

Heart Transplant

A Guide for Patients and Families

Please bring this guide with you to the Halifax Infirmary.

Patient name: _____

Contents

The health care team	1
Referral for heart transplant.....	3
Workup for heart transplant	3
How long is the heart transplant process?	7
Waiting period	8
Antibodies.....	9
Advance care planning.....	10
Powers of attorney	11
Transplant process.....	12
A suitable heart becomes available	12
Testing the donor heart	12
Getting ready for surgery	13
Heart transplant surgery.....	14
What should my designated contact person/family members expect?	15
On the day of surgery.....	15
During your surgery	15
After your surgery.....	15
Donor information	16
After the surgery	16
Cardiovascular Intensive Care Unit (CVICU)	16
Coronary Care Unit (CCU)	17
Transfer to Cardiology Intermediate Care Unit (IMCU)	18
Discharge instructions	19
Exercise.....	19
Sex.....	20
Pregnancy.....	20

Adjusting to life after your transplant	20
Weight.....	21
Smoking.....	21
Driving	22
Sun protection	22
Going back to work	22
Dental care	23
MediAlert® bracelet	23
Followup schedule	24
Rehabilitation (rehab).....	25
Immune response	25
Acute rejection	26
Medications	30
Tacrolimus (Prograf®, Advagraf®, FK506) – Calcineurin Inhibitor (CNI)	30
Mycophenolate mofetil (CellCept®, Myfortic®)	33
Prednisone	35
General warnings – Immunosuppressants	39
Other medications	41
Enteric coated aspirin (Entrophen®, Novasen®)	41
Nystatin (Mycostatin®)	41
Antihypertensives (blood pressure medications)	41
Cholesterol medications	42
Antiviral medications	42
Infection prevention	42
Tips for preventing infections.....	44
Healthy eating after your heart transplant	47
Physiotherapy and rehabilitation	56
Outpatient cardiac rehabilitation	56
Cardiac rehabilitation programs	58
Exercise guidelines before and after your transplant	59
Helpful physical activity tips	60
Stretching exercises	61

This guide will help you and your family during the transplant process.

As you read through this guide, write down your questions so you can review them with your doctor or nurse later.

The health care team

The transplant team works with you and your family to help you return to an active and productive life after your transplant. Both the health care team and your loved ones will be directly and indirectly involved in your care.

The transplant team consists of the following health care professionals:

Transplant Cardiologists

Dr. M. Rajda

Dr. R. Crowell

Dr. D. Hayami

Dr. K. Anderson

Dr. A. Moeller

Transplant Surgeons

Dr. G. Hirsch

Dr. R. Baskett

Dr. K. Stewart

Dr. E. Chedrawy

Heart Transplant Coordinator

Kate Storm – 902-473-5511

Heart Transplant Clinic Clerk

Megan Wilson – 902-473-8597

Social Workers

Cherlyn Layton – 902-473-4077

Debbie Erickson – 902-473-2720

Dietitian

Rachael Thomson – 902-473-2200 (Locating)

Psychologist

Sulaye Thakrar – 902-473-4788

Ventricular Assist Device (VAD) Coordinators

Sonya Osmond and Maggie Banfield – 902-473-8597



Social workers

The social worker can help you with:

- Disability pensions and financial information
- Community resources and services to support lifestyle changes
- Drug benefit plans

Dietitian

The dietitian will go over your diet 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're feeling about your health, and help you work through any worries or concerns you may have. They help us to determine if you have the support and mental health resources to go through a transplant.

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 transplant team includes:

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

The team will review your medical history, diagnostic test results, social history, and the results of any consultations. They will decide whether you will be able to survive the heart transplant procedure and follow the continuous care needed to live a long and healthy life after your transplant.

Once the decision is made, your cardiologist will give you the results.

If the team finds that a heart transplant will not help you, you will continue to be followed by your cardiologist as an outpatient.

If the team finds that a heart transplant could help you, they will review what is involved in the heart transplant process with you and your family.

Referral for heart transplant

You have been referred for a heart transplant evaluation by your doctor. Your doctor feels that your heart failure symptoms are getting worse. They may no longer be well managed with medication or a less-invasive surgical procedure, such as a special pacemaker.

Heart failure may happen because of:

- › coronary artery disease (blocked arteries)
- › hereditary condition (passed from one generation to the next)
- › congenital heart disease
- › hypertension (high blood pressure)
- › viral infection
- › side effects of medication
- › history of alcohol use
- › pregnancy
- › idiopathic (exact cause unknown)

Workup for heart transplant

Your workup will have a number of tests to see if you are eligible for a heart transplant. We are looking for 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 enough to require 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 (e.g., smoking, drinking and/or drugs) that you need to quit before you are eligible for a transplant
- Are willing to follow the steps needed after a heart transplant (e.g., frequent followup 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 evaluation can be done on an inpatient basis, but it is usually done outside of the hospital. It can take from 1 week up to a couple of months, depending on other special tests needed and/or other specialist consults.

Tests

You may have some or all of these tests:

- **Blood work** - to check how well your organs are working and other specialty blood work
- **Urine (pee) and stool (poop) samples**
- **Chest X-ray**
- **Electrocardiogram**

Other tests may be needed. Any other tests will be explained to you. These may include:

- **Echocardiogram**
 - › An echocardiogram is an ultrasound of your heart. It 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 put on a patient gown and to take off your top. 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 a special 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 (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 and you can usually walk afterward. 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 (such as Ativan®).
- **Left heart catheterization**
 - › This test is done if you have not had one recently. A catheter is inserted in your groin and then moved up to your heart. A dye is injected that shows 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 the electrical activity of your heart. An electrocardiogram (ECG) is done while you exercise on a treadmill or 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 placed 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 maybe your abdomen (stomach area). You may or may not 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, which is shaped like a large doughnut.

- **Carotid Doppler ultrasound**

- › You will have a carotid Doppler ultrasound 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 probe.

- **Arterial blood flow**

- › Arterial blood flow studies will be done on your legs to make sure there are no blockages of the arteries. Cuffs similar to 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**

- › A pulmonary function test will be done if needed. This test measures your lung function. You will be asked to blow into a mouthpiece before and after using an inhaler.

