** change the dose of, or stop taking, any medication unless you are told to do so by your transplant cardiologist.
- If you have diabetes, monitor your blood sugar level more often (especially with high doses of prednisone), and tell your diabetes doctor about any increases in your blood sugar level.
- If you are having higher levels of anxiety and stress, tell your cardiologist.
- **It is important to have an eye exam every year when taking immunosuppressants because they can increase your risk of glaucoma and cataracts.**
- These medications may cause high blood pressure. You should have a blood pressure monitor so that you can check your blood pressure regularly at home.
- Immunosuppressants will make your skin more sensitive to the sun. You should wear a sunscreen with an SPF of 30 or higher and try to limit sun exposure.

Interactions

- Drinking alcohol is not recommended. Alcohol irritates the stomach lining, putting you at a higher risk for ulcers.
- Limit caffeine intake.
- Grapefruit and grapefruit juice may increase blood levels of some medications and their toxic effects on your body.
- High fat foods will lower your blood levels of tacrolimus. Try to limit your intake of high-fat foods.
- **Do not** take St. John's wort, cat's claw, or echinacea, as they can interfere with immunosuppressant medications.
- Antacids containing calcium, magnesium, and aluminum (Tums[®], Rolaids[®], Diovol Plus[®]) can affect how your body takes in some medications. **Do not** take them within 2 hours of taking immunosuppressants.
- Avoid anti-inflammatory medications, like ibuprofen (Advil[®], Motrin[®]), indomethacin (Indocin[®]), naproxen (Naprosyn[®], Aleve[®]), and diclofenac.
- Avoid macrolide antibiotics (erythromycin, azithromycin, clarithromycin).

Medications

Tacrolimus (Prograf®, Advagraf®, FK506) – Calcineurin Inhibitor (CNI)

Tacrolimus blocks the action of immune cells that might cause your body to reject your transplanted heart.

How to take tacrolimus

- **It is important to take tacrolimus at the same time each day, every 12 hours.** You can take tacrolimus with or without food. **Do not** crush or chew the capsules. **Do not** stop or adjust this medication unless your transplant cardiologist or your heart transplant coordinator tells you to.
- Your dose of tacrolimus is determined by the level of the medication in your blood. Over time, your dose of tacrolimus will change. Higher doses are needed right after your transplant, but over time you will need less. Blood levels of tacrolimus will be checked from time to time.
- **It is important to take your evening dose 12 hours before your morning blood work.** For example, if you take your evening dose at 8 p.m., your blood work should be done at 8 a.m. the next day, before you take your morning dose. This reading of your blood will tell your cardiologist if your dose needs to change.
- **While taking tacrolimus, you may have:**
 - › Higher risk of infection
 - › High blood pressure
 - › Dizziness, headache, poor sleep, tremors (movements you cannot control), seizures (sudden electrical brain activity that can change how you act, move, or feel for a short time)
 - › Ringing in the ears
 - › Numbness and tingling around the mouth, flushing
 - › Higher blood sugar (diabetes)
 - › High blood potassium levels
 - › Constipation, diarrhea, nausea, vomiting, gas, cramps,
 - › Feeling more hungry
 - › Anemia (low blood iron), skin bruising
 - › Feeling of “pins and needles” in the hands and feet, increased sensitivity to touch
 - › Leg cramps, muscle pain, joint pain
 - › Osteoporosis (weakened bones)
 - › Abnormal kidney function
 - › Unusual dreams, elevated mood or mood changes
 - › Acne (pimples), hair loss, increased sweating
 - › Higher risk of skin cancer

Foods, drinks, and supplements to avoid

- Grapefruit juice may raise your blood levels of tacrolimus and cause toxic (harmful) effects on your body.
- High fat foods will lower your blood levels of tacrolimus.
- St. John's wort will lower your blood levels of tacrolimus.
- Avoid cat's claw and echinacea. These will stimulate your immune system (make it work harder), which may possibly raise the risk of rejection.

Important

- Antacids can affect how your body takes in tacrolimus. Take them at least 2 hours before or 4 hours after taking tacrolimus.
- Avoid anti-inflammatory medications, like ibuprofen (Advil[®], Motrin[®]), indomethacin (Indocin[®]), naproxen (Naprosyn[®], Aleve[®]), and diclofenac. They can increase stomach irritation when combined with prednisone.
- Avoid the antibiotic erythromycin and any other antibiotics in the macrolide medication family. There are many prescription and non-prescription medications that can interact with tacrolimus, changing the way it works in your body. Make sure your pharmacist knows you are on tacrolimus. Call your transplant cardiologist or your heart transplant coordinator to find out if new medications, including vitamins and herbal products, are safe to take with tacrolimus.

Mycophenolate mofetil (CellCept®, Myfortic®)

Mycophenolate mofetil prevents organ rejection by suppressing your immune system.

