

Patient & Family Guide

After Your Liver Transplant

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Multi-Organ Transplant Program

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Halifax, Nova Scotia

The Multi-Organ Transplant Program is at the Nova Scotia Health Authority in Halifax, Nova Scotia. This handbook will help you and your family members learn about your care after a liver transplant. The handbook will answer many of your questions about the transplant process. The Team members are also available to discuss your concerns with you. Remember that everyone is different so you may not have or develop all of the conditions that you read about in this handbook.

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In hospital

The Transplant Unit

When you are ready to leave the Intensive Care Unit, you will be moved to the Intermediate Care Unit on the 6th floor of the Centennial Building at the Victoria General site. This is a 4 bed room where 2 nurses care for 4 patients around the clock. You will be cared for here until the Transplant Team feels your condition is stable enough for you to move to the main unit on 6B. The focus of your care will now shift to helping you get ready to go home. For example, you will be expected to do more of your daily care, learn about your medications, and work with the physiotherapist. The Team will be working closely with you during this time.

What can I expect?

Incision

Your nurse will clean your incision as needed. If you have staples, they will be removed in about 10-14 days. After a few days, your incision may not need a dressing.

IVs/tubes/drains

You may have:

- A drain coming out of your abdomen
- A catheter (tube) into your bladder
- A large intravenous (IV) line in your neck
- A tube inserted through your nose into your stomach

Your nurse will care for and empty the drains as needed. If you have to go home with a drain, your nurse will help you learn how to look after it.

All tubes, catheters, and IVs will be removed when the doctor feels you no longer need them.

TED stockings

These elastic stockings go up to your thighs to help the circulation in your legs. You should wear them until you are walking around the unit on your own.

Blood tests

Blood is taken every morning and as needed. The results of these blood tests keep your Team updated on how your new liver is working. The transplant specialists also use the results of these tests to adjust your anti-rejection medication. You must have your blood work drawn **BEFORE** you can take your medication.

Monitoring

Your Team continues to support you on the Transplant Unit. Your nurses will monitor you very carefully. They will:

- Check your vital signs (temperature, blood pressure, breathing rate, and pulse)
- Listen to your breathing
- Assist with your breathing exercises
- Check your oxygen levels with a special machine
- Monitor your drains
- Clean your incision
- Listen to your abdomen
- Encourage you to be active
- Help you with your personal care
- Help you to learn about your medications and other things you need to know so you can care for yourself safely at home.

Activity

Your progress will be checked and your exercise program adjusted by your physiotherapist.

You may be weak when walking and need to use a walker or cane.

You can increase your activity by going to the fridge for your water and gathering your towel and face cloth in the morning to start washing.

The physiotherapist will plan for you to continue your rehabilitation exercise program after you leave the hospital.

The exercise program is important to:

- Minimize the effects of a medication called prednisone that can cause bone and muscle weakness.
- Minimize or control the effects of medications, which can cause high blood pressure, diabetes, and depression.
- Keep your joints healthy and muscles strong.
- Strengthen your heart and lungs so it will be easier to exercise.

Nutrition

You are usually unable to eat for a few days. Eating and drinking will upset your stomach until your bowel has awakened after surgery. Nutrition is given through a feeding tube or directly into a vein. After a few days, you will be drinking and eating solid foods. A dietitian will be involved in your care.

Before you leave the hospital, the dietitian will review healthy eating guidelines and other information with you. Most patients are able to follow a normal, healthy meal plan with few or no restrictions. You may also be advised to take calcium and vitamin D pills.

Research has shown that some people with a liver transplant have problems with weight gain, high blood fat, and high blood sugar levels. Because of this, it is important for you to follow the healthy eating guidelines.

Coping

Your psychologist and/or social worker will visit with you and your family to see how you are coping emotionally. She/he will check on how well you are learning about your medications, exercising, eating, and becoming more independent. If there seems to be a problem in any area, the psychologist and/or social worker will work with you, your family members, and the Team to help get things back on track.

Keep in mind that there may be good and bad days. No two people recover in the same way. Even on the bad days, it is important to do as much as possible for yourself.

If you are taking Prednisone, it may cause you to be very emotional and have mood swings. This is a common side effect of this medication.

The social worker will help you with practical concerns so you and your family can focus on recovery. She/he will help you connect with outside agencies if needed.

Medications

After transplant, your immune system must be suppressed (controlled) to prevent rejection of the new liver. You will need anti-rejection medications immediately after your surgery. At first, your medications are given through your IV and/or a tube in your stomach. You can take them by mouth when you are able to drink.

You will need these medications every day for the rest of your life to protect you from rejection.

You need to learn about your medications and will start to take them on your own while still in hospital. This will help you to take your medications safely at home. A nurse will help you with this by making out a medication calendar for you to follow. Be sure to let your nurse know if you have a vision, hearing, or memory problem. **You must also learn the symptoms of rejection and infection and what to do if either should happen.**

Please read the medications section of this handbook to find out more about the self-medication program and your medications.

Possible complications

Short-term complications

Complications are common after a transplant. Sometimes the road after transplant is not smooth. Members of the Transplant Team will do their best to lower your chances of having problems and will treat them quickly if they happen.

Bleeding

Bleeding may happen during or shortly after surgery. If needed, blood, plasma, and/or platelets will be given. A patient may need to return to the Operating Room to have the bleeding stopped.

Wound infections

Signs:

- Fever
- Redness, swelling, tenderness, a change in the type of pain, or change in the type of drainage around the site of your wound or tube

Treatment:

Tell your doctor or nurse right away if you have any of the above signs. You must be checked and treated quickly.

Bile leak

Bile may leak outside of the bile ducts into the stomach.

Signs:

- Fever
- Feeling sick to your stomach
- Pain above the liver

Treatment:

Tell your doctor, nurse, or Clinic nurse immediately if you have any of these signs. You must be checked and treated quickly.

Biliary stenosis or stricture

This is a narrowing of the bile ducts. Your liver enzyme levels are higher.

Sign:

- Skin and eyes are yellow

Treatment:

You must be checked and treated quickly. A stent (tube) may be inserted or surgery may be needed if the bile ducts are blocked.

Rejection

Your immune system protects you from “foreign invaders” such as bacteria (a type of germ). A rejection episode is when your body sees your new liver as a threat to you and starts to fight it. Most rejection episodes happen within the first few weeks after surgery and are common. This does not mean that the organ will be lost as rejection can be treated or controlled by making changes to your anti-rejection medications. The sooner a rejection episode is found, the sooner it can be reversed. Rejection may range from mild to severe. You may need a liver biopsy at any time after your transplant, as this is the only true way to find out if a rejection episode is happening. **You will always be at risk for rejection.**

You must learn these signs of rejection:

- Flu-like symptoms
 - › Fever (greater than 38 degrees Celsius)
 - › Feeling tired
 - › Loss of appetite
- Nausea (sick stomach) and/or throwing up
- Abdominal pain or pain over your liver area
- Dark coloured urine (pee)
- Pale or grey coloured stool (bowel movement)
- Yellow colour of the skin and/or eyes

Prevention of rejection:

- Tell your family doctor right away if you have any symptoms of rejection
- Take all of your medications as ordered
- **Go to all Clinic visits as scheduled**
- Have all your blood work checked as instructed

Kidney problems

The kidneys may be damaged during or right after surgery so you may pass less urine. This is usually only a short-term problem. It may go away on its own or it may need treatment.

Diabetes

In the short term, some of the anti-rejection medications can increase the level of sugar in your blood. Diabetes can also be a long-term complication.

Signs:

- Increased thirst
- Passing urine often
- Feeling tired
- Drowsiness
- Blurred vision
- Muscle cramps
- Poor healing of wounds

Prevention and/or treatment:

Healthy eating and exercise may prevent diabetes. You should lose weight if you are above your ideal body weight.

Treatment for diabetes starts with changes in your diet and, if needed, pills or insulin to lower your blood sugar.

Primary graft nonfunction (acute liver failure)

Sometimes, the new liver does not start to work right away. This is rare. Another liver transplant is needed if this happens.