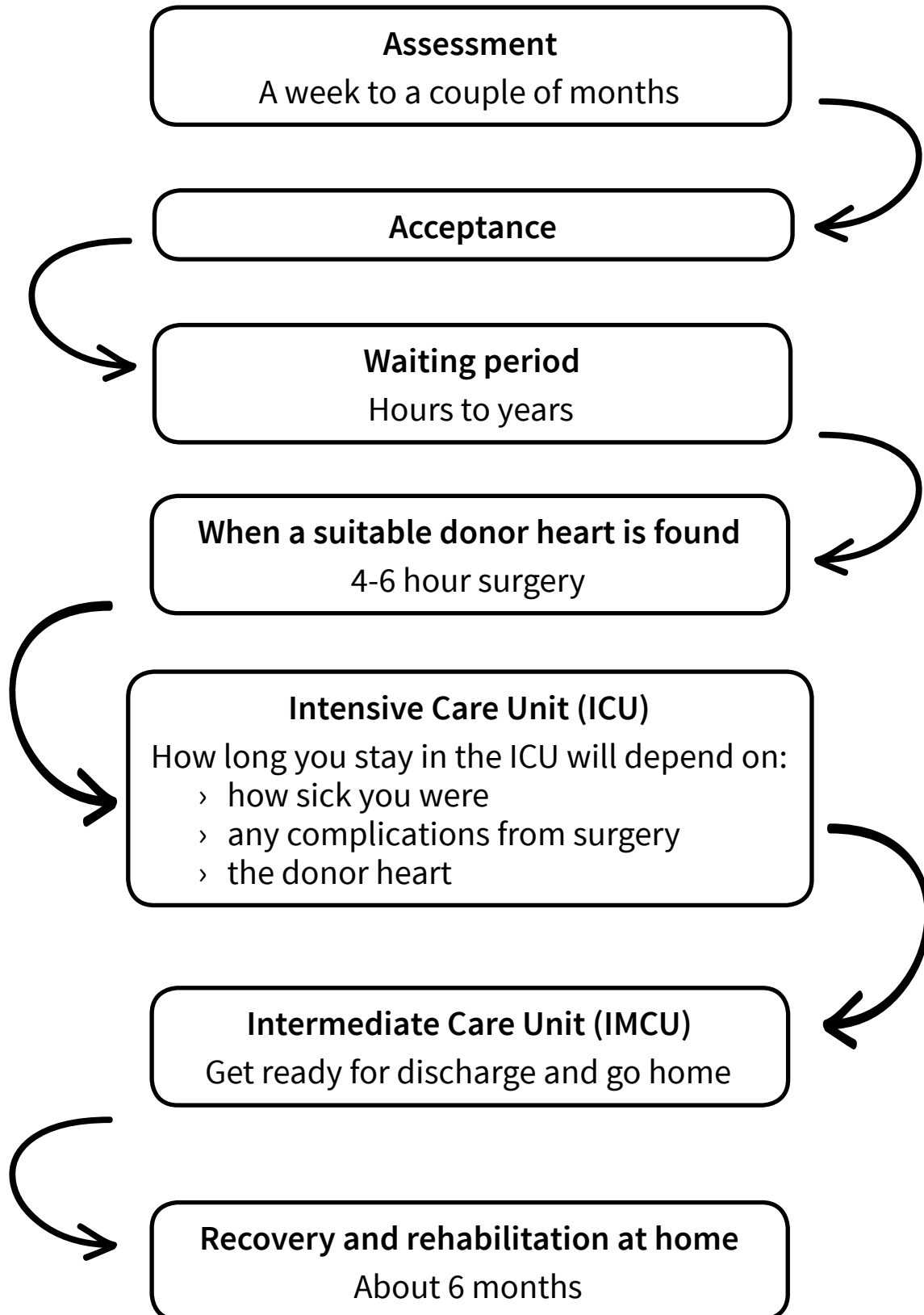
- **Bone mineral density**
 - › This test measures the density of minerals (such as calcium) in your bones using a special X-ray. As we age, we do not build up calcium in our bones as quickly as when we were young. Immunosuppressive drugs can decrease bone density, so it is important that your baseline level is assessed if you are at risk of low bone density.

- **Tuberculin skin test**
 - › This test will be done if you had tuberculosis.

- **Consultations**
 - › During the evaluation, you will be referred to different health care professionals for consultations. These professionals may see you while a transplant is being considered, after the transplant team has completed their assessment, while you are waiting for a transplant, or after you have received a transplant.

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

Wait list

Once you have been accepted for a transplant, an active search for a donor heart will start. Your time on the wait list will be determined by 4 things:

- › your blood type
- › your body size
- › how sick you are (this determines your status on the 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 type O patients can receive only type O hearts.

Your body size

The size of your body is also a factor in how long you will wait. 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.

Status on the wait list

You will be put on the transplant wait list according to the following criteria:

Status 1	Patients who are waiting at home.
Status 2	Patients who are admitted to hospital because their heart failure is not under good control.
Status 3	Patients who need an intravenous (IV) medication to support their hearts. Patients who need a mechanical device to support their hearts.
Status 3.5	Patients who need to be in the intensive care unit (ICU) and are on two IV medications for their hearts.
Status 4S	Patients with lots of antibodies in their blood.
Status 4	Patients who are in the ICU on life support. Patients who have mechanical support devices that have become infected.

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 women, past pregnancies.

When there is a heart offer for you, your antibodies are compared to the donor antigens. If the donor heart has any antigens that match your antibodies, the donor heart is not accepted for you. This can cause your wait to be longer.

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

If you are hospitalized for any reason, it is important that you 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 and this is new for you). It is possible that you may have to be placed on hold on the wait list due to this new health problem. This is mandatory (must be done) if the new condition may increase your risk of dying at the time of a transplant. If you are on hold, you will not lose the time you already spent on the wait list.

Advance care planning

Advance care planning is also known as 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 situation 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 two important things we need to know:

1. What are your specific wishes regarding 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 family, your SDM, and anyone else who might make decisions for you in the future. We are always happy to answer any questions you have about advance care planning.

Powers of attorney

It is important that you 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 powers of attorney. There are two 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 that you choose to make decisions about your care when you are not able to make them yourself. This person is also called your Substitute Decision Maker (SDM). To appoint a POA for personal care, you need to create a legal document.

If you do not assign a POA for personal care, the law states who may make these decisions on your behalf, in the following order:

- › your spouse
- › adult children
- › parents
- › siblings
- › extended family members

Sometimes recipients have a POA for health care that 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 best if you can 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 that 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 legal document states who will be responsible for making your financial decisions or any payments.

Transplant process

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 organs. It is an anonymous gift — you will not know who donated the heart. Brain death is a permanent condition that usually results from a head trauma or bleeding into the brain.

When a matching heart becomes available, you will be contacted by phone or beeper by the organ recipient coordinator of the Nova Scotia Gift of Life organization, or by the heart transplant doctor on call. **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 of these blood tests are for cytomegalovirus (CMV) and toxoplasmosis. A positive test for CMV and/or toxoplasmosis does not mean that the donor heart is unsafe. It depends on your immunity and your risk of getting a disease from the virus.