How to take mycophenolate mofetil

- Mycophenolate mofetil is taken 2 times a day, once in the morning and once in the evening. It is best to take this medication on an empty stomach, but you can take it with food. **Do not** break, crush, or chew the tablets. **Do not** use a pill that is broken.
- Your white blood cell count will be monitored regularly. If your white blood cell count drops too low, your dose of mycophenolate mofetil may need to be adjusted. **Do not** stop or adjust this medication unless your transplant cardiologist or the heart transplant coordinator tells you to.
- **While taking mycophenolate mofetil, you may have:**
 - › Higher risk of infection
 - › Nausea, vomiting, stomach pain, diarrhea, constipation
 - › Headache, mild weakness
 - › High blood pressure
 - › Swelling, numbness, or tingling in your hands or feet
 - › Anxiety, sleep problems, mood changes
 - › Skin bruising or bleeding
 - › Muscle and joint pain
 - › Higher risk of cancer
 - › Low blood iron, low white blood cell count, low platelets
 - › Higher cholesterol, higher blood sugar level
 - › Abnormal kidney function

Foods, drinks, and supplements to avoid

- None

Prednisone

Prednisone is prescribed to prevent organ rejection. It is prescribed in high doses to treat acute rejection.

How to take prednisone

- Prednisone is taken once a day. It is best to take this medication with food to prevent stomach upset. Prednisone comes in 5 mg and 50 mg tablets. If large doses are needed, 50 mg tablets are available.
- Over time, you may be weaned off (your dose will be lowered until you stop taking it) of prednisone. **DO NOT** stop or adjust this medication unless your transplant cardiologist or your heart transplant coordinator tells you to.
- While taking prednisone, you may have:
 - › Higher risk of infection
 - › Poor sleep, nervousness
 - › Headache
 - › Mood swings
 - › Feeling more hungry
 - › Nausea, vomiting, belly swelling, irritation of the stomach lining (ulcers)
 - › Hair growth, acne, skin bruising, fragile skin
 - › Higher blood sugar (diabetes)
 - › Lower potassium levels
 - › Joint pain, muscle wasting
 - › Fluid retention, rounding of the face
 - › Osteoporosis (weakening of the bones)
 - › Slower wound healing
 - › Cataracts (lens of your eye becomes cloudy)
 - › Higher blood pressure
 - › More sensitive to the sun

Storage

Store your prednisone at room temperature and away from moisture, heat, and direct sunlight. Always keep your medication away from children and pets.

Warnings

- **Do not** change the dose of this medication unless you are told to do so by your transplant cardiologist.
- **Do not** suddenly stop taking this medication. You must be gradually weaned off prednisone.
- If you have diabetes, monitor your blood sugar level more often (especially with high doses of prednisone), and tell your diabetes doctor about any increases in your blood sugar level.
- If you are having higher levels of anxiety and stress, tell your cardiologist.

- **It is important to have an eye exam every year when taking prednisone because it can increase your risk of glaucoma and cataracts.**
- This medication may cause high blood pressure. Get a blood pressure monitor so that you can check your blood pressure regularly at home.
- Take calcium and vitamin D supplements. Prednisone makes your bones fragile and they could break more easily.
- Tell your doctor that you are on prednisone before:
 - › Having any skin tests
 - › Any kind of surgery or emergency treatment
 - › Treatment for an injury

Foods, drinks, and supplements to avoid

- Drinking alcohol is not recommended. Alcohol and prednisone both irritate your stomach lining putting you at higher risk for ulcers.
- Prednisone interferes with calcium absorption (how much your body takes in). Because caffeine also affects calcium absorption, limit your caffeine intake.
- St. John's wort may lower prednisone levels.
- Avoid cat's claw and echinacea. These will stimulate your immune system, which may raise the risk of rejection.

Medication interactions

- Antacids can affect how your body takes in prednisone. Take them at least 2 hours before or 2 hours after taking prednisone.
- Taking diuretics with prednisone can increase the loss of potassium from your body.
- Avoid anti-inflammatory medications, like ibuprofen (Advil[®], Motrin[®]), indomethacin (Indocin[®]), naproxen (Naprosyn[®], Aleve[®]), and diclofenac. They can increase stomach irritation when combined with prednisone.
- The anticoagulation (blood-thinning) effects of warfarin (Coumadin[®]) may be increased with prednisone. It is important to monitor your international normalized ratio (INR) if you are taking warfarin and prednisone.

Other medications

- The medications used to suppress your immune system have side effects, which will need to be managed with other medications. These medications are described below.

Enteric-coated aspirin (Entrophen[®], Novasen[®])

- Aspirin[®] will help prevent narrowing of your coronary arteries. You will take 81 mg (1 baby Aspirin[®] tablet) every day.

Nystatin (Mycostatin[®])

- Nystatin will prevent yeast (thrush) infections in your mouth. You will take:
 - › 5 ml 4 times a day for the first 3 months after your transplant
 - › Then 1 ml 4 times a day for 2 more months
- Swish the medication around in your mouth and hold it there for as long as you can, then gargle and swallow. You will be discharged from the hospital on this medication and will take it until you are on a lower dose of prednisone.