Infections

The anti-rejection medications that you need to prevent the rejection of your new liver lowers your ability to fight an infection. This makes you at greater risk of getting infections.

Some common infections are:

CMV (Cytomegalovirus)

This is a common virus. Most adults who have been exposed to this virus do not develop CMV disease. A healthy immune system will keep the CMV virus quiet. The virus can become active if a person's ability to fight infection is lowered. It happens more often in a patient who is classified as CMV negative and if his/her donor was positive. This can happen long after your transplant, but the highest risk of infection is the first 3 months after transplant.

Signs of CMV infection are:

- Fever
- Feeling tired
- Aching joints
- Headaches

Prevention and/or treatment:

If you are at a high risk for getting a CMV infection, you may be treated with an intravenous or oral medication while you are in the hospital. You will keep taking this medication for some time after you are discharged from the hospital. This medication helps to prevent you from getting a CMV infection. Even if you are not at high risk, we will check your blood regularly for any signs of CMV infection. If you pick up this virus, then the doctors will prescribe medication to treat it.

Herpes simplex

Herpes simplex is a viral infection that causes painful cold sores or blisters around the mouth or sex organs (genitals).

Signs of herpes simplex:

- Feeling weak
- Fever
- Painful cold sores or blisters around the mouth or sex organs

Treatment:

You will be treated with an antiviral medication if needed.

Candida (yeast)

Candida is commonly called yeast.

Signs:

- Mouth:
 - › White patchy lesions (sores)
 - › White film on tongue
 - › Problems swallowing
- Sex Organs:
 - › Pain
 - › Redness and/or itching
 - › Yellow or white discharge

Prevention and/or treatment:

- Mouth – a liquid antibiotic called Nystatin[®] is taken by mouth 4 times a day, until you leave the hospital
- Sex organs – a cream can be helpful

PCP (Pneumocystis Carinii Pneumonia)

This type of pneumonia occurs in people whose immune system is suppressed.

Signs:

- Fever
- Dry cough
- Shortness of breath

Prevention and/or treatment:

You may be treated with a medication called sulphatrim (Septra[®]) to help prevent you from getting this type of pneumonia.

Long-term complications

Osteoporosis

Osteoporosis makes the bones weak and thin. Some of the medications needed after a transplant, such as Prednisone, may place you at greater risk for this problem. Exercise, such as walking, decreases the risk of osteoporosis.

It is important to have enough calcium in your diet (1200-1500 mg every day). Milk and milk products are good sources of calcium. We may suggest vitamin D (800 IU daily) and calcium pills such as TUMS®. You should never take more calcium than the amount recommended by your doctor.

Diabetes

This can be a short- or long-term complication of transplant. Some anti-rejection medications increase your blood sugar levels. This is more likely to happen if you have ever had high blood sugar before your transplant.

Diabetes can affect many parts of your body. It is important to keep your blood sugar under control. See diabetes symptoms and prevention items listed under short-term complications on the previous page.

High blood pressure

This is a very common problem after transplant. It can be caused by the anti-rejection medications, but may also have other causes.

If left untreated, high blood pressure can damage your heart, blood vessels, and even your new transplant.

A healthier lifestyle may help control your blood pressure. Watching your weight, not eating salty foods, exercising, and not smoking are all things that might help you lower your blood pressure.

You might also need medications to control your blood pressure. The medication that works well for one person may not be best for another. Your doctor will adjust and change these medications and doses to find the best treatment for you. All blood pressure pills can have side effects. Always let your doctor know if your blood pressure pills are giving you any side effects. **Never stop or change blood pressure pills on your own.**

High cholesterol

Cholesterol has many useful roles in our body but too much cholesterol can clog arteries.

Anti-rejection medications can increase your cholesterol levels. If your cholesterol was elevated before surgery, it may be even higher after surgery.

Eating foods low in cholesterol or saturated fat, losing weight, and exercising may control this problem. Medication may be needed.

You may be reluctant to take any more medications, but it is vital that your cholesterol be as normal as possible. Your chances of having a stroke or heart attack will increase if your cholesterol is elevated for a long period of time.

Cancer

Liver cancer is more common in people with cirrhosis (scarring) of the liver. After transplant, this risk is reduced. However, medications needed to prevent rejection may increase the overall risk of cancer. People who have had previous cancers are at greater risk and need to have regular check-ups.

Planning for discharge

The average hospital stay for individuals who are well going into the transplant is 7-14 days, unless complications arise. If you are unwell at the time of your transplant, your hospital stay may be longer. You will need to stay in the Halifax area for a period of time after surgery.

Options for housing following discharge

Depending on your condition and your doctor, you may:

- Stay with family or friends who live nearby, or
- Be transferred to your home hospital (only if you have been at the QEII for a long period of time), or
- Go home upon discharge from the hospital, if you live nearby.

If you are from outside of Nova Scotia, you will stay at Point Pleasant Lodge (PPL) for a period of time before going home. There is no charge for your room or the shuttle to and from the hospital while staying at PPL.

Each province has made arrangements for meal coverage:

- **Nova Scotia and Newfoundland**

When you are discharged, staff on 6B will give you meal tickets that will last until your first Clinic visit. A nurse in the Clinic will then give you two \$5.00 meal tickets per day if you are staying at PPL. This is a subsidy and will not cover all meal costs. **Family members will have to pay for their own meals.**

Meal tickets can be used at PPL or in the hospital cafeteria.

- **New Brunswick and Prince Edward Island**

You will receive approximately \$25.00 + tax towards your meals while at PPL which can only be used at PPL. This is arranged by a NB or PEI liaison nurse.

Your family will have to pay for their stay at Point Pleasant Lodge unless they are approved as an essential escort. The cost will be \$40 + tax each night (subject to change). They may be asked for a security deposit of \$100 to be paid by credit card or cash.

The psychologist will talk with you and your family about coping with the transition from hospital to home. Even though this is a very positive step, you may find a few bumps on the road. Most patients have been so focused on the transplant that they assume that what comes after will take care of itself.

Remember that you would not be discharged from the hospital if we did not feel that you were ready to go. Please talk to your doctor or the nurses about any concerns you may have about going home.

You will need a follow-up appointment for the Clinic and instructions about blood tests. Your nurse will provide this information before you leave hospital.

Common tests

Tests are often needed to assess your liver function and the flow of blood around the liver and/or bile, as well as your heart and lungs.

Some of these tests may be ordered:

- Abdominal ultrasound
- Abdominal MRI scan
- Blood tests
- Chest X-ray
- Colonoscopy
- Echocardiogram
- Electrocardiogram
- ERCP/MRCP
- Gastroscopy
- Liver biopsy
- Triphasic abdominal CT scan

These tests are explained at the end of this guide.

Looking to the future

You are the lifetime caretaker of your new liver.

The Transplant Team will provide lifelong support. Regular visits to the Clinic are an important part of your care after you leave the hospital.

Always be aware of how you feel. Pay attention to your body and mind. Don't think twice about getting help when you sense something isn't right. Call your family doctor right away and keep in touch with the Transplant Team.

The Post-Liver Transplant Clinic

When you are discharged from the hospital and staying in Halifax, before you return to your home, the Post-Liver Transplant Clinic will be your main contact for any transplant-related questions or concerns.

If the Clinic is not open and you need help, go to the QEII Emergency Department on Robie Street.

The nurses' office of the Post-Liver Transplant Clinic is on 6 South, Victoria building, which is close to the Inpatient Transplant Unit.

The Post-Liver Transplant Clinic, where you will be going for appointments, is on the 4th floor of the Dickson Building, VG site. This is the same area as the Kidney Transplant Clinic.

At first, you will need to visit the Clinic 1-2 times a week. You will see the Clinic nurse on each visit.

The Clinic nurse will:

- Assess your overall condition
- Answer your questions
- Help you learn about life after your transplant
- Review your medications with you

In the beginning, you will see the doctor every week at the Clinic and then less often. The doctor will check on your progress, review your blood tests, and may make changes in your medications.

Review the information on blood tests at the end of this guide.