Getting ready for surgery

Once you arrive at the Halifax Infirmary, the following things will happen to get you ready for surgery:

- › blood tests
- › 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 will visit you

Two surgeons will be involved in your surgery, one who gets the new heart and one to get you ready to accept the heart. They will work together to decide when to move you to the Operating Room (OR). They will also do a final check to be sure the donor heart is in good shape for transplantation.

Sometimes the heart must be refused (turned down) at the last minute because it has become unsuitable for use. If this happens, your transplant surgery will be cancelled. Try not to be discouraged.

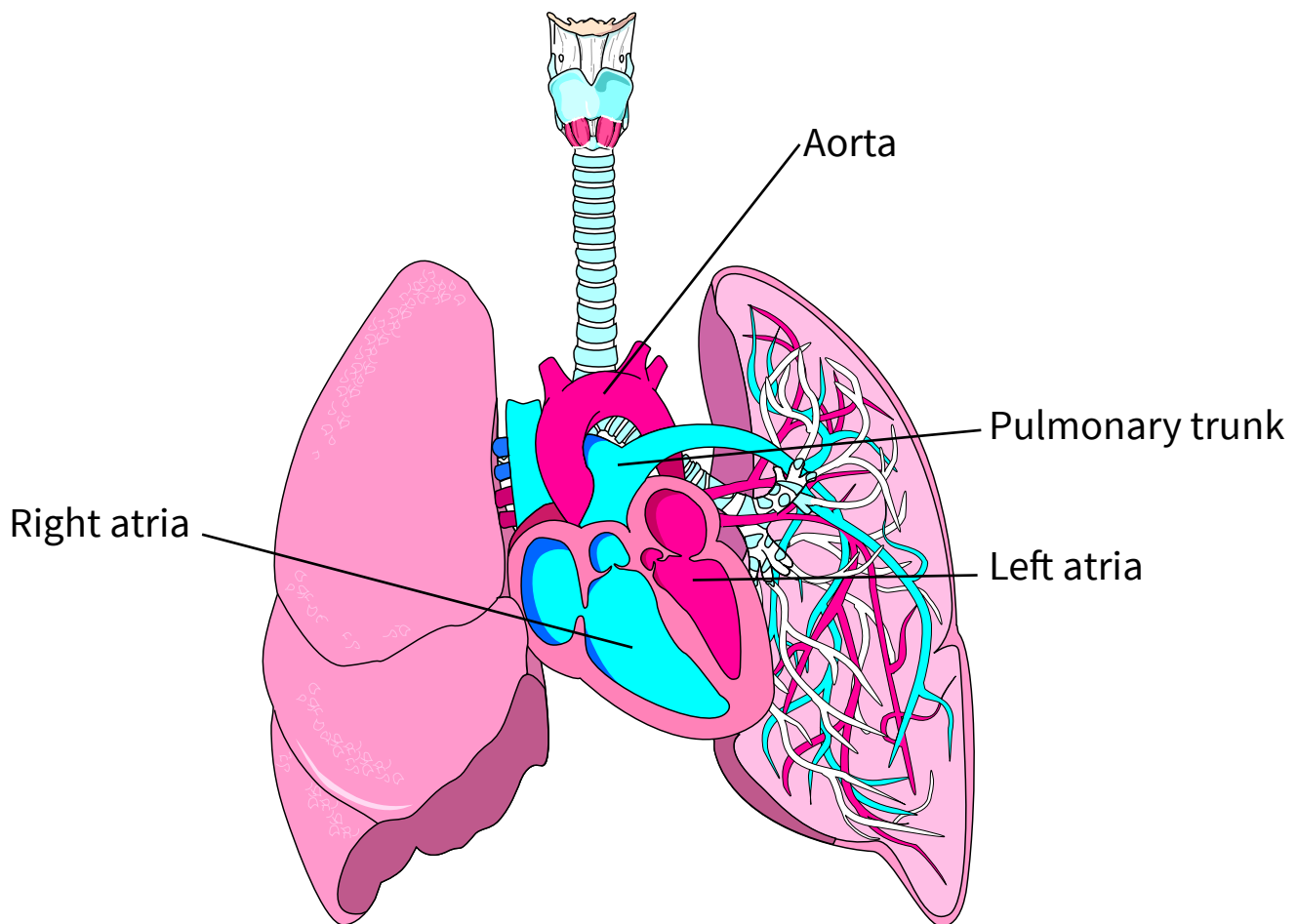
If the heart is accepted and you are taken to the OR, send your personal belongings home with your family, but make sure to keep your dentures, glasses, and hearing aids, if you have them.

Heart transplant surgery

The surgery will last many hours. It may take longer if:

- › you have had heart surgery in the past
- › you are on Coumadin®
- › 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 OR.
- Once you leave to go to the OR, your family should take all of your belongings from your room, since we don't 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 the surgery, they should tell the nursing coordinator and the surgeon will call them at the number you have provided.

You will get daily updates from the heart transplant team after the surgery.

Staff on each unit will give your family member or contact person information about the unit you will be staying in. Unit staff will be able to answer questions specific to their areas.

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

Donor information

Both parties are to remain anonymous. Details will not be shared between the donor and the recipient. This is the current policy of NSHA and in all of Canada.

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 the heart to come to you, who will review it and then give it to the donor family. Some donor families find it very helpful to receive a letter from the recipient. On the other hand, some donor families may not want to receive any information. This is why the transplant organization coordinator makes the connection between the two parties.

After the surgery

Cardiovascular Intensive Care Unit (CVICU)

After the surgery, you will be cared for in the CVICU. The number of days patients stay in this unit varies, but it is often more than 1 week.

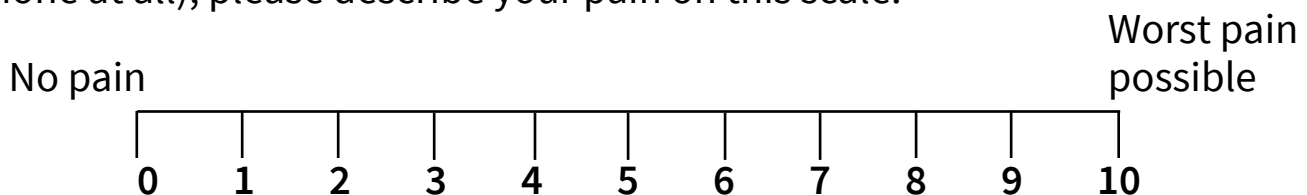
You will have many tubes attached to you after surgery. This table explains what these tubes are for and when they will be taken out:

Type of tube	Description
Breathing tube	<ul style="list-style-type: none">• Tube connected to a ventilator passing between your vocal cords• 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

Type of tube	Description
Arterial line in your wrist	<ul style="list-style-type: none"> Measures your blood pressure Removed when your vital signs are stable
Catheter in your neck	<ul style="list-style-type: none"> Measures pressure levels 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
Catheter in your bladder	<ul style="list-style-type: none"> Drains urine (pee) from your bladder Makes some patients feel like they have to urinate (pee) Removed once you are more active

Pain

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



Coronary Care Unit (CCU)

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

Transfer to 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 one person. When you are transferred to the IMCU, you will still have an IV line, 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 your own pills
- › getting you and your family ready for discharge through education
- › continuing to watch for changes in your condition

It is important for you to get up and move as soon as possible. This will prevent you from developing complications such as pneumonia, clots in your legs, and constipation (not being able to poop).