Antihypertensives (blood pressure medications)

- It is common to have high blood pressure after a heart transplant. Some of the medications used to treat high blood pressure include:
 - › Calcium channel blockers, like diltiazem
 - › ACE inhibitors, like perindopril
 - › Angiotensin receptor blockers, like candesartan
 - › Beta blockers, like metoprolol
- It can help to have a blood pressure monitor at home so that you can check your own blood pressure.
 - › The top blood pressure number (systolic reading) should be around 130. A top number over 140 may need to be treated.
 - › The bottom number (diastolic reading) should be around 80. A bottom number over 95 needs to be treated.

- It is also possible to have low blood pressure. Tell your transplant cardiologist or your heart transplant coordinator if you have any of these symptoms after starting this medication:
 - › Fatigue, no energy
 - › Dizziness and light-headedness when changing positions
 - › Fainting
 - › Blurred vision
 - › Poor concentration
 - › Nausea
 - › Cold, clammy, pale skin
 - › Feeling very thirsty
- To help with these symptoms:
 - › Get up slowly and move gradually from lying down to sitting, and then from sitting to standing. This will lower the drop in blood pressure you may have if you go directly from lying to standing.
 - › If you are taking an ACE inhibitor for your blood pressure, try taking it at bedtime instead of in the morning. If these suggestions do not help your symptoms, call your transplant cardiologist or your heart transplant coordinator.

Cholesterol medications

- Taking a cholesterol medication, along with healthy eating and exercise, will help to lower the levels of cholesterol and other fats in your blood. Lowering cholesterol and fat will help prevent narrowing of your coronary arteries. Cholesterol medications include:
 - › Pravastatin (Pravachol[®])
 - › Ezetimibe (Ezetrol[®])
 - › Atorvastatin (Lipitor[®])
 - › Rosuvastatin (Crestor[®])
- The goal is to have LDL, or bad cholesterol, of less than 2.0.

Antiviral medications

- You may need to take an antiviral medication after your transplant, or you may need one later on as a result of a viral infection. They include:
 - › Valganciclovir (Valcyte®)
 - › Acyclovir (Zovirax®)

Medications for your stomach

- You will be started on a medication to protect your stomach from the risk of ulcers. You may already be taking something, and you can keep taking it. These medications include:
 - › Omeprazole (Losec®)
 - › Rabeprazole (Pariet®)
 - › Pantoprazole (Pantoloc®)
 - › Esomeprazole (Nexium®)
 - › Ranitidine (Zantac®)

Medications for bone health

- You may be prescribed medications and supplements to keep your bones healthy. These include:
 - › Alendronate (Fosamax®) or risedronate (Actonel®). These are taken once a week to prevent bone deterioration (breakdown) and osteoporosis.
 - › Vitamin D supplement
 - › Calcium supplement

Infection prevention

- You may receive an antibiotic called sulfamethoxazole/trimethoprim (Septra®), to prevent infection. This is usually taken 3 times a week for the first year after your transplant.

Cytomegalovirus (CMV)

- CMV is related to the herpes virus. Eight (8) or 9 out of every 10 adults has CMV.
 - › Most people are infected by the time they are 2 years old or during their teens.
 - › Most people do not have any symptoms. Some will have a mono-like illness or a cold.
 - › CMV does not cause a serious illness or need treatment in people with a normal immune system.
- While CMV is not a problem for most people, it is a concern for transplant patients.
 - › Based on your results and the donor's results for CMV, you may be given the antiviral medication valganciclovir for the first 3 months after your transplant.
 - › Valganciclovir prevents infections caused by CMV. You may also be given immunoglobulin (an antibody specifically against CMV).

Toxoplasmosis

- Toxoplasmosis is an infection caused by the parasite *Toxoplasma gondii*, which is found in cat feces (poop) and in contaminated foods. You can get the parasite by touching cat litter or dirt with contaminated cat feces.
 - › The parasite can sometimes be found in raw, unwashed vegetables and undercooked meat products, and in contaminated drinking water.
- The number of people with toxoplasmosis goes up with age and ranges from 8 to 60% of the population, depending on location.
- The parasite causes either no symptoms or a flu-like illness in healthy people.
- Toxoplasmosis is not a problem for most people, but it is a concern for someone who has had a heart transplant.
- Based on your results and the donor's results for toxoplasmosis, you may be given the antibiotic sulfamethoxazole/trimethoprim (Septra®) for the first year after your heart transplant or for the rest of your life. Septra® prevents infections caused by toxoplasmosis. If you have an allergy to Septra®, please tell your transplant cardiologist.