Getting ready for your first Clinic visit:

- Before you leave the hospital, a nurse will tell you when you need to have your blood tested. The Blood Collection Service is on the main floor of the Dickson Building, VG Site. Go past Tim Hortons going towards the Victoria Building. It will be on your left. **Do not take any anti-rejection medications until after your blood is taken.**
- Allow plenty of time to get to the hospital for your appointment so you don't feel rushed. If you are staying at Point Pleasant Lodge, ask the staff about the shuttle service. If someone is driving you, it sometimes takes extra time to find a parking place.
- Bring your medication schedule and all of your medications to your first Clinic visit.
- **Remember that you must drink bottled water when you are in any of the hospital buildings.**

When you return to your hometown, the Post-Liver Transplant Clinic will provide the follow-up and care specific to your liver transplant and other related medical concerns.

The Transplant Team will:

- Continue to answer any questions you may have as you adjust to life after your transplant.
- Continue to assess your blood reports.
- Adjust your anti-rejection medications.
- Call you with medication changes made by the Clinic doctor.
- It would be helpful if you have an answering machine and/or answering (voicemail) service. We will only leave a message on the answering machine or voicemail with the person who answers the phone if we have received your permission to do this.
- A letter will be sent in the mail to confirm medication changes.

Your family doctor

Your care is complex and needs the effort of many people. **Your family doctor is a very important member of your healthcare team.**

You should visit your family doctor during the first 2 weeks that you are home. It is important to see your family doctor and your local specialist regularly. This will reduce the number of trips that you will need to make to Halifax.

You must rely on your family doctor for routine care. We will keep your family doctor and local specialist up-to-date by sending a letter to each of them after each Clinic visit. They will also be notified if there are any changes in your anti-rejection medications.

Tell your pharmacist and dentist that you have had a liver transplant and are on anti-rejection medication. Your dentist will need to give you antibiotics before any dental work, including cleaning.

In the event of an emergency, call your family doctor or go to your local hospital's Emergency Department. Please call the Transplant Clinic to let them know if you go to Emergency or are admitted to hospital.

Taking care of yourself

Rejection

Remember that you will always be at risk for rejection. Adjusting your anti-rejection medications can control most rejection episodes. Steroids may be injected through an intravenous (IV) line to treat acute rejection. When steroids do not work, other anti-rejection medications may be used. You will need to take medication every day for the rest of your life to prevent rejection of your new liver.

These are signs of rejection:

- Flu-like symptoms
- Fever (greater than 38 degrees Celsius)
- Feeling tired
- Loss of appetite
- Nausea (sick stomach) or throwing up
- Abdominal pain or pain over your liver area
- Dark-coloured urine
- Pale or grey coloured stool (bowel movement)
- Yellow colour of the skin and/or eyes
- Changes in your blood test results

Infection

The anti-rejection medications that you take to prevent the rejection of your new liver lower your body's ability to fight an infection.

Be alert to the signs of infection:

- Fever over 38 degrees Celsius
- Cough with sputum (phlegm)
- Shortness of breath
- Cold sores around your lips or mouth
- Headaches
- Changes in your eyesight
- A white coating on your tongue or the roof of your mouth, pain, and difficulty swallowing
- Aching joints
- Burning or stinging when passing urine
- Passing more urine than usual
- Fatigue (feeling tired for no reason)
- More than the usual amount of redness, swelling, discharge or pain around an incision, sore, or cut

MedicAlert™

MedicAlert™ identification (ID) could save your life in an emergency. If you already have MedicAlert™ ID, it needs to be updated and replaced. It is important that your MedicAlert™ ID reads “**Transplant Recipient - Immunosuppression**”. Any allergies or other medical conditions should be listed on the MedicAlert™ ID. Make sure that you always wear your MedicAlert™ bracelet or necklace.

Ask your nurse to help you fill out a MedicAlert™ form and send it as soon as possible. It can take up to 8 weeks for delivery.

Emotional and social adjustment

This is a very exciting time in your life. Receiving a transplant is a precious gift but it is also a time of loss for others. You, your donor, and his/her family must remain unknown to each other to protect you, your donor, and the donor's family.

You may write a letter of thanks to the donor family for being given a new chance at life.

Your nurses can give you a pamphlet on how to write this letter. Send your letter to the Transplant Clinic Nurse who will give it to a Coordinator to mail to the family.

There are many changes to get used to after a long hospital stay and perhaps a long illness.

You may be having mood swings and trouble sleeping while you are still on high doses of anti-rejection medications. You may be taking an active role in your family life again, returning to work, and coping with anxiety about the possible rejection of your new liver. Be patient with yourself and others. Pace yourself.

Do not expect your life to return to "normal" right away. Sharing your feelings and concerns with family, friends, and the Team can be very helpful. Exercise can also reduce stress and tension. If you wish, the psychologist will meet with you and/or your family members to help you cope with these changes. You can also make arrangements for counseling in your own area.

If there are complications after transplant, you may feel you have just changed one set of problems for another. You may ask "why me?" or believe nothing in your life is going right. This is especially true if you see other transplant patients who seem to be doing well. The Team will try to help you deal with these issues and find supports.

Sometimes people feel so much better after they return home that they wonder if they really need to continue taking their medications or following their exercise or healthy eating program. It is very important to discuss this issue with the Clinic nurses and doctors before you make any changes.

Sexual health

General information

You will probably have a lot more energy after your transplant.

You may resume sexual activity whenever you feel well enough.

Everyone should be concerned about sexually transmitted diseases such as AIDS, herpes, and hepatitis. After a transplant, you are at a greater risk of getting an infection because your immune system is suppressed. Practice safe sex: use a condom if you have a new sexual partner or your regular partner is at risk of an infection.

Some medications may decrease your desire and ability to be sexually active. If this happens, talk about it with your doctor.

Medications can be helpful for some people.

Pregnancy and birth control

A woman who was not having periods before transplant may start menstruating after transplant and may become pregnant. It is important to talk about birth control options with your doctor.

The choice to have a child is an important decision that you and your partner should discuss with your transplant doctor **before becoming pregnant**. Transplant recipients can have successful pregnancies. Some anti-rejection medications could harm a baby during pregnancy, so make sure that you discuss this with your transplant doctor before you decide to become pregnant. A woman should not become pregnant for a year after transplant and she should be doing well. Her obstetrician will watch her carefully during her pregnancy in case of any problems.

Exercise

You may do your usual activities. Moderation is the key. The amount of time and work needed to regain your strength depends on how ill you were before surgery.

Do not lift anything over 15 pounds for the first 3 months. You can then resume normal lifting if you are not having any discomfort around your incision. Do not strain yourself.

Follow the home exercise program that your physiotherapist may give you. Exercise is a very important part of a healthy lifestyle.

The physiotherapist may ask you to go to the physiotherapy gym 2-3 times a week while you are in Halifax. She/he may give you a home exercise program or arrange for you to visit your local physiotherapy department when you return to your own home.

Healthy eating

You need regular healthy meals. The dietitian can meet with you at the Clinic if you have questions or concerns about what you should be eating. Ask the nurse to arrange this meeting.

Dental care

It is very important to keep your gums and teeth healthy. Your medications increase your risk of mouth infections.

- Brush your teeth at least twice a day and floss your teeth every day.
- Visit your dentist every 6 months.
- Tell your dentist about your transplant. **You will need antibiotics before you have any dental work, including cleaning.** Your dentist can call the Clinic for advice about which antibiotic to use.

Eye care

High doses of prednisone can affect your vision. Do not have your glasses changed right after your transplant when your dose of prednisone is being changed often. Wait until the dosage is stabilized before you have your eyes checked for new glasses.

You should have your eyes checked at least every 2 years by an eye specialist. Cataracts can develop if you are on prednisone for a long period of time.

Alcohol

Do not drink any alcohol. Drinking alcohol interferes with anti-rejection medications and will lead to liver damage.

Smoking

Do not smoke. Smoking will damage your lungs, heart, and blood vessels. You are at a greater risk of developing cancer than other people because your immune system is lower.