When you move, it is important for you to remember not to use your arms. Using your arms will cause the bones in your chest to rub together and get inflamed. 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.
- Show no sign of infection and your blood work is stable (blood, kidney).
- Are mobile and independent.
- Can safely take your own medications.
- Have your home care and other services in place, if needed.
- Have had one biopsy showing no signs of rejection.

Before you are discharged, the health care team will review information about your new medications, including anti-rejection medications and self-monitoring, with you and your family.

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 anyone to help you once you are discharged, please tell the social worker. Arrangements will be made for you.
- A list of your medications.
- A followup appointment with the heart transplant team.
- Appointments for your next biopsy and blood work.
- Requisition forms for your blood work.
- Followup appointments with other services you were followed by (infectious disease, endocrinology, etc.) if needed.

For the first 6 weeks after discharge, do not drive or lift anything over 5 pounds. This includes children, pets, heavy shopping bags, etc.

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, and build your strength and endurance.

Usually by the time you are ready for discharge, you will be able to walk around the Cardiology IMCU and climb 2 flights of stairs.

After discharge, you will gradually be able to go back to your normal activities. It is important that you do an exercise program. Increase your walking bit by bit over time, to 20 minutes in both the morning and afternoon. It is important that you walk every day. Do what you can and gradually increase how long and how fast you walk.

Sex

Early on in your recovery, you may feel too tired to think about sex. This is normal. 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 don't 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.

Pregnancy

Pregnancy is not recommended when taking medications needed after a heart transplant. Some of the medications have been shown to be associated with a higher risk of miscarriage and birth defects. Other medications have no information about how the drug affects a human fetus. Pregnancy after a heart transplant has been possible for a few people, but it carries a higher risk for the mother and the baby, including cardiac rejection and death of the mother. 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 drug 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 initial excitement of having the surgery comes the realization of lifelong monitoring, taking care of your body and staying in shape, and possible changes to your career or activities. The support of your family and friends is very important during this time. Remember that the first year after your transplant is usually the hardest. Things get easier after the first year.

Weight

Weight control can be hard for some post-transplant patients. Some medications may make you feel hungrier. Use common sense to help your eating habits, including eating 3 meals a day and drinking low-calorie beverages such as 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 also harms your lung tissue and can lead to lung infection and cancer. Because you are taking immunosuppressive drugs, you are already at risk for developing lung infections and cancer. Smoking will add to this risk.

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. They may decide to do further 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 licence, you cannot drive for 6 months after your transplant (e.g., taxi driver).

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 sun. You must use sunscreen with a sun protection factor (**SPF**) of **at least 30** before going out in the sun. This will give 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 hat and lightweight long-sleeved shirts and pants when possible to protect your skin from the sun.

Going back to work

The goal of transplantation is to help you return to work or to your pre-transplant activities.

When and if you return to work will depend on how well you are recovering and the type of work you do.

Dental care

After your transplant, when you are on immunosuppressive drugs, it will be 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 twice a day
- › using dental floss at least once a day
- › cleaning dentures or prostheses after every meal

Regular dental checkups, every 6 to 12 months, will also help. We recommend taking a preventive dose of antibiotic 30 to 60 minutes before any dental work involving gingival mucosa manipulation (working on the gums). Ask your dentist if it is needed. If in doubt, we recommend taking the preventive antibiotic. It can be prescribed by the heart transplant team.

MedicAlert® bracelet

In an emergency, this bracelet will tell medical personnel that you are a heart transplant recipient and are on immunosuppressive drugs.

The following should be engraved on your bracelet:

- Heart Transplant
- Immunosuppressive Drugs
- Any drug allergies



Followup 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 drug levels are stable. Then it will be 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

You will need frequent clinic visits for the first 6 to 12 months after your transplant.

Once your medications are stabilized, these visits will become less frequent and you will be seen once or twice per year.

During your clinic visits, the cardiologist will assess you, review your lab work and medications, and tell you of any changes.

Cardiac biopsy schedule

You will have at least one 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 according to your condition.

Diagnostic tests

Several diagnostic tests are needed at different times. The heart transplant coordinator will make arrangements 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 near 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 your body's way of protecting against infection by foreign invaders, such as bacteria and viruses. Through a series of steps called the immune response, the immune system attacks organisms and substances that invade your body and can cause disease. The immune system is made up of cells, tissues, and organs.

The cells in the donor heart carry markers that identify them as not belonging to your body. Your immune system sees these cells as foreign and triggers an immune response. This causes your immune system to attack the donor heart. We call this rejection. Immunosuppressive drugs stop your 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 drugs during this time. Over time, your immune system will be less active and your medication doses will change. Because your immune system remembers foreign invaders, **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 successfully with medications while you are at home.

You may not know that rejection is happening. It is often found during a regular followup 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.**

You should know the signs and symptoms of rejection and report them immediately. 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, aches, fever)

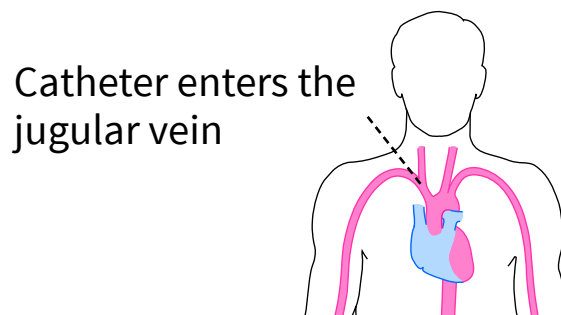
Rejection is an ongoing concern for transplant recipients, so it is extremely important for you to take your medications exactly as prescribed.

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 don't 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 placed 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 vein in your neck or in your groin once your skin is numb.
- Have an instrument called a biptome inserted through the catheter into your heart. The biptome 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 millimetres 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 be painful.
- Have pressure and a bandage applied over the puncture site.