Tips for preventing infection

- Wash your hands (even after using gloves) with soap and water:
 - › Before preparing food
 - › Before eating
 - › Before and after touching wounds (broken skin), including your own or someone else's
 - › Before touching mucous membranes (rubbing your eyes or touching the inside of your mouth or nose)
 - › After touching secretions (saliva) and excretions (urine)
 - › After touching pets and animals
 - › After gardening (touching plants or soil)
 - › After changing diapers
 - › After touching anything that has touched human or animal feces (like bedpans, bedding, toilets, litter boxes)
 - › Wash cutting boards, dishes, counters, utensils, and hands with hot, soapy water after contact with raw meat, poultry, seafood, or fruits or vegetables that have not been washed

Preventing respiratory (airway) infections

- Most respiratory infections are spread through direct contact or by breathing them in. The tips below can help lower your chance of getting a respiratory infection.

Preventing infections from other people:

- Wash your hands often and well, especially before touching your mouth or nose.
- Avoid being near anyone with a cold or a virus. If this is not possible, people who are sick should wear a mask when they are near you.
- Avoid tobacco smoke. Smoking and second-hand smoke put you at risk for bacterial and viral infections.
- Avoid exposure to people with known active tuberculosis (TB).
- Avoid activities or jobs where exposure to TB is more likely (like in prisons, homeless shelters, and some health care settings). Talk with your cardiologist to help you decide whether to continue working in these places.

Preventing exposure to mold and fungus

- **Do not** smoke cannabis. It can expose you to mold spores (aspergillus) that can cause a possibly deadly pneumonia.
- Avoid construction, excavation areas, and other dusty places. There may be high amounts of mould spores in these areas.
- Avoid contact with soil, fertilizer, and decaying vegetation (compost heaps), which can contain mold. Gardening and farming are not recommended for the first year after a transplant. If you must garden or farm, wear a mask and gloves.
- Avoid areas like chicken coops, silos, and caves where there are bird droppings. Fungal spores can be spread through bird droppings. Wear a mask and gloves if you must be near these kinds of areas.

Water safety

- If there is a boil water advisory in your community, make sure you boil the water for at least 1 minute or use personal-use filters and/or bottled water. Make sure the filter and bottled water are good quality.
- Avoid water from private and public wells that are not tested regularly for bacteria.
- **Do not** drink water from a lake or a river.
- Avoid swimming in water that is likely to be contaminated with human waste, and avoid swallowing water when swimming.

Food safety

- Wash raw fruits and vegetables well.
- Avoid drinking unpasteurized drinks and eating foods made with unpasteurized milk.
- **Do not** eat raw or undercooked eggs, including foods with raw eggs. Yolks should be cooked.
- Avoid eating raw or undercooked meat, poultry, fish, and seafood. Hot dogs and sausages should be fully cooked.
- Avoid eating all raw seed sprouts and raw green onions.
- Avoid cross-contamination when preparing food:
 - › Keep raw and cooked foods separate.
 - › Use clean or separate cutting boards for raw and cooked foods.
- Avoid fast-food restaurants and salad bars to avoid salmonella. Reheat leftovers so they are steaming hot.

Signs and symptoms of infection

It is important to know the signs and symptoms of an infection. **If you have any of these, talk to your primary health care provider (family doctor or nurse practitioner), transplant cardiologist, or heart transplant coordinator as soon as possible.** The sooner you get treatment, the better the outcome. Call your heart transplant coordinator if you are not sure and what you should do.

Where in your body:	If you have any of these symptoms...	... then you should:
Lungs	<ul style="list-style-type: none">• Fever above 38 °C or 100.4 °F• Ongoing cough• Sputum (phlegm) that is brownish, yellow, or green• Chest pain that gets worse when you cough or breathe in deeply• Trouble breathing• Fast heartbeat• Aches and pains, more tired• Headache, less hungry	<ul style="list-style-type: none">• See your primary health care provider• If you are prescribed an antibiotic for the infection, ask your pharmacist about any possible interactions between the antibiotic and your other medications<ul style="list-style-type: none">› If your pharmacist is not sure about interactions, call your heart transplant coordinator
Sinuses	<ul style="list-style-type: none">• Yellow or green mucus• Pain around your eyes and nose• Head pain when bending over	<ul style="list-style-type: none">• Same as lungs section above

Where in your body:	If you have any of these symptoms...	... then you should:
Skin (cuts)	<ul style="list-style-type: none"> • A cut or wound that is red, swollen, and warm to the touch • A cut or wound that is draining yellow or green liquid 	<ul style="list-style-type: none"> • Clean any cuts or wounds right away • See your primary health care provider if you think you might have an infection • Go to the nearest Emergency Department right away if you need stitches
Skin (rash)	<ul style="list-style-type: none"> • A rash with fluid-filled blisters that travels in a straight line on one side of your body — this could be shingles 	<ul style="list-style-type: none"> • Call your heart transplant coordinator or your transplant cardiologist if you have any signs of shingles. You will need an antiviral medication. • Antiviral medication will not interact with your medications, but the dose may need to be adjusted based on your kidney function • If you are prescribed an antibiotic for the infection, ask your pharmacist about any possible interactions between the antibiotic and your medications <ul style="list-style-type: none"> › If your pharmacist is not sure about interactions, call your heart transplant coordinator
Mouth	<ul style="list-style-type: none"> • Sores on your lips, in your mouth, or down your throat • Discomfort when swallowing 	<ul style="list-style-type: none"> • Same as skin (rash) section above