Skin cancer

We all need to protect our bodies from the sun's harmful rays. Your medications make your skin more sensitive to damage from the sun.

Protect yourself in the sun:

- Use a sunscreen with an SPF of 30 or greater.
- Wear a hat, a long-sleeved cotton shirt, and cotton pants.
- Avoid the sun between 11 a.m. and 3 p.m. as this is when the sun's rays are most damaging.
- Wear UV-filtering sunglasses to protect your eyes.

Be alert for any signs of skin cancer:

- Check all your skin for changes in freckles, moles, or spots every month. A friend or family member should check the areas that you can't see.
- Tell your doctor if you see any changes.

Follow-up care

Regular visits to your family doctor are an important part of taking care of yourself.

- See your family doctor if you have any kind of infection. Don't wait for it to clear up on its own.
- Have a flu shot every fall. Your family should also have flu shots.
- If you pass any blood in your bowel movements, tell your family doctor.
- People with primary sclerosing cholangitis and inflammatory bowel disease should have a yearly colonoscopy.
- You should be checked for cancer of the colon and rectum if you are over 50.
- All women need a yearly Pap test and breast examination. A woman who is over 40 should have a yearly mammogram.
- Men over 50 should have a PSA blood test every year to check for prostate cancer. They should also be checked for testicular cancer.
- You need yearly blood tests for TSH to measure how your thyroid is working, a lipid profile to check your cholesterol and triglyceride levels, and HgbA1C to see your average blood sugar.
- You will be asked to collect an early morning urine specimen once a year to see how well your kidneys are working.
- You will have a bone mineral density test every 2 years to check the strength of your bones.

Immunizations

You should not receive a vaccination for 6 months after your transplant. You may have most immunizations, including flu shots and hepatitis B vaccines. You should not have vaccines made from live sources. Check with your family doctor or the Transplant Clinic about the immunizations you need.

Your environment

Personal hygiene

- The best way to prevent most infections is by washing your hands often with soap and hot water. Wash them before and after you touch food, after you use the bathroom, after touching an animal, and many times during the day.
- Take good care of your teeth and gums to prevent infections.

Housekeeping

In the kitchen:

- Keep countertops and cutting boards clean. Disinfect them regularly.
- Do not use wooden cutting boards.

Around the house:

- If you are planning major renovations, demolition could expose you to moulds and possible fungal infections.
- Be aware of the risk of food poisoning.

Pets

After your transplant, you will have a weakened immune system. Your pet could make you ill.

- Keep your pet healthy, clean, and groomed.
- Wear gloves when cleaning your pet's body fluids (vomit, bowel movements, urine, and saliva) and when changing kitty litter. Fluids should be cleaned up with a disinfectant. If possible, have someone else do this.
- Some animals are more likely to carry diseases. This makes them harmful to you.

Stay away from:

- › Stray or wild animals
- › Animals with diarrhea
- › Sick animals
- › Exotic animals, including turtles and monkeys

Outdoor activities

- When you are gardening or digging in the soil, wear gloves to protect yourself from fungi.
- You can take part in sports and activities. Talk about this with your Team before you take part in any sports. Pace yourself, especially right after your transplant, so you do not get too tired.
- West Nile virus is spread to humans by the bite of an infected mosquito. Because your immune system is now weaker, you are more likely to get sick if bitten by an infected mosquito. Prevent mosquitoes from biting you by wearing long-sleeved shirts and pants when mosquitoes are out. Use insect repellent with DEET. Get rid of standing water where mosquitoes breed.

Returning to work

Talk about this with your transplant doctor. He or she will suggest the best time for you to go back to work based on the physical demands of your job, your age, your overall health, and job stress. Most people are able to return to work within 6 months.

Driving

Ask yourself if you feel well enough to drive. Your incision should be well healed and your mind should be clear. **Do not drive if you are taking narcotics.** You must wear a seatbelt. A towel under the seat belt may be helpful if the belt bothers your incision.

If you gave up your driver's license before your transplant, ask your family doctor or the Transplant Clinic about getting it back.

Travelling

it is OK for you to travel after your transplant. Always talk about your travel plans with the Clinic staff or your doctor. Make arrangements well in advance.

Blood tests can often be arranged in the area you are visiting. The transplant doctors may be able to give you the name of a doctor in the area you are visiting.

Travel guidelines:

- Wait 6 months before travelling outside the country.
- Always carry your medications in your carry-on luggage when you are travelling.
- Leave your medications in their original bottles.
- Carry enough medication for at least an extra week in case your return is delayed.
- Always buy health insurance and cancellation insurance.
- Ask the Clinic staff or your family doctor for a travel letter that includes a list of medications that you are currently taking.
- Ask your travel agent if there are any special medical concerns about the country you plan to visit.
- If you are crossing time zones, talk with the Clinic staff about how this affects the times when you take your medications.
- Be prepared to return home if you become ill on the trip.

The self-medication program

Introduction

You need to learn about your medications. During your hospital stay, you will start to take your medications on your own. The nurse will help you with this by making out a medication calendar for you to follow. This helps you get ready to take your medications at home. Be sure to let your nurse know if you have a vision, hearing, or memory problem.

Your nurse will help you learn:

- The name of each medication that you are taking
- Why you need to take each medication
- When and how to take each medication
- The side effects that can happen with each medication
- How to get your supply of each medication

A supply of medications and a medication record will be given to you. You will start to get your medications ready on your own and take them at the right times. During your hospital stay, your nurses will check how you are doing each day.

Reminders

- **You will need to take anti-rejection medications for the rest of your life.**
- Take your medications as directed by your doctor.
- Do not stop taking any medication without asking your doctor.
- Take your medications at the same time each day.
- If you forget a dose of your anti-rejection medication:
 - › **Medications you take twice a day:** if you miss a dose and remember it before the halfway point between the 2 doses, take the medication. Otherwise skip this dose and take the next dose at the regularly scheduled time.
 - › **Medications you take once a day:** take your dose as soon as you remember it.

- If you are vomiting, you are probably bringing up your medications. If you vomit within half an hour of taking a dose of anti-rejection medication, repeat that dose of medication after your stomach settles. If it is longer than half an hour, do not repeat that dose unless you saw the pills come up. Take your usual dose at the next regular scheduled time. Do not double dose. If your nausea continues, contact your doctor.
- If you have diarrhea that lasts more than a couple of days, contact the Team, as well as your family doctor.
- Make sure you have enough medication. **Do not run out.** Get your refills while you still have **at least a 2-week supply of medications left.**
- Tell your dentist, pharmacist, and family doctor about the medications you are taking.
- Carry a list of your medications with you at all times in your purse or wallet.
- **Some over-the-counter medications may affect the level of your anti-rejection medications.** Do not take medications such as cold medications without speaking with your doctor or pharmacist.
- Do not take any other medications, such as large doses of vitamins or herbal remedies, without asking your doctor or pharmacist.

How to get your anti-rejection medications

- If you live in PEI, NS, or NL your anti-rejection medications are provided to you through a government-funded program. They are not available in the local drug store.

You will be given instructions on how to get your medications before you leave the hospital.

- If you live in NB, you can get your anti-rejection medications from your local drug store. Before your discharge from the hospital, please make sure that you know how to get these medications.

Storing your medications

- Keep medicine out of the reach of children.
- Do not store in damp areas such as the bathroom.
- Do not store in direct sunlight.
- Do not store pills or tablets in the fridge.
- Any medication in a foil package should not be removed from the package until you are going to take them.
- Do not keep old medicine or medicine that you no longer need. Take these to your local drugstore. They will get rid of them safely.
- Do not share your medicines with anyone.

Your medications

After your transplant, your medications will include some of the following: acyclovir, cyclosporine, mycophenolate mofetil, mycophenolate sodium, prednisone, ranitidine, sirolimus, sulfamethoxazole/trimethoprim, tacrolimus, valganciclovir.

You may take other medications to prevent infection, or control high blood pressure or diabetes, as well as medications that you took before transplant, such as thyroid medication.

Information on your medications can be found on the following pages.

Acyclovir

Generic name: Acyclovir

Brand name: Zovirax®

What is acyclovir?