The samples are sent to the pathologist (doctor who looks at tissue to diagnose diseases) for examination.

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
- › shortness of breath
- › fast or irregular heartbeat

Remove the bandage after 24 hours. Do not do any heavy lifting for 24 hours 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.**

Biopsy results

The number of rejection cells found in the biopsy samples shows the amount of rejection, called a “grade.” The grade levels 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 IV 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 more closely during this anti-rejection therapy. Call the doctor who takes care of your diabetes if your sugar increases.

Your cardiologist may decide to change the other immunosuppressive drugs 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, cholesterol medication and aspirin are given. Sometimes we may suggest a change in your immunosuppressive drugs to include a medication called sirolimus (Rapamune®), which lowers the risk of CAV getting worse.

Immunosuppressive drugs

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 drugs 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 decision will be based on the results of 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 or continued nausea, vomiting, or diarrhea.
- Are having possible side effects or new symptoms from your medications.
- Have been prescribed a new medication by a doctor or dentist.
- Choose to take over-the-counter medications or natural health products, as some of these drugs may interact with 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.

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 the heart transplant coordinator tells you to.
- Your dose of tacrolimus is determined by the level of the drug 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.

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

While taking tacrolimus, you may have:

- › higher risk of infection
- › high blood pressure
- › dizziness, headache, poor sleep, tremors, seizures
- › 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, needing to urinate at night, urinating more often, in general
- › unusual dreams, elevated mood or mood changes
- › acne (pimples), hair loss, increased sweating
- › higher risk of skin cancer

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

Foods, beverages, and supplements to avoid

- Grapefruit juice may increase your blood levels of Prograf® and its toxic (harmful) effects on your body.
- High-fat foods will lower your blood levels of tacrolimus.
- St. John's wort will lower the amount of tacrolimus in your system.
- Avoid cat's claw and echinacea - these will stimulate your immune system, which can possibly increase the risk of rejection.

Important

- Antacids can affect how your body takes in tacrolimus. They should be taken at least 2 hours before or 4 hours after you take tacrolimus.
- Avoid anti-inflammatory medications, such as ibuprofen (Advil®, Motrin®), Indocin®, Naprosyn®, and diclofenac.
- Avoid the antibiotic erythromycin and any other antibiotics in the same drug family.

Mycophenolate mofetil (CellCept®, Myfortic®)

Mycophenolate mofetil prevents organ rejection by suppressing your body's immune system.

How to take mycophenolate mofetil

- Mycophenolate mofetil is taken two times each day, once in the morning and once in the evening. It is best to take this medication on an empty stomach, but it may be taken 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, the 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.

Mycophenolate mofetil (CellCept®, Myfortic®)

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
- › abnormal kidney function

Foods, beverages, and supplements to avoid

- None.

Prednisone

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

How to take prednisone

- Prednisone is taken one time each 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 the heart transplant coordinator tells you to.

Prednisone

While taking prednisone, you may have:

- › higher risk of infection
- › poor sleep, nervousness
- › headache
- › mood swings
- › feeling more hungry, upset stomach
- › nausea, vomiting, belly swelling, irritation of the stomach lining (ulcers)
- › hair growth, acne, skin bruising, fragile skin
- › higher blood sugar (diabetes)
- › lower potassium
- › 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
- › greater sun sensitivity

Storage

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

Prednisone

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 more often (especially with high doses of prednisone), and tell your diabetes doctor about any increases in your blood sugar.
- If you are having higher levels of anxiety and stress, tell your cardiologist.
- Annual eye exams are important when taking prednisone because it can increase the risk for glaucoma and cataracts.
- This medicine 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

Prednisone

Foods, beverages, and supplements to avoid

- Drinking alcohol is not recommended. Alcohol irritates the stomach lining, as does prednisone, 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 can possibly increase the risk of rejection.

Drug interactions

- Antacids can affect how your body takes in prednisone. They should be taken at least 2 hours before or after prednisone.
- Taking diuretics with prednisone can increase the loss of potassium from your body.
- Avoid anti-inflammatory medications, such as ibuprofen (Advil[®], Motrin[®]), idomethacin (Indocin[®]), naproxen (Naprosyn[®], Aleve[®]), and diclofenac as they can increase the irritation to your stomach 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.

General warnings – Immunosuppressants

Missed doses

- It is very important that you take all your doses. If you do 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 the 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 more often (especially with high doses of prednisone), and tell your diabetes doctor about any increases in your blood sugar.
- If you are having higher levels of anxiety and stress, tell your cardiologist.
- Annual eye exams are important when taking immunosuppressants, because these drugs 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.

General warnings – Immunosuppressants

Interactions

- Drinking alcohol is not recommended. Alcohol irritates the stomach lining, putting you at 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®, Roloids®, Diovol Plus®, etc.) can affect how your body takes in some medications. They should not be taken within 2 hours of taking immunosuppressants.
- Avoid anti-inflammatory medications, such as ibuprofen (Advil®, Motrin®), indomethacin (Indocin®), naproxen (Naprosyn®, Aleve®), and diclofenac.
- Avoid macrolide antibiotics (erythromycin, azithromycin, clarithromycin).
- There are many prescription and non-prescription medications that can interact with tacrolimus, changing the way the drug works in your body. Make sure your pharmacist knows you are on tacrolimus. Call your transplant cardiologist or the heart transplant coordinator to find out if new medications, including vitamins and herbal products, are safe to take with tacrolimus.

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 the coronary arteries in the transplanted heart. You will take 81 mg (1 baby aspirin tablet) every day.

Nystatin (Mycostatin®)

Nystatin will prevent yeast (thrush) infections in your mouth. The usual dose of 5 ml is taken 4 times a day for 3 months after your transplant, and then 1 ml is taken 4 times a day for 2 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 a problem with high blood pressure after a heart transplant. Some of the drugs used to treat high blood pressure include:

- › Calcium channel blockers, such as diltiazem
- › ACE inhibitors, such as perindopril
- › Angiotensin receptor blockers, such as candesartan
- › Beta blockers, such as metoprolol

It is helpful if you 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.

Low blood pressure can also happen. The following are possible symptoms of low blood pressure. Tell your transplant cardiologist or the heart transplant coordinator if you have any of the following after starting the medication:

- › fatigue (tiredness), no energy
- › dizziness and light-headedness when standing up and moving around
- › 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 lessen the drop in blood pressure that you will 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 the heart transplant coordinator or your transplant cardiologist.

