Patient & Family Guide

2021

After Your Liver Transplant

This guide will help you and your family learn about your care after a liver transplant. This guide will answer many of your questions about the transplant process. Members of the Multi-Organ Transplant Program Team (Transplant Team) are also available to talk with you about your concerns. Everyone is different, so you may not have or develop all of the conditions that you read about in this guide.

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After Your Liver Transplant

In the hospital

Transplant Unit

When you are ready to leave the Intensive Care Unit (ICU), we will take you to the Intermediate Care Unit (IMCU) on the 6th floor of the Centennial Building at the Victoria General (VG) hospital site. This Unit has 4 beds 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, on the same floor. When you move to 6B, the focus of your care will 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 Transplant Team will work closely with you during this time.

What can I expect?

Incision (cut)

Your nurse will clean your incision as needed. If you have staples, they will be taken out in about 10 to 14 days. After a few days, your incision may not need a dressing (bandage).

Drains, tubes, and IVs

You may have:

- a drain coming out of your abdomen (belly)
- a catheter (tube) in 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 take care of it.

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

TED stockings

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

Blood tests

Blood is taken each morning and as needed. Your blood test results tell the Transplant Team how your new liver is working. The transplant specialists also use the results of these tests to adjust your anti-rejection medication(s). You must have your blood taken each morning **BEFORE** you can take your medication(s).

Monitoring

The Transplant Team will continue 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.
- help 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 personal care.
- help you to learn about your medications and other things you need to know so you can safely care for yourself at home.

Activity

- Your physiotherapist will check your progress and adjust your exercise program as needed.
- You may be weak when walking and need to use a walker or cane.
- You can add to your activity by going to the fridge for water and getting your towel and facecloth in the morning for washing.
- The physiotherapist will plan for you to continue your rehabilitation exercise program after you leave the hospital.

This exercise program will help to:

- Lower the effects of a medication called prednisone that can cause bone and muscle weakness.
- Lower 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 will likely not be able to eat for a few days. Eating and drinking will upset your stomach until your bowel has started working again after surgery. Nutrition will be 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 part of your care team.
- 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.
- Some people with a liver transplant have problems with weight gain, high blood fat, and high blood sugar levels. **It is important for you to follow the healthy eating guidelines to help you stay healthy**.

Coping

- Your psychologist and/or social worker will visit you and your family to check how you are coping emotionally. They will check how well you are learning about your medications, exercising, eating, and becoming more independent. If there is a problem in any area, the psychologist and/or social worker will work with you, your family, and the Transplant Team to help get things back on track.
- Remember that you may have good and bad days. No one recovers in the same way. Even on bad days, it is important to do as much as you can for yourself.
- If you are taking prednisone, it may cause you to feel emotional and have mood swings. This is a common side effect.
- The social worker will help you with practical concerns so you and your family can focus on recovery. They will help you connect with outside groups, if needed.

Medications

- After transplant, your immune system must be suppressed (controlled) to prevent rejection of your new liver. You will need anti-rejection medications right away after your surgery. At first, your medications will be 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 to take these medications every day for the rest of your life to prevent rejection.**
- You will learn about your medications and start to take them on your own while you are still in the hospital. This will help you to take your medications safely at home. A nurse will help you with this by making a medication calendar for you to follow. Be sure to tell your nurse 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 self-medication program section of this guide (page 33) to find out more about your medications.

Possible complications

Short-term complications

Complications are common after a transplant. Members of the Transplant Team will do their best to lower your chances of having problems and will treat them quickly if they do happen.

Bleeding

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

Wound infections

Signs:

- fever over 38° C/100.4° F
- redness, swelling, tenderness, a change in the type of pain, or a change in the type of drainage around the site of your wound or tube

Treatment:

Tell your doctor, nurse, or the Post-Liver Transplant Clinic 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 your stomach.