- Acyclovir is a drug used to treat or prevent infections caused by viruses.
- It is prescribed to treat or prevent viral infections such as chicken pox, shingles, and cold sores.

How do I use acyclovir?

- Do not stop taking acyclovir on your own - talk to your doctor first.
- Acyclovir can be taken with or without food.
- Acyclovir can cause problems if you take it with other medicine. Talk to your doctor, pharmacist, or transplant nurse before taking any other medicine, including prescription/non-prescription medicine, natural products, and/or supplements.
- If you are not sure of how much medicine to take, or if you think you may be experiencing any side effects, talk to your Transplant Clinic nurse or your pharmacist.
- If you have started taking new medicine and worry it might have an effect on acyclovir, or you forgot to take your medicine and are not sure what to do, talk to your Transplant Clinic nurse or your pharmacist .
- Store acyclovir at room temperature away from heat, light, and moisture.

What are the side effects?

(Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Talk to a healthcare professional if you do not feel well while taking acyclovir. Below is a list of side effects to be aware of:

- **Stomach upset:** Taking this medicine with food may help prevent stomach upset.
- **Blood problems:** Acyclovir can lower red blood cells, white blood cells, and platelets (a part of the blood which helps make blood clot). This can make you feel tired, increasing your risk of infections, bruising, and/or bleeding problems. The Transplant Team will watch closely for these problems and will change the amount of your medicine if needed. Please talk to your Transplant Clinic nurse, your pharmacist, or your doctor about any tiredness, bruising, or infections.
- **Kidney problems:** Rarely, acyclovir can cause kidney problems. The Transplant Team will watch closely for these problems and will change the amount of medicine you take as needed.
- **Rash:** Contact a healthcare professional or the Transplant Clinic if you develop a rash.

Cyclosporine

Generic name: Cyclosporine

Brand name: Neoral®

What is cyclosporine?

- Cyclosporine is an “immunosuppressant” or “anti-rejection” drug that weakens the immune system in your body.
- It is prescribed to prevent rejection of your transplanted organ.

How do I use cyclosporine?

- In order to control your immune system, it is very important that you take this medication at the same time each day.
- Do not stop taking cyclosporine on your own. Talk to your doctor first.
- Take cyclosporine with a glass of water.
- Cyclosporine can be taken with or without food.
- Avoid grapefruit and grapefruit juices.
- On days when you are going to get drug levels done, it is important that your blood is drawn 2 hours after you have taken your cyclosporine.
- Cyclosporine may interact with other medications. Speak to your doctor, pharmacist, or transplant nurse before taking any medications, including nonprescription or prescription medications.
- Drug levels and bodily functions are monitored to adjust the dose. If you are not sure of your dosage, if you think you may be experiencing a side effect, if you are started on new medication and need information on drug interactions, or if you have missed a dose and are uncertain what to do, contact your doctor, pharmacist, or transplant nurse.
- Store cyclosporine at room temperature away from heat, light, and moisture.

What are the side effects?

(Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Talk to a healthcare professional if you do not feel well while taking cyclosporine. Below is a list of side effects to be aware of:

- **Increased risk of infection:** This risk is present with all medications which suppress the immune system. Report the first signs and symptoms of infection (such as fever, chills, fast pulse) to your doctor immediately.
- **Increased risk of developing cancer:** This risk is present with all medications that suppress the immune system. Report any signs of skin discoloration and/or lumps to your doctor.
- **Stomach upset, loss of appetite, nausea, vomiting, diarrhea:** If these symptoms appear, they usually go away soon after you have started taking cyclosporine. Since excessive diarrhea can decrease the amount of drug absorbed by your body, notify your doctor if it persists or before you take any other medications to treat these symptoms.
- **Increased blood pressure, cholesterol, or toxic effects on the kidney:** You will be monitored for these possible effects. If they occur, you may require a change in dosage or medication.
- **Increased hair growth:** The degree to which this happens is variable.
- **Increased growth of the gums:** Good mouth hygiene and regular dental checkups can minimize and control this problem. Let your dentist know you are taking cyclosporine.
- **If you are a female of child-bearing age:** Pregnancy should be avoided while you are taking cyclosporine. It may present risks to an unborn baby. Ask your doctor or pharmacist to help you choose an appropriate contraceptive method.

Mycophenolate Mofetil

Generic name: Mycophenolate Mofetil (MMF)

Brand name: CellCept®

What is MMF?

- MMF is an immunosuppressant or anti-rejection drug that weakens the immune system in your body.
- It is prescribed to prevent your body from rejecting your transplanted organ.

How do I use MMF?

- Do not stop taking MMF on your own - talk to your doctor first.
- Take MMF at the same time each day.
- MMF can be taken with or without food though it is best absorbed on an empty stomach. Be consistent with how you take your medicine each day.
- MMF can cause problems if you take it with other medications. Talk to your doctor, pharmacist, or transplant nurse before taking any other medications, including prescription/non-prescription medications, natural products, and/or supplements.
- Your blood counts will be monitored regularly. The amount of MMF you take may have to be adjusted because of the results of your blood count.
- If you are not sure how much medication to take, or if you think you may be experiencing any side effects, talk to your Transplant Clinic nurse or your pharmacist.
- Leave MMF in its packaging until you are ready to take it.
- If you have started taking new medication and worry it might have an effect on MMF, or you forgot to take your medication and are not sure what to do, talk to your Transplant Clinic nurse or your pharmacist .
- Store MMF at room temperature away from heat, light, and moisture.

What are the side effects?

(Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Talk to your healthcare professional if you do not feel well while taking MMF. Below is a list of side effects to be aware of:

- **Higher risk of infection:** Report the first signs and symptoms of an infection (such as fever, sore throat, chills, fast pulse, etc.) to your doctor **immediately**.
- **Higher risk of developing cancer:** Report any lumps or changes in skin color and moles to your doctor.
- **Stomach upset, loss of appetite, nausea, vomiting, diarrhea:** These symptoms often occur early in treatment and should go away. **Talk to your doctor or pharmacist before taking any over-the-counter medications to treat these symptoms.**
- **Headache, light-headedness, dizziness, weakness:** If these symptoms continue, or if you experience any fainting, see your doctor right away.
- **Blood problems:** MMF can lower red blood cells, white blood cells, and platelets (the part of the blood which helps make blood clots). This can increase your risk of infections, bruising or bleeding problems, and tiredness. You will be carefully monitored for any signs of these blood problems and the amount of MMF you take may need to be adjusted. Please report any extreme tiredness, bruising, or infections to your Transplant Clinic nurse, pharmacist, or your doctor.
- **If you are a woman of child-bearing age:** Pregnancy should be avoided while you are taking MMF as it can cause harm to an unborn baby. Ask your doctor or pharmacist for help in choosing the right birth control method. If you are planning to get pregnant, talk with the Transplant Team months beforehand, as some of your medicines may need to be changed.

Mycophenolate Sodium

Generic name: Mycophenolate Sodium

Brand name: Myfortic®

What is mycophenolate sodium?

- Mycophenolate sodium is an immunosuppressant or anti-rejection drug that weakens the immune system in your body.
- It is prescribed to prevent your body from rejecting your transplanted organ.

How do I use mycophenolate sodium?

- Do not stop taking mycophenolate sodium on your own - talk to your doctor first.
- Take this medicine at the same time each day.
- Mycophenolate sodium can be taken with or without food though it is best absorbed on an empty stomach. Be consistent with how you take your medicine each day.
- Mycophenolate sodium may cause problems if you take it with other medicines. Talk to your doctor, pharmacist, or transplant nurse before taking any other medicine, including prescription/nonprescription medications, natural products, and/or supplements.
- Your blood counts will be monitored regularly and the amount of medicine you take may have to be adjusted because of the results of your blood count.
- If you are not sure how much medicine to take, or if you think you have any side effects, talk to your doctor.
- If you have started taking new medicine and worry it might have an effect on mycophenolate sodium, or you forgot to take your medicine and are not sure what to do, talk to your Transplant Clinic nurse or your pharmacist.
- Store mycophenolate sodium at room temperature away from heat, light, and moisture.