Cholesterol medications

This group of drugs is used along with diet and exercise to lower the levels of cholesterol and other fats in your blood. Lowering cholesterol and fat will help prevent narrowing of the coronary arteries in the transplanted heart. 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. These drugs can be expensive. These medications include:

- › Valganciclovir (Valcyte®)
- › Acyclovir (Zovirax®)

Infection prevention

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

Medications for your stomach

You will be started on a medication to protect your stomach from the risk of an ulcer. You may already be taking something, and this may be continued. These medications include:

- › Omeprazole (Losec®)
- › Esomeprazole (Nexium®)
- › Rabeprazole (Pariet®)
- › Ranitidine (Zantac®)
- › Pantoprazole (Pantoloc®)

Medications for bone health

You may be prescribed medications and supplements to maintain bone health. These include:

- › Alendronate (Fosamax®) or risedronate (Actonel®) - taken once a week to prevent bone deterioration (breakdown) and osteoporosis
- › Vitamin D supplement
- › Calcium supplement

Cytomegalovirus (CMV)

Cytomegalovirus is related to the herpes virus. Eight 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. This medication is very expensive. Check to see if it's covered by your current drug plan. You may be given immunoglobulin (an antibody specific against CMV) after your transplant as well.

Toxoplasmosis

Toxoplasmosis is an infection caused by the parasite *Toxoplasma gondii*, which is found in the feces of cats 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 geographical 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. Septra® prevents infections caused by toxoplasmosis. If you have an allergy to Septra®, please tell your transplant cardiologist.

General information about infections

The drugs that you take to prevent rejection of your heart interfere with your body's ability to fight infection. You will be most at risk of infections during the first 6 months after your transplant, and when you have to be treated for rejection with increased doses of immunosuppressants.

Make sure you get enough rest, eat a balanced diet, and exercise regularly. Keeping a healthy lifestyle will increase your resistance to infections and help you fight any infections you do get.

You need to balance safe practices with the routines of your daily activities. You do not need to live in a plastic bubble. Everyone gets most germs either through direct contact (usually with your hands) or by breathing them in.

Tips for preventing infections

Wash your hands (even after using gloves) with soap and water:

- Before preparing food.
- Before eating.
- Before and after touching wounds (broken skin) - your own or someone else's.
- Before touching mucous membranes (e.g., rubbing your eyes or touching the inside of your mouth or nose).
- After touching secretions (e.g., saliva) and excretions (e.g., 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 (e.g., 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 unwashed fruits or vegetables.

Preventing respiratory (airway) infections

Most respiratory infections spread through direct contact or by breathing them in.

The tips that follow can help lower your chance of getting a respiratory infection.

Preventing infection from other people:

- Wash your hands often and well, especially before touching mucous membranes.
- Avoid being near anyone with a cold. If this not possible, people who are sick should wear surgical masks when 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 occupations where exposure to tuberculosis is more likely, such as prisons, homeless shelters, and certain health care settings. Talk with your cardiologist to help you decide whether to continue working in these environments.

Preventing exposure to mould and fungus:

- Do not smoke marijuana (cannabis). It will expose you to mould spores (aspergillus) that can cause a possibly deadly pneumonia.
- Avoid construction, or excavation areas, and other dusty places. There may be a high concentration of mould spores (aspergillus) in these areas.
- Avoid contact with soil, fertilizer, and decaying vegetation (compost heaps), which can contain mould. Gardening and farming are not recommended for the first year after transplant. If you must garden or farm, wear a mask and gloves.
- Avoid areas such as 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 one minute. You can use personal-use filters and/or bottled water instead of boiling your 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 river.
- Avoid swimming in water that is likely to be contaminated with human waste, and avoid swallowing water when swimming.

Food safety

- Avoid drinking unpasteurized beverages 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, and fish.
- Avoid all raw or undercooked seafood, raw seed sprouts, and raw green onions.
- Avoid cross-contamination when preparing food: keep cooked and raw foods separate and use clean or separate cutting boards for each.
- Wash raw fruits and vegetables well. Avoid fast-food restaurants and salad bars to avoid salmonella.
- Hot dogs and sausages should be completely cooked.
- Reheat leftovers so they’re steaming hot.

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 eating a balanced diet by choosing a variety of foods each day.

These include:

- › vegetables and fruit
- › whole grains
- › protein-rich foods

Nutrition after your transplant

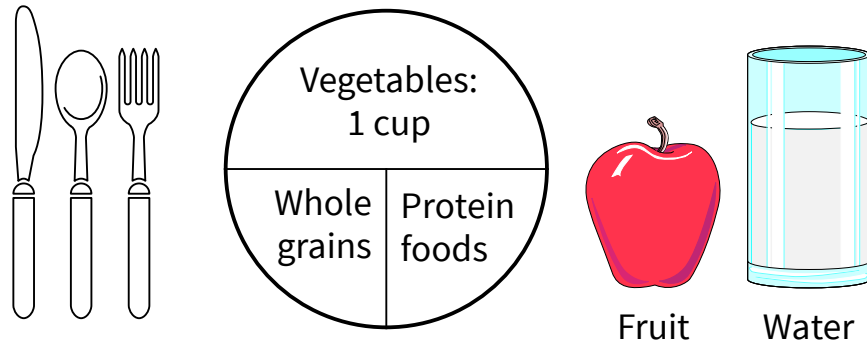
Your body will need extra calories and protein in the first few weeks after your transplant to help with healing. Even if you do not feel hungry, it's important to eat. Eating small meals more often and taking oral nutrition supplements (e.g., Ensure®, Boost®) may help. Your dietitian will also support you in meeting 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 (e.g., 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 fruit

- Eating vegetables and fruit can lower your risk of many diseases, including coronary artery disease. Vegetables and fruit give you vitamins, minerals, antioxidants, and fibre that your body needs for good health.
- Aim 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 grains.
- Try a variety of whole grains, including oats, quinoa, brown rice, whole grain pasta, and whole grain bread.
- Aim for a quarter of your plate to be whole grains.
- 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 a healthy diet. This includes plant-based proteins.
- Aim for a quarter of your plate to be protein foods.
- 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 beverages, 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 per week, but avoid deep fried, batter-coated fish.

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 diet 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. Don't keep salt at the table.
- Season food with fresh or dried herbs, unsalted spices, lemon juice, or pre-made seasoning blends (e.g., Mrs. Dash®).

Sugar

- You may experience high blood sugars after your transplant because of certain medications, such as 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) and 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 in your diet for your bones to stay healthy.