Signs:

- fever over 38°C/100.4°F
- nausea (feeling sick to your stomach)
- pain above your liver area

Treatment:

Tell your doctor, nurse, or the Post-Liver Transplant Clinic nurse right away if you have any of the above signs. You must be checked and treated quickly.

Biliary stenosis or stricture

Your liver enzyme levels are high.

Sign:

- › yellow skin and/or eyes

Treatment:

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

Rejection

Your immune system protects you from “foreign invaders” such as bacteria (germs). A rejection episode is when your body sees your new liver as a threat and starts to fight it. Rejection episodes are common and most happen within the first few weeks after surgery. This does not mean that the organ will be lost. Rejection can be treated or controlled by changing your anti-rejection medications. **The sooner a rejection episode is found, the sooner it can be reversed**. Rejection may range from mild to severe (very bad). You may need a liver biopsy at any time after your transplant, as this is the only way to find out for sure 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 over 38° C/100.4° F
- › feeling tired
- › not feeling hungry
- › nausea (feeling sick to your stomach) and/or throwing up
- › abdominal pain or pain above your liver area
- › dark-coloured pee
- › pale or grey-coloured poop
- › yellow skin and/or eyes

Preventing rejection: Tell your primary health care provider right away if you have any symptoms of rejection.

- Take all of your medications as ordered.
- **Go to all Post-Liver Transplant Clinic visits as scheduled.**
- Have all of your blood tests done as told.

Kidney problems

Your kidneys may be damaged during or right after surgery, so you may pass less pee. This usually goes away quickly. It may go away on its own or it may need treatment.

Diabetes

Some of the anti-rejection medications may increase the level of sugar in your blood for a short time. Diabetes may also be a long-term complication.

Signs:

- very thirsty
- peeing often
- feeling tired
- drowsiness
- blurred vision
- muscle cramps
- poor healing of wounds

Prevention:

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

Treatment:

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. If this happens, you will need another liver transplant.

Infections

The anti-rejection medications that you will need to prevent the rejection of your new liver lower your ability to fight infections. This means you are at a higher risk of getting infections.

Some common infections are:

CMV (cytomegalovirus)

CMV is a common virus. Most adults who have been exposed to this virus do not develop a CMV infection. A healthy immune system keeps the CMV virus inactive. The virus may become active if your ability to fight infection is lowered. This happens more often in patients who are classified as CMV negative, and whose donor was CMV positive. This can happen long after your transplant, but the highest risk of infection is in the first 3 months.

Signs:

- fever over 38° C/100.4° F
- feeling tired
- aching joints
- headaches

Prevention:

If you are at a high risk for getting a CMV infection, you may be treated with an intravenous (IV) or oral (taken by mouth) medication while you are in the hospital. This medication will help to prevent you from getting a CMV infection. You will keep taking this medication for some time after you are discharged. Even if you are not at a high risk, we will test your blood regularly for any signs of CMV infection.

Treatment:

If you get an infection, the transplant doctors will prescribe medication to treat it.

Herpes simplex

Herpes simplex is an infection caused by a virus. This infection causes painful cold sores or blisters around the mouth or sex organs (genitals).

Signs:

- feeling weak
- fever over 38° C/100.4° F
- painful cold sores or blisters around the mouth or sex organs

Treatment:

You will be treated with an antiviral medication, if needed.

Candida infection

Candida is commonly called yeast. A candida infection may also be called a yeast infection.

Signs:

Mouth:

- white, patchy sores
- white film on the tongue
- trouble swallowing

Sex organs:

- pain
- redness and/or itching
- yellow or white discharge

Prevention and/or treatment:

Mouth: You will be given a liquid antibiotic medication called nystatin to be taken by mouth 4 times a day, until you leave the hospital.

Sex organs: An over-the-counter medicated cream may help symptoms. Talk to your primary health care provider before using this cream.

Pneumocystis jirovecii pneumonia

This type of pneumonia (lung infection) happens in people whose immune system is suppressed.