What are the side effects?

(Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Talk to your doctor if you do not feel well while taking mycophenolate sodium. Below is a list of side effects to be aware of:

- **Higher risk of infection:** Talk to your doctor **immediately** if you see the first signs and symptoms of infection: fever, sore throat, chills, or fast pulse.
- **Higher risk of developing cancer:** Report any lumps or changes in skin colour and moles to your doctor.
- **Stomach upset, loss of appetite, nausea, vomiting, diarrhea:** These symptoms often happen early in treatment and should go away. **Talk to your doctor or pharmacist before taking any over-the-counter medications to treat these symptoms.**
- **Headache, light-headedness, dizziness, weakness:** If these symptoms continue, or if fainting happens, see your doctor immediately.
- **Blood problems:** Mycophenolate sodium can lower red blood cells, white blood cells, and platelets (the part of the blood which helps make blood clots). This can cause fatigue, higher risk of infection, and bruising or bleeding problems. Your doctor will watch closely for these blood problems and will change the amount of medicine you take if needed. Please talk to your Transplant Clinic nurse, your pharmacist, or your doctor if you have any unusual fatigue, bruising, or infections.
- **If you are a woman of child-bearing age:** Pregnancy should be avoided while you are taking mycophenolate sodium as it can cause harm to an unborn baby. Ask your doctor or pharmacist for help in choosing the right birth control method. If you are planning to get pregnant, talk with the Transplant Team months, as some of your medicines may need to be changed.

Prednisone

Generic name: Prednisone

Brand name: none

What is prednisone?

- Prednisone is an immunosuppressant or anti-rejection drug that weakens the immune system in your body.
- It is taken to prevent your body from rejecting your transplanted organ.

How do I use prednisone?

- Do not stop taking prednisone on your own - talk to your doctor first.
- Prednisone can be taken with or without food.
- Prednisone may cause problems if you take it with other medicines. Talk to your doctor, pharmacist, or transplant nurse before taking any new medicines, including prescription/nonprescription medications, natural products, and/or supplements.
- If you are not sure of how much medicine to take, or if you think you may be experiencing any side effects, talk to your Transplant Clinic nurse, your pharmacist, or your doctor.
- If you have started taking new medicine and worry it might have an effect on prednisone, or you forgot to take your medicine and are not sure what to do, talk to your Transplant Clinic nurse, your pharmacist, or your doctor.
- Store prednisone at room temperature away from heat, light, and moisture.

What are the side effects?

(Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Talk to your doctor if you do not feel well while taking prednisone. Below is a list of side effects to be aware of:

- **Mood changes:** Prednisone can change your mood. Some people may become depressed, while others may feel extremely happy or energetic. Prednisone can also make psychiatric disorders worse. If you have a psychiatric illness and think it is getting out of control, or if you think you may be having mood problems, contact your healthcare professional immediately.
- **Higher risk of infection:** Talk to your doctor **immediately** if you experience any signs and symptoms of infection: fever, sore throat, chills, or a fast pulse.
- **High blood pressure/cholesterol:** Prednisone can make your blood pressure and cholesterol levels higher. Eating well and exercising can help.
- **Stomach upset:** Taking this medicine with food may help prevent stomach upset.
- **Fluid retention:** Prednisone can make your body hold onto fluid causing edema (puffiness). If you think you are retaining fluid and becoming “puffy”, contact the Transplant Clinic.
- **Weakened bones:** Prednisone can weaken bones over time and may cause osteoporosis. Make sure you have enough calcium in your diet to help cut down on the risk of this side effect.
- **High blood sugar:** Prednisone can make your blood sugars higher and some people will develop diabetes. Eating well and exercising can help.

Ranitidine

Generic name: Ranitidine

Brand name: Zantac®

What is ranitidine?

- Ranitidine is a type of antacid that lowers the amount of acid the stomach makes.
- It is taken to prevent heart burn, stomach upset, and stomach ulcers.

How do I use ranitidine?

- Do not stop taking ranitidine on your own. Talk to your doctor first.
- Ranitidine can be taken with or without food.
- Ranitidine can cause problems if you take it with other medicine. Speak to your doctor, pharmacist, or transplant nurse before taking any new medications, including prescription/nonprescription medications, natural products, and/or supplements.
- If you are not sure of how much medicine to take, or if you think you may be experiencing any side effects, contact the Transplant Clinic or your pharmacist.
- If you have started taking new medicine and worry it might have an effect on ranitidine, or you forgot to take your medicine and are not sure what to do, contact the Transplant Clinic or your pharmacist.
- Store ranitidine at room temperature away from heat, light, and moisture.

What are the side effects?

(Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Contact a healthcare professional if you do not feel well while taking ranitidine. Below is a list of side effects to be aware of:

- **Stomach upset:** Taking this medicine with food may help prevent stomach upset.
- **Blood problems:** Rarely, ranitidine can lower white blood cells and a part of the blood (platelets) which helps make blood clots. This can cause a higher risk of infection and bruising or bleeding problems. Your doctor will watch closely for these blood problems and change how much medicine you take if needed. Please report any unusual bruising, bleeding, or infections to your Transplant Clinic nurse, your pharmacist, or your doctor.
- **Rash:** Contact the Transplant Clinic if you develop a rash.

Sirolimus

Generic name: Sirolimus

Brand names: Rapamune®

What is sirolimus?

- Sirolimus is an “immunosuppressant” or “anti-rejection” drug that weakens the immune system in your body.
- It has been prescribed for you to prevent rejection of your transplanted organ.

How do I use sirolimus?

- In order to control your immune system, it is very important that you take the medication at the same time each day.
- Do not stop taking sirolimus on your own. Talk to your doctor first.
- Take sirolimus with a glass of water.
- Sirolimus can be taken with or without food.
- Avoid grapefruit and grapefruit juices.
- On days when you are going to get drug levels done, take sirolimus after your blood is drawn.
- Sirolimus may interact with other medications. Speak to your doctor, pharmacist, or transplant nurse before taking any medications, including nonprescription or prescription medications.
- Drug levels and bodily functions are monitored to adjust the dose. If you are not sure of your dosage, if you think you may be experiencing a side effect, if you are started on new medication and need information on drug interactions, or if you have missed a dose and are unsure what to do, contact your doctor, pharmacist, or transplant nurse.
- Store sirolimus at room temperature away from heat, light, and moisture.

What are the side effects?

(Please note this is not a complete list of all possible side effects.)

Side effects are possible with all medicines. Contact a healthcare professional if you do not feel well while taking sirolimus. Below is a list of side effects to be aware of:

- **Increased risk of infection:** This risk is present with all medications which suppress the immune system. Report the first signs and symptoms of infection (such as fever, chills, fast pulse) to your doctor immediately.
- **Increased risk of developing cancer:** This risk is present with all medications that suppress the immune system. Report any signs of skin discolouration and/or lumps to your doctor.
- **Stomach upset, loss of appetite, nausea, vomiting, diarrhea:** If these symptoms appear, they usually go away soon after you have started taking sirolimus. Since excessive diarrhea can decrease the amount of drug absorbed by your body, notify your doctor if it persists or before you take any other medications to treat these symptoms.
- **Increased blood pressure, cholesterol, or toxic effects on the kidney:** You will be monitored for these potential effects. If they occur, you may require a change in dosage or medication.
- **Water retention:** Inform your healthcare team if you notice swelling in your hands/feet/legs.
- **Mouth sores:** Inform your healthcare team if you notice painful sores in your mouth.
- **Poor wound healing:** You may notice it takes longer for wounds to heal while taking sirolimus.
- **If you are a female of child-bearing age:** Pregnancy should be avoided while you are taking sirolimus. It may present risks to an unborn baby. Ask your doctor or pharmacist to help you choose an appropriate contraceptive method.

Sulfamethoxazole/Trimethoprim

Generic name: Sulfamethoxazole/Trimethoprim

Brand names: Septra[®], Bactrim[®], cotrimoxazole, Sulfatrim[®]

What is sulfamethoxazole/trimethoprim?