Calcium

- Good food sources 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 needs through your diet. 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 your diet. You will need to take a vitamin D supplement.
- Food sources of vitamin D include:
 - › fish (especially salmon, mackerel, trout, and herring)
 - › fortified drinks, such as cow's milk and soy, rice, or almond drinks

Animal contact

- Avoid contact with animals that have diarrhea.
- Be careful about what your pet eats and drinks. Do not let your pet eat raw meat, garbage, or another animal's stool (poop), or drink water from the toilet bowl.
- Wash your hands carefully after handling pets.
- Avoid cleaning birdcages, litter boxes, and animal feces. If this is not possible, wear disposable gloves and a surgical mask. Change out cat litter every day (i.e., dump litter box completely 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.
- Wear gloves to clean an aquarium.
- Avoid getting new pets, especially cats that are younger than one year old.
- Do not let your pet lick your mouth or nose or any open cuts or wounds.
- Avoid exotic pets (such as monkeys and ferrets) and wild animals (such as raccoons, bats, and skunks).
- 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.

Safer sex

When not in a long-term monogamous (with only one person) relationship, always use latex condoms during sex to avoid exposure to sexually transmitted infections (STIs). Avoid unprotected exposure to feces during sex.

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 beverages
- › avoid tap water, as well as ice and beverages 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 (on page 46)

Finally, be flexible when planning your travel. By making small changes in your itinerary, 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 your family should make sure that your vaccinations are up to date.

Here are some important things for you to know about vaccinations:

- Live vaccinations should never be given after transplantation. Examples include Sabin oral polio, measles, mumps, rubella, yellow fever, and smallpox.
- Inhaled influenza (flu) vaccine is a live vaccine and should not be given to transplant recipients or their family members.
- Talk with your transplant cardiologist about the timing of vaccinations after heart transplant. Usually vaccinations can started 1 year after surgery.
- Sometimes the vaccinations given after transplant do not last as long. The levels of some vaccines in your blood can be monitored to check if they are still high enough.
- Pneumovax®23, for pneumonia, should be repeated regularly (every 3 to 5 years) after transplantation.
- Travel vaccines should be reviewed with your transplant cardiologist.
- Get the influenza vaccine (by injection) every year.
- Your vaccinations should be up to date before you are listed for a heart transplant.

Signs and symptoms of infection

It is important for you to know the signs and symptoms of an infection. If you notice any of these, talk to your family health care provider, transplant cardiologist, or heart transplant coordinator as soon as possible. The sooner you get treatment, the better the outcome. Call the heart transplant coordinator if you are not sure about your condition and what you should do.

The signs and symptoms of common sites of infections, along with what to do, are described in the following table.

Where in your body:	If you notice any of these symptoms...	... then you should do this:
Lungs	<ul style="list-style-type: none"> • Fever above 38° C, may also have chills • Persistent (ongoing) cough • Sputum (phlegm) that is brownish, yellow, or green • Chest pain that gets worse when you cough or breathe in deeply • Shortness of breath • Heartbeat speeds up • Aches and pains, more tired • Headache, less hungry 	<ul style="list-style-type: none"> • See your family 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 • If your pharmacist isn't sure about interactions, call the 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 notice any of these symptoms...	... then you should do this:
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 family health care provider if you think you might have an infection • Go to the nearest Emergency Department 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 — could be shingles 	<ul style="list-style-type: none"> • Call the heart transplant coordinator or your transplant cardiologist if you notice signs of shingles. You'll need an antiviral medication. • Antivirals do 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 • If your pharmacist isn't sure about interactions, call the 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 notice any of these symptoms...	... then you should do this:
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 it down • Take Graval™ 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, such as bananas, applesauce, rice, tea biscuits, or toast • If you can't take your medications or keep any fluids down, call the heart transplant coordinator or your family doctor, or go to the nearest Emergency Department
Urinary tract / bladder	<ul style="list-style-type: none"> • Burning or stinging when peeing • Feeling like you need to pee often, but having little output • Bad-smelling or cloudy urine (pee) • Bloody urine 	<ul style="list-style-type: none"> • See your family health care provider • If in doubt, call the heart 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 isn't sure about interactions, call the 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

Physiotherapy and rehabilitation

After transplant

After your transplant, the physiotherapist will start to work with you in the intensive care unit. The main goals of physiotherapy after your transplant are:

- Helping you keep your lungs clear and well expanded. You will be taught deep breathing and coughing exercises. If needed, the physiotherapist will use hands-on techniques to help you with secretion clearance.
- Helping you improve your strength and flexibility. You will be taught arm and leg exercises.
- Helping you improve your endurance. This will start with short daily walks that will get longer as your condition improves. The nurses will also help you with your walks. When you are steady on your feet and your condition is stable, you will be expected to do some of the exercise sessions on your own while in hospital. This will help to improve your confidence in exercising on your own.
- Reviewing general exercise principles as they apply after heart transplant.
- Getting you ready for discharge home. Your physiotherapist may give you a home exercise program.

Outpatient cardiac rehabilitation

It is very important that you continue leading a heart-healthy lifestyle after your transplant. Cardiac rehabilitation programs can help you manage risk factors such as high blood sugar, high blood pressure, high cholesterol, weight gain, inactivity, and stress.

What is cardiac rehabilitation (rehab)?

The cardiac rehab program combines exercise, education, support, and lowering risk factors to improve your heart health.

The health care team includes: nurses, dietitians, physiotherapists, and consultation with a transplant cardiologist, as needed. You may be referred to other health professionals as needed.

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
- › lessen your symptoms of shortness of breath
- › 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 return to work
- › help you become and stay a non-smoker
- › lower anxiety and depression

The exercise classes are one hour, once or twice a week. During the exercise classes, you will use treadmills and stationary bicycles. 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:

- › heart disease and how your heart works
- › risk factors for heart disease
- › behaviour change
- › medications
- › nutrition
- › exercise
- › managing stress
- › managing your heart disease
- › strategies for weight management

Cardiac rehabilitation programs

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

<p>Hearts and Health in Motion Halifax Phone: 902-473-3846</p>	<p>Cardiac Maintenance Program Truro Phone: 902-893-5528</p>
<p>Cardiac Rehab Program Yarmouth Phone: 902-742-3524 ext. 1460</p>	<p>Extended Warranty II Valley Cardiac Rehab Program Kentville Phone: 902-679-2657 ext. 1360</p>
<p>South Shore Hospital Cardiac Rehab Program Lunenburg, Queens, Shelburne, Yarmouth, and Digby counties Phone: 902-543-4604 ext. 2222</p>	<p>Bridgewater and Area Family Health Clinic Cardiac Rehab Program Bridgewater area Phone: 902-527-2417</p>
<p>One Door Chronic Disease Management Centre Pictou County Phone: 902-752-7600 ext. 4700</p>	<p>Heart Health Clinic (to register for Hearts & Health in Motion) Antigonish, Canso, Guysborough, Port Hawkesbury, and Sherbrooke Phone: 902-867-4500 ext. 4720</p>
<p>Community Cardiovascular Hearts in Motion Antigonish Phone: 902-863-7192 or 7193</p>	<p>Cape Breton Heart & Lung Wellness Centre Sydney Phone: 902-563-8566</p>
<p>Heart & Lung Wellness Centre Baddeck Phone: 902-563-8566</p>	<p>Cardiac Health & 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), such as walking, stationary bike, treadmill, light weights
3. Cool-down: slower activity and stretching

Each of these 3 parts is important to any exercise program. The warm-up and cool-down activities let your heart and limbs adjust to the more strenuous (harder) peak activity.