Where in your body:	If you have any of these symptoms...	... then you should:
Stomach and bowels	<ul style="list-style-type: none"> • Diarrhea, nausea, or vomiting 	<ul style="list-style-type: none"> • Make sure you can take your medication and keep them down • Take Gravol™ 30 minutes to 1 hour before your medications are due if you are having nausea and vomiting • Sip small amounts of fluid throughout the day • Eat food that is easy on your stomach, like bananas, applesauce, rice, tea biscuits, or toast • If you cannot take your medications or keep any fluids down, call your heart transplant coordinator or your primary health care provider, or go to the nearest Emergency Department right away
Urinary tract / bladder	<ul style="list-style-type: none"> • Burning or stinging when peeing • Feeling like you need to pee often, but only able to pee a little bit • Bad-smelling or cloudy urine • Bloody urine 	<ul style="list-style-type: none"> • See your primary health care provider or call your transplant coordinator • If you are prescribed an antibiotic for the infection, ask your pharmacist about any possible interactions between the antibiotic and your medications • If your pharmacist is not sure about interactions, call your heart transplant coordinator
Genital area	<ul style="list-style-type: none"> • Painful sores in your genital area 	<ul style="list-style-type: none"> • Same as urinary tract/bladder section above

Healthy eating after your heart transplant

- Healthy eating after your transplant can help you control your weight, cholesterol, blood pressure, and diabetes. Healthy eating means choosing to eat a variety of foods each day. These include:
 - › Vegetables and fruit
 - › Whole grains
 - › Foods high in protein

Nutrition after your transplant

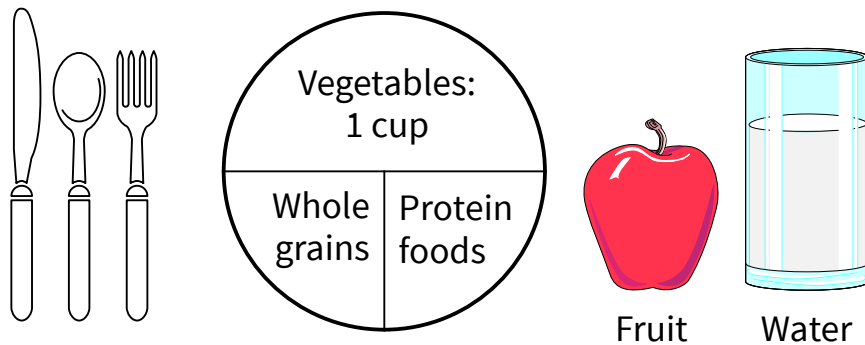
- Your body will need extra calories and protein in the first few weeks after your transplant to help with healing.
- Even if you do not feel hungry, it is important to eat.
 - › It may help to eat small meals more often and take oral nutrition supplements (like Ensure[®], Boost[®]).
- Talk with your dietitian about how to meet your nutritional needs.

What can I do to eat heart healthy?

- Make meals at home using fresh, whole foods.
- Eat fewer processed foods, which often have added sugar, salt, and fat.
- Choose whole foods to get the most nutrition and least additives.
- Limit distractions while you are eating (put down your cellphone, turn off the TV).
- Eat slowly and focus on enjoying your food.
- **Do not** skip meals. Try to eat 3 meals a day plus snacks.

Vegetables and fruits

- Eating vegetables and fruits can lower your risk of many diseases, including coronary artery disease. Vegetables and fruits give you vitamins, minerals, antioxidants, and fibre that your body needs for good health.
- Try to fill half your plate with vegetables at each meal.
- Choose a variety of colours, especially green and orange vegetables.
- Include more whole fruits and vegetables instead of fruit juices.



Whole grains

- Whole grain foods have important nutrients, including fibre, vitamins, and minerals. Whole grains are a healthier choice than refined (processed) grains.
- Try a variety of whole grains, including oats, quinoa, brown rice, whole grain pasta, and whole grain bread.
- Try to fill a quarter of your plate with whole grains at each meal.
- Look at the ingredient list and choose items that have “whole grain” followed by the name of the grain, as the first ingredient.
- Add oat bran, natural bran, or flax to muffins, casseroles, or cereals to get more fibre.

Protein

- It is important to include a variety of foods with extra protein as part of eating healthy. This includes plant-based proteins.
- Try to fill a quarter of your plate with protein foods at each meal.
- Choose protein foods that come from plants more often. They have more fibre and less saturated fat. Good sources include:
 - › Nuts and seeds
 - › Beans, peas, and lentils
 - › Fortified soy drinks, tofu, and soybeans
- Look for lean cuts of meat and trim off visible fat. Remove skin from poultry before cooking.
- Choose fish 2 to 4 times a week, but avoid deep fried fish that is coated in batter.