- Sulfamethoxazole/trimethoprim is an antibiotic which is used to treat or prevent infections caused by bacteria.
- It is taken to either treat or prevent different bacterial infections including one caused by PneumoCystis (jirovecii) Pneumonia or “PCP”.

How do I use sulfamethoxazole/trimethoprim?

- If you have allergies to “sulfa drugs” or to sulfonamides, tell your doctor before you start taking sulfamethoxazole/trimethoprim.
- If you are glucose-6-phosphate dehydrogenase (G6PD) deficient, contact the Transplant Clinic before you start taking sulfamethoxazole/trimethoprim.
- Do not stop taking sulfamethoxazole/trimethoprim on your own – contact the Transplant Clinic first.
- Sulfamethoxazole/trimethoprim can be taken with or without food.
- Sulfamethoxazole/trimethoprim can cause problems if you take it with other medicine. Speak to your doctor, pharmacist, or Transplant Clinic nurse before taking any new medications, including prescription/nonprescription medications, natural products, and/or supplements.
- If you are not sure how much medicine to take, or if you think you may be experiencing any side effects, contact your Transplant Clinic nurse or your pharmacist.
- If you have started taking new medication and are worried it might have an effect on sulfamethoxazole/trimethoprim, or you forgot to take your medicine and are not sure what to do, contact the Transplant Clinic nurse or your pharmacist.

- Store sulfamethoxazole/trimethoprim at room temperature away from heat, light, and moisture.

What are the side effects?

(Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Contact a healthcare professional if you do not feel well while taking sulfamethoxazole/trimethoprim. Below is a list of side effects to be aware of:

- **Stomach upset:** Taking this medicine with food may help prevent stomach upset.
- **Blood problems:** Sulfamethoxazole/trimethoprim can lower red blood cells, white blood cells, and a part of the blood (platelets) which helps make blood clots. This can cause fatigue, a higher risk of infection, and bruising or bleeding problems. Your doctor will watch closely for these problems and change the amount of medicine you take if needed. Please report any unusual fatigue, bruising, or infections to your Transplant Clinic nurse, your pharmacist, or your doctor.
- **Kidney problems:** Rarely, sulfamethoxazole/trimethoprim can cause kidney problems. Your doctor will watch closely for these problems and change the amount of medicine you take if needed.
- **Electrolyte problems:** Sulfamethoxazole/trimethoprim can cause potassium levels to go up. Rarely, this can lead to heart problems, especially if your body has difficulties getting rid of potassium. Your doctor will watch closely for these problems and change the amount of medicine you take if needed.
- **Rash:** Contact the Transplant Clinic if you develop a rash.

Tacrolimus

Generic names: Tacrolimus, FK506

Brand names: Advagraf[®], Prograf[®]

What is tacrolimus?

- Tacrolimus is an immunosuppressant or anti-rejection drug that weakens the immune system in your body.
- It is taken to prevent your body from rejecting your transplanted organ.

How do I use tacrolimus?

- Do not stop taking tacrolimus on your own – contact your doctor first.
- Take tacrolimus at the same time each day.
- Tacrolimus can be taken with or without food though it is best taken on an empty stomach. Be consistent with how you take your medication each day.
- Your doctor will test your blood regularly. The amount of tacrolimus you take may be changed because of the results of these blood tests.
- Do not take tacrolimus before your blood tests. Bring it with you so you can take it just after your blood test is done.
- Tacrolimus can cause problems if you take it with other medications. Talk to your doctor, pharmacist, or transplant nurse before taking any drugs, including prescription/nonprescription drugs, natural products, and/or supplements.
- If you are not sure how much medicine to take, or if you think you are experiencing any side effects, contact your Transplant Clinic nurse or your pharmacist.
- If you have started taking any new medication and are worried it may have an effect on tacrolimus, or you forgot to take your medication and are not sure what to do, contact your Transplant Clinic nurse or your pharmacist.
- Store tacrolimus at room temperature away from heat, light, and moisture.

What are the side effects?

(Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Contact a healthcare professional if you do not feel well while taking tacrolimus. Below is a list of side effects to be aware of:

- **Higher risk of infection:** Report the first signs and symptoms of infection (such as fever, sore throat, chills, fast pulse) to your doctor **immediately**.
- **Higher risk of developing cancer:** Report any lumps or changes in skin colour and moles to your doctor.
- **Stomach upset, loss of appetite, nausea, vomiting, diarrhea:** These symptoms often happen early on in treatment and should go away. **Talk to your doctor or pharmacist before taking any over-the-counter drugs to treat these symptoms.**
- **Headache, light-headedness, dizziness, weakness:** If these symptoms keep happening, or if you experience any fainting, see your doctor immediately.
- **Higher blood pressure, blood sugar, or cholesterol levels:** Your doctor will check for these possible effects. If you experience any of these symptoms, your doctor may change the amount of medicine you take.
- **Toxic effects on the kidneys:** Tacrolimus can be toxic to the kidneys. It is important that you get your blood tested regularly so this side effect can be checked.
- **Slight hand trembling:** This usually depends on the amount of tacrolimus in your blood. The trembling tends to go away with time as the concentration of the dose decreases.
- **If you are a woman of child-bearing age:** Pregnancy should be avoided while you are taking tacrolimus as it may cause harm to an unborn baby. Ask your doctor or pharmacist to help you choose the right birth control. If you are planning to become pregnant, talk with your Transplant Team months in advance, as some of your medications may need to be changed.

Valganciclovir

Generic name: Valganciclovir

Brand name: Valcyte®

What is valganciclovir?

- Valganciclovir is an antiviral drug used to treat or prevent infections caused by viruses.
- It is taken to treat or prevent different viral infections such as one caused by Cytomegalovirus or “CMV”.

How do I use valganciclovir?

- Take valganciclovir according to your doctor’s directions.
- Do not stop taking valganciclovir on your own – talk to your doctor first.
- Valganciclovir can be taken with or without food.
- Valganciclovir may cause problems if taken with other medications. Contact your doctor, pharmacist, or transplant nurse before taking any medications, including prescription/nonprescription medications, natural products, and/or supplements.
- If you are not sure how much medicine to take, or if you think you may be experiencing any side effects, contact your Transplant Clinic nurse or your pharmacist.
- If you are taking new medication and are worried it may have an effect on valganciclovir, or you forgot to take your medication and are not sure what to do, contact your Transplant Clinic nurse or your pharmacist.
- Store valganciclovir at room temperature away from heat, light, and moisture.

What are the side effects?

(Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Talk to a healthcare professional if you do not feel well while taking valganciclovir. Below is a list of side effects to be aware of:

- **Stomach upset:** Taking this medication with food may help prevent stomach upset.
- **Blood problems:** Valganciclovir can lower red blood cells, white blood cells, and platelets (the part of the blood which helps make blood clots). This can cause tiredness, higher risk of infection, and bruising or bleeding problems. Your doctor will watch closely for these problems and change the amount of your medicine if needed. Please contact your Transplant Clinic nurse, pharmacist, or doctor about any unusual tiredness, bruising, or infections.
- **Kidney problems:** Rarely, valganciclovir can cause kidney problems. Your doctor will watch closely for these problems and change the amount of medicine if needed.
- **Rash:** Contact the Transplant Clinic or a healthcare professional if you develop a rash.

Common tests

Abdominal MRI scan gives detailed pictures of the liver and surrounding organs from different angles without using X-rays. It shows if the blood vessels and bile ducts are open. This test takes 60-75 minutes.

Abdominal ultrasound/ultrasound with Doppler studies is a painless and quick test. Sound waves are used to take pictures of your liver and other organs. It can also show if the bile ducts and the large blood vessels that flow to and from your liver are open.

Bone density is a special kind of X-ray that measures the thickness of your bones, usually of the hip and spine.

Bone scan is needed regularly if you had a liver tumour at the time of transplant. This test checks to see if cancer has spread to the bones. It is done by injecting a dye, then taking pictures of the bones.

Colonoscopy is a test where a special tube and camera is passed through your rectum into your large bowel. This test checks for bowel disease, tumours, bleeding, internal hemorrhoids, and polyps. You will be put to sleep for this test.