During the warm-up and cool-down, your heart gets messages from your nerves. These messages tell your heart rate to speed up and slow down. However, a transplanted heart acts differently. Your new heart relies on special chemicals in your bloodstream called catecholamines. These chemicals let your heart to respond to exercise, but more slowly than before. **For this reason, the warm-up and cool-down parts of your exercise program are even more important after transplantation.**

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.

Weight lifting may be OK, as long as you focus on more repetitions with lower weights. If this is something you would like to add to your exercise routine, talk with your transplant cardiologist.

Helpful physical activity tips

Eating: It is best to wait an hour after a meal before you exercise. This is because your body needs extra energy for digestion.

Pace and intensity: Exercise at a level that lets you keep up light conversation during the activity.

Terrain: Walk on flat ground at first. If you must walk on hills, walk slower when going uphill.

Weather: Avoid exercising in extreme temperatures. If it is very hot and humid, walk earlier in the morning or later in the evening, when it is cooler and the sun is less intense. If it is extremely 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 decrease the time.

Stretching exercises

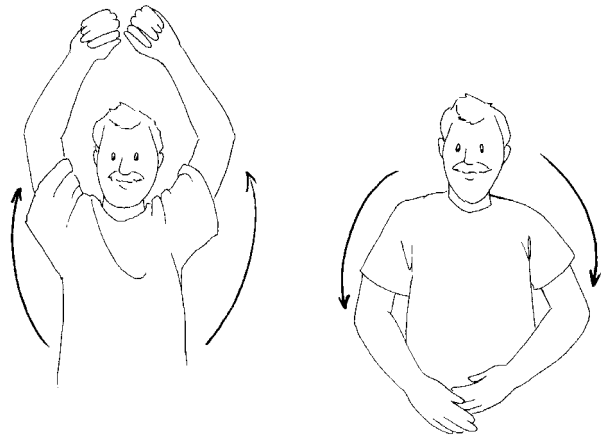
These stretching exercises will:

- › 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 return home. Sit on a firm chair with a straight back and no arms. Repeat each stretch 3 to 5 times. Make sure that you don't hold your breath when stretching. Keep breathing normally.

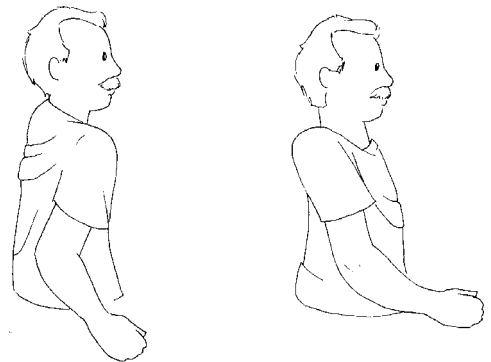
1. Arm lift

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.



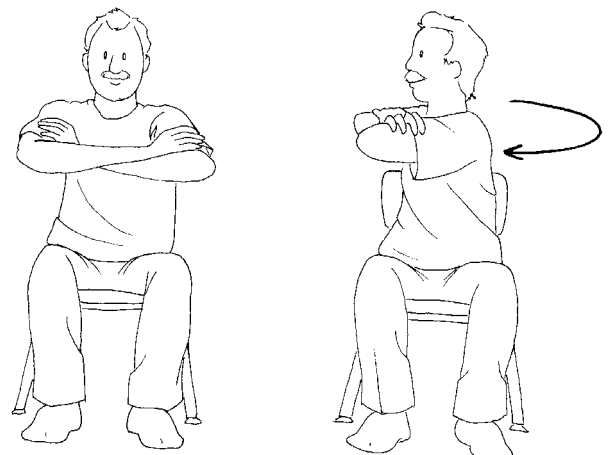
2. Shoulder circle

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



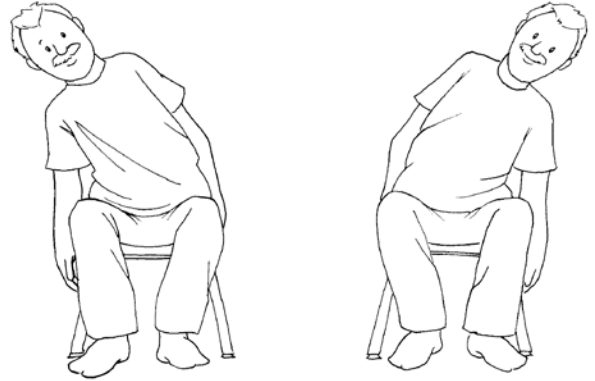
3. The twist

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.



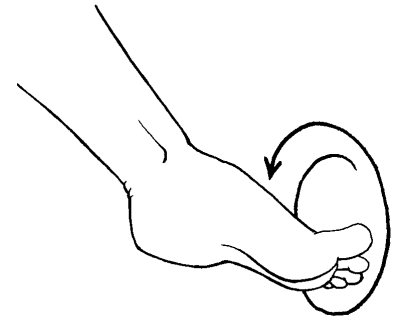
4. Side stretch

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.



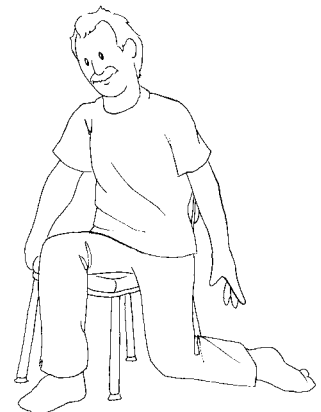
6. Hamstring stretch

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.



Notes:

Lined area for taking notes, consisting of horizontal lines spaced evenly down the page.

Looking for more health information?

Find this pamphlet and all our patient resources here: <http://library.nshealth.ca/PatientGuides>

Contact your local public library for books, videos, magazines, and other resources.

For more information, go to <http://library.novascotia.ca>

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

Learn about other programs and services in your community: call 211 or visit <http://ns.211.ca>

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