Fats and oils

- Our bodies need fat to help absorb vitamins. Since fat is high in calories, it is important to choose healthy fats. Healthy unsaturated fats help improve your cholesterol levels.
- Choose olive, canola, sesame, corn, or peanut oils.
- Choose non-hydrogenated margarines.
- Limit store-bought baked goods and avoid “ready to serve” meals.
- Choose low fat milk and milk products.
- **Do not** deep fry foods.

Salt

- We recommend that you keep following a low sodium eating plan after your transplant.
- Read food labels. Any item with more than 10% Daily Value (DV) of sodium is too high.
- Avoid adding salt when cooking. **Do not** keep a salt shaker on your table.
- Season food with fresh or dried herbs, unsalted spices, lemon juice, or pre-made seasoning blends (like Mrs. Dash™).

Sugar

- You may have high blood sugar levels after your transplant because of certain medications, like prednisone. It is important to keep your blood sugar levels in the normal range.
- Limit sugars, sweets, fruit juices, regular soft drinks, candies, jams, syrups, and honey.
- Eat more fibre.
- Eat regularly (3 meals a day). **Do not** skip meals.

Bone health

- Some medications needed after transplant may put you at greater risk of developing osteoporosis (weak bones). It is important that you get enough calcium and vitamin D for your bones to stay healthy.

Calcium

- Good food sources of calcium include:
 - › Cow's milk, calcium fortified or enriched soy, rice, or almond drinks
 - › Cheese
 - › Yogurt
- You may need to take a calcium supplement if you are not able to meet your nutritional needs. Please ask your dietitian or cardiologist if you need to take a supplement.

Vitamin D

- It is hard to meet your vitamin D needs through the foods you eat. You will need to take a vitamin D supplement.
- Food sources of vitamin D include:
 - › Fish (especially salmon, mackerel, trout, and herring)
 - › Fortified drinks, like cow's milk and soy, rice, or almond drinks

Pets and animals

- Be careful about what your pet eats and drinks. **Do not** let them eat raw meat, garbage, or animal stool (poop), or drink water from the toilet bowl.
- Avoid contact with pets or animals that have diarrhea.
- **Do not** let your pet lick your mouth or nose, or any open cuts or wounds.
- **Wash your hands well after handling pets or animals.**
- Avoid cleaning birdcages, litter boxes, and animal feces. If this is not possible, wear disposable gloves and a mask.
- Wear gloves to clean an aquarium.
- Change cat litter every day (dump litter box fully and fill with new litter).
- Avoid animal scratches.
 - › Avoid stray animals because you could get scratched or bitten.
- Avoid contact with reptiles, chicks, and ducklings.
- Avoid exotic pets (like monkeys and ferrets) and wild animals (like raccoons, bats, and skunks).
- Avoid getting new pets, especially cats that are younger than 1 year old.
- Avoid mosquito bites.
 - › Use bug spray and stay inside at dawn and dusk to help prevent exposure to West Nile virus during mosquito season.
- Cover sandboxes.

Travel safety

- Get expert travel advice, including a review of your vaccination status, before travelling to tropical or developing countries.
- While travelling in developing countries, you should:
 - › Drink only bottled water or canned drinks
 - › Avoid tap water, as well as ice and drinks made with tap water
 - › Avoid fresh fruit juices
 - › Eat only fruits and vegetables that can be peeled
 - › Eat steaming hot foods
 - › Follow the warnings found in the “Food safety” section (see page 42)
- Be flexible when planning your travel. By making small changes in your schedule, you may be able to lower your risk for certain infections. Wherever you go, make sure you have travel insurance and an extra supply of medications.

Vaccinations

You and the people close to you should make sure that your vaccinations are up to date.

- **Do not get any live vaccinations (like Sabin oral polio, measles, mumps, rubella, yellow fever, and smallpox) after your transplant.**
- You and your family members should not get the inhaled (breathed in) influenza (flu) vaccine after your transplant. This is a live vaccine.
- Talk with your transplant cardiologist about the timing of vaccinations. Usually vaccinations can be started 1 year after your transplant.
- Sometimes the vaccinations given after transplant do not last as long. Your health care team can check the levels of some vaccines in your blood to make sure they are still high enough.
- Get the pneumonia vaccine (Pneumovax® 23) 3 to 5 years after your transplant.
- Travel vaccines should be reviewed with your transplant cardiologist.
- Get the influenza and COVID-19 vaccine (by injection) every year.
- Your vaccinations should be up to date before you are added to the waiting list for a heart transplant.

Physiotherapy and rehabilitation (rehab)

While you are in the hospital

- After your transplant, your physiotherapist will start to work with you while you are in the ICU. The main goals of physiotherapy after your transplant are:
 - › helping to keep your lungs clear and well expanded. You will be taught deep breathing and coughing exercises. If needed, your physiotherapist will use hands-on techniques to help you clear secretions.
 - › helping to improve your strength and flexibility. You will be taught arm and leg exercises.
 - › helping to improve your endurance. You will start with short, daily walks that will get longer as your condition improves. Your nurses will also help you walk. When you are steady on your feet and your condition is stable, you will be expected to do some of the exercises on your own. This will help to improve your confidence.
 - › getting you ready for discharge. Your physiotherapist may give you a home exercise program.