CT scan is a computerized image that shows the size and shape of the liver, other abdominal organs, major blood vessels, and bile ducts.

Endoscopy or gastroscopy uses a special tube or scope to look into your throat, stomach, and small bowel to find out if you have any enlarged blood vessels or ulcers. You will be put to sleep for this test.

ERCP (Endoscopy Retrograde Cholangiopancreatography) uses a special tube with a light and camera to look at the bile ducts. The doctor will pass the tube through your mouth into the first part of the small bowel. You will be put to sleep for this test.

Liver biopsy shows how well your liver is working. A small piece of tissue is taken from the liver with a special needle. This procedure will not hurt your new liver. The sample shows if there is any rejection, infection, or if a medication is causing changes in your liver enzymes. If you have had hepatitis C, you will need regular biopsies to see if the hepatitis virus is active.

MRCP (Magnetic Resonance Cholangiopancreatography) uses magnetic rays to take pictures of the liver and bile ducts.

Common lab tests: Words to know

Alanine Transaminase (ALT) is an enzyme made in the liver that is released into the blood when the liver is injured.

Albumin is a protein made by the liver and released into the blood. A higher level of this protein can show recovery from a serious illness. A lower level of this protein could mean kidney disease, liver cirrhosis, malnutrition, or that the body is not absorbing nutrients from food.

Alkaline phosphatase is an enzyme made in the liver and bone. A higher level of this enzyme could mean inflammation in the bile ducts inside the liver.

Aspartate transaminase (AST) is an enzyme released into the blood when the liver is injured.

Bilirubin is a digestive enzyme made by the liver.

Cholesterol measures a fat like substance in your blood that helps make hormones and build cell walls. A higher level of cholesterol could be a side effect of some anti-rejection medications.

Creatinine is a protein waste substance removed from the body by the kidneys. This measurement can show how well the kidneys are working. A higher level of creatinine could mean dehydration, kidney disease, or a possible side effect of some anti-rejection medications.

Glucose measures how well the body regulates the use of sugar after a meal. A higher level of glucose could mean that a person has developed diabetes.

Hemoglobin measures the red blood cells that carry oxygen from the lungs to the tissues. A lower level of hemoglobin could be caused by bleeding or some anti-rejection medications.

INR measures the ability of the liver to make the protein prothrombin, which is important for blood clotting. A higher level of prothrombin could mean liver damage or that the person is taking anti-clotting medications.

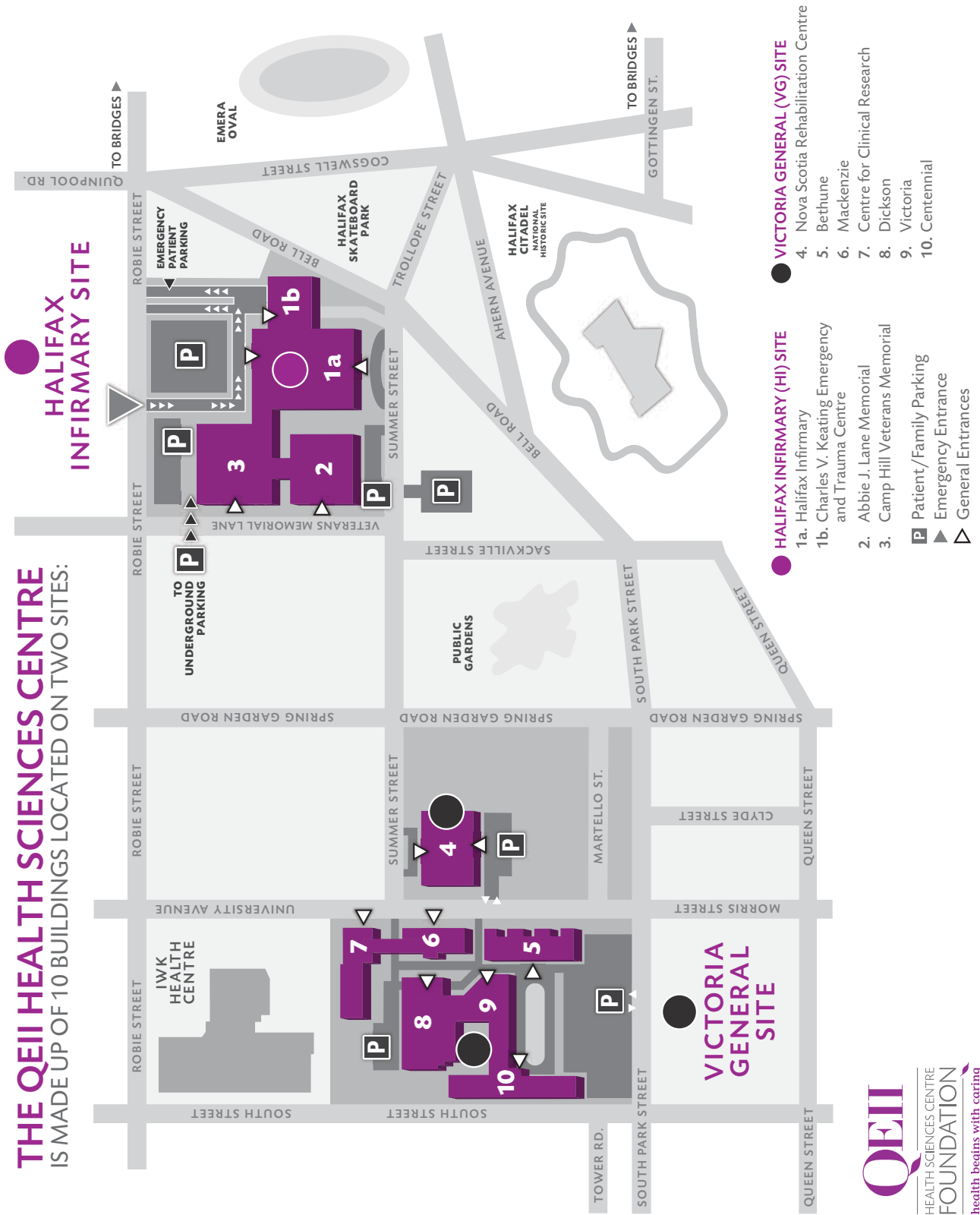
Platelets stop bleeding by clumping and forming a clot. A higher level of platelets could mean the blood is too thick and prone to clot. A lower level could be caused by some antibiotics and anti-rejection medications.

Potassium is an electrolyte in the body. It is needed to change carbohydrates into energy, build protein, and help the heart muscle and nerves work.

Sodium measures the balance between electrolytes (salts) and water in the body. A higher or lower level of sodium could mean kidney problems.

White blood cell count (WBC) measures the cells that fight off infection. A higher level of white blood cells could mean that you have an infection, inflammation, or tissue destruction. Anti-rejection medications can raise or lower your WBC.

Queen Elizabeth II Health Sciences Centre map



Important phone numbers

We want you to become an independent member of your community. Your local doctor and healthcare workers can answer many of your questions.

Local numbers

Hospital _____

Pharmacy _____

Family doctor _____

Friend or family to contact in an emergency _____

Queen Elizabeth II Health Sciences Centre, Halifax

Transplant Clinic 902-473-5631

Transplant Social Worker 902-473-7485

QEII Switchboard - After hours, ask for the liver transplant doctor on call.

902-473-2222

QEII Outpatient Pharmacy 902-473-7986

Transplant Unit Manager / Transplant Clinic Manager 902-473-7008

Patient Representative 902-473-2133

Looking for more health information?

Contact your local public library for books, videos, magazines, and other resources.
For more information go to <http://library.novascotia.ca>

*Nova Scotia Health Authority promotes a smoke-free, vape-free, and scent-free environment.
Please do not use perfumed products. Thank you!*

Nova Scotia Health Authority
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The information is not intended to be and does not constitute healthcare or medical advice.
If you have any questions, please ask your healthcare provider.

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The information in this pamphlet is to be updated every 3 years or as needed.