Signs:

- fever over 38° C/100.4° F
- dry cough
- shortness of breath

Prevention:

You may be given a medication called sulfamethoxazole-trimethoprim (Septra®) to help prevent you from getting this type of pneumonia.

Long-term complications

Osteoporosis

- Osteoporosis makes your bones weak and thin. Some of the medications needed after a transplant, such as prednisone, may place you at higher risk for this problem. Exercise, such as walking, lowers the risk of osteoporosis.
- It is important to have enough calcium in your diet (1200 to 1500 mg every day). Milk and milk products are good sources of calcium. We may also suggest taking vitamin D (800 IU a day) and calcium pills (such as TUMS®). Never take more calcium than your primary health care provider recommends.

Diabetes

- Diabetes can be a short or long-term complication of a transplant. Some anti-rejection medications raise your blood sugar levels. This is more likely to happen if you 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 page 8).

High blood pressure

- This is a very common problem after a transplant. It can be caused by anti-rejection medications, but may also have other causes.
- If not treated, high blood pressure can hurt your heart, blood vessels, and even your new liver.
- A healthier lifestyle may help control your blood pressure. This includes keeping a healthy weight, not eating salty foods, exercising, and not smoking.
- You may also need medications to control your blood pressure. A medication that works well for one person may not work well for another. Your doctor will adjust and change your medications and doses to find the best treatment for you. All blood pressure pills can have side effects. Always tell your doctor if you notice any side effects. **Never stop or change blood pressure pills on your own.**

High cholesterol

- Cholesterol has many useful roles in your body, but too much cholesterol can clog your arteries.
- Anti-rejection medications can raise your cholesterol levels. If your cholesterol was high before your transplant, it may be even higher after.
- Eating foods low in cholesterol and saturated fat, losing weight, and exercising may help to lower your cholesterol. Medication may be needed to make sure your cholesterol is as low as possible. If your cholesterol is high for a long time, you have a higher chance of having a stroke or heart attack.

Cancer

Liver cancer is more common in people with cirrhosis (scarring of the liver). After your transplant, this risk is lower. But, anti-rejection medications may increase your risk of cancer. People who have had cancer before are at higher risk and need to have regular check-ups.

Planning for discharge

If you are well before your transplant, the average hospital stay is 7 to 14 days, unless you have complications. If you are not well before your transplant, your hospital stay may be longer. You will need to stay in the Halifax area for a period of time after your surgery.

Housing options after discharge

Depending on your condition and the availability of your primary health care provider, you may:

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

If you are from outside of Nova Scotia or greater than 50 km (one way) from the Victoria General Hospital, you will stay at offsite patient accommodations before going home. There will be no charge for the taxi to and from the hospital while staying at offsite patient accomodations.

Meal coverage

Each province has its own arrangements:

Nova Scotia

When you are discharged from the hospital, staff on 6B will give you two (2) $5 meal tickets a day to last until your first Post-Liver Transplant Clinic visit. If you are staying at offsite patient accommodation, a Clinic nurse will then give you two (2) $5 meal tickets a day. This will not cover all meal costs. **Family members must pay for their own meals**.

Meal tickets can be used at offsite patient accomodations or in the hospital cafeteria.

New Brunswick and Prince Edward Island

You will be given $25 plus tax towards your meals while at offsite patient accomodations. This money can only be used at offsite patient accomodations. This will be arranged by a NB or PEI liaison nurse.

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

Newfoundland

When you are discharged, the nurses will help you book offsite patient accommodations. You will need to keep record of all medical, accommodation, and food expenses while here so that you will be reimbursed (paid back) in your own province.

Concerns about going home

- The psychologist will talk with you and your family about the transition from the hospital to home. Even though this is a positive step, you may have a few challenges. Many patients have been so focused on the transplant that they have not thought much about what will happen after.
- Remember that you