When you are at home

- **It is very important to keep up a heart-healthy lifestyle after your transplant.**
- A cardiac rehab program can help you manage risk factors like:
 - › High blood sugar levels
 - › High blood pressure
 - › High cholesterol
 - › Weight gain
 - › Not doing enough activity
 - › Stress

What is cardiac rehab?

- The cardiac rehab program combines exercise, education, support, and lowering risk factors to improve your heart health.
- The health care team includes: nurse practitioners, nurses, dietitians, and physiotherapists. The team also consults with the transplant cardiologist as needed. If needed, you may be referred to other health care providers.

We strongly recommend that you attend a cardiac rehab program, if possible.

What are the benefits of cardiac rehab?

- Cardiac rehab may help to:
 - › Improve your energy
 - › Increase your fitness level
 - › Strengthen your heart
 - › Improve your breathing
 - › Control your diabetes
 - › Control/lower your blood pressure
 - › Control/lower your cholesterol level
 - › Control/lower your weight
 - › Improve your flexibility and muscle strength
 - › Strengthen your bones
 - › Help you go back to work
 - › Help you stop smoking and not start again
 - › Lower anxiety and depression
- The exercise classes are 1 hour, 1 or 2 times a week. During the classes, you will use a treadmill and an exercise bike. Every class has a group warm-up and cool-down.
- A home-based exercise program is also available. A specific exercise program will be made for you based on your exercise stress test, medical history, and goals.

What will I learn about in the education sessions?

You will learn about:

- › How your heart works
- › Heart disease and risk factors for heart disease
- › Changing your behaviour
- › Medications
- › Nutrition
- › Exercise
- › Managing stress
- › Managing your heart disease
- › Ways to manage your weight

Cardiac rehab programs

- The programs below offer exercise, education, and support.
- Please note this is not a full list and numbers may have changed. For more information, please call 211 or visit:
 - › <http://ns.211.ca>

<p>Hearts and Health in Motion Phone: 902-473-3846</p>	<p>Cardiac Maintenance Education Program Truro Phone: 902-893-5528</p>
<p>Cardiac Rehab Program Yarmouth Phone: 902-742-3524 extension 1460</p>	<p>Extended Warranty II - Valley Cardiac Rehab Program Kentville Phone: 902-679-2657 extension 1360</p>
<p>South Shore Regional Hospital Cardiac Rehab Program Lunenburg, Queens, Shelburne, Yarmouth, and Digby counties Phone: 902-543-4604 extension 2222</p>	<p>Bridgewater and Area Family Health Centre Bridgewater area Phone: 902-527-2417</p>
<p>One Door Chronic Disease Management Centre - Aberdeen Hospital Pictou county and New Glasgow Phone: 902-752-7600 extension 4700</p>	<p>Heart Health Clinic (to register for Hearts and Health in Motion) Antigonish, Canso, Guysborough, Port Hawkesbury, and Sherbrooke Phone: 902-867-4500 extension 4720</p>
<p>Community Cardiovascular Hearts in Motion Antigonish Health and Wellness Center Antigonish Phone: 902-863-7192 or 7193</p>	<p>Cape Breton Heart and Lung Wellness Centre Sydney Phone: 902-563-8566</p>
<p>Heart and Lung Wellness Centre Membertou Phone: 902-563-8566</p>	<p>Cardiac Health and Wellness Inverness Phone: 902-258-1905</p>

Exercise guidelines before and after your transplant

- Your exercise routine should include 3 parts:
 1. **Warm-up:** general exercises involving lying/sitting/standing, range of movement, and strengthening
 2. **Aerobic training** (peak activity to work out your heart), like walking, stationary bike, treadmill, light weights
 3. **Cool-down:** slower activity and stretching
- Each of these parts is important to any exercise program. The warm-up and cool-down activities let your heart and limbs (arms and legs) adjust to the more strenuous (harder) peak activity.
- During the warm-up and cool-down, your heart receives messages from your nerves. These messages tell your heart rate to speed up and slow down, but a transplanted heart acts differently. Your new heart relies on special chemicals in your bloodstream called catecholamines. These chemicals let your heart respond to exercise, but more slowly than before. **Because of this, the warm-up and cool-down parts of your exercise program are even more important after a transplant.**
- Try to walk or exercise each day, increasing your time and effort slowly. After your heart transplant, your health care team will show you precautions to follow to protect your chest after surgery.
- Weightlifting may be OK, as long as you use light weights with more repetitions. If this is something you would like to add to your exercise routine, talk with your transplant cardiologist.

Physical activity tips

Eating

- It is best to wait 1 hour after eating before you exercise. This is because your body is using extra energy for digestion.

Pace and intensity

- Exercise at a level that lets you keep up a conversation with someone during the activity.

Terrain

- Walk on flat ground at first.
- If you must walk up hills, walk slower.

Weather

- Avoid exercising in extreme temperatures.
 - › If it is very hot and humid, walk early in the morning or late in the evening, when it is cooler and the sun is less intense.
 - › If it is very cold and windy, it may be best to exercise indoors or during the middle of the day.

Progression

- If you miss a day of exercise, get back to your program at the same level the next day instead of increasing your activity level.
- If you have been sick, start at a slower pace and exercise for a shorter time.

Stretching exercises

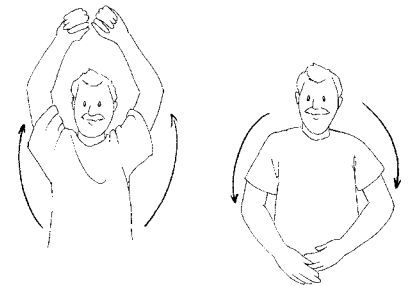
These stretching exercises will:

- › Be a good warm up before exercising
- › Be a good cool-down after exercising
- › Help with stiffness you may have from bed rest
- › Help you move more easily

You may start these stretches as soon as you go home. Sit on a firm chair with a straight back and no arms. Repeat each stretch 3 to 5 times. Make sure that you do not hold your breath when stretching. Keep breathing normally.

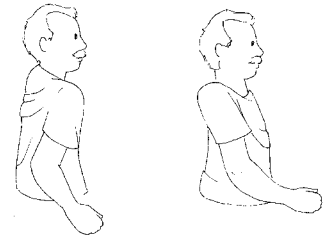
1. Arm lift

Breathe in as you lift your arms up and out to the sides. Touch your hands together over your head. Breathe out as you lower your arms. Repeat each stretch 3 to 5 times.



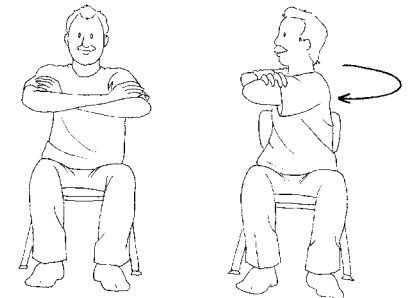
2. Shoulder circle

Circle your shoulders backwards. Now circle your shoulders forward. Repeat 5 times in each direction. Repeat each stretch 3 to 5 times.



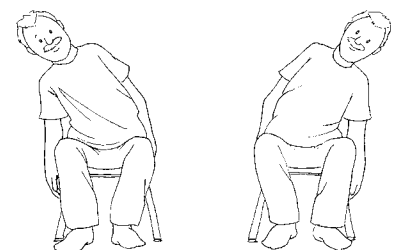
3. The twist

Fold your arms in front of you. Twist from the waist to the right and return to the centre. Now twist to the left. Repeat 5 times for each side.



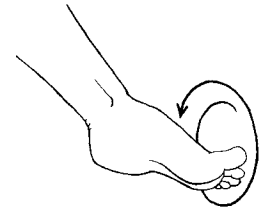
4. Side stretch

Sit up with your back straight. Lean slowly to one side and slide your arm down the side of the chair. Now slide back up and lean to the other side.



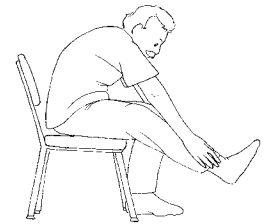
5. Ankle pumping

Lift one leg so your foot is slightly off the floor. Move your foot up and down in a pumping motion. Then circle your ankle in each direction. Put that foot back down on the floor. Repeat with the other foot.



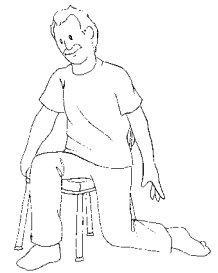
6. Hamstring stretch

Stretch one leg out in front of you. Reach toward your foot with both arms as far as you can go comfortably. Hold for 10 to 20 seconds. **Do not** bounce. Sit upright, then repeat with the other leg.



7. Quadriceps stretch

Slide your bottom to the left side of the chair. Let your left leg drop off the edge so that your knee is facing the floor. Hold for 10 to 20 seconds, then come back to a sitting position. Repeat with the right leg.



8. Calf stretch

Stand a little way from a wall or the back of your chair. Bend one leg and put your foot on the ground in front of you. Keep the leg behind you straight. Both heels should be on the floor. Slowly move your hips forward until you feel a stretch. Hold for 20 to 30 seconds. **Do not** bounce. Repeat with the other leg.



This pamphlet is for educational purposes only. It is not intended to replace the advice or professional judgment of a health care provider. The information may not apply to all situations. If you have any questions, please ask your health care provider.

Find this pamphlet and all our patient resources here:
<https://library.nshealth.ca/Patients-Guides>

Connect with a registered nurse in Nova Scotia any time:
Call 811 or visit: <https://811.novascotia.ca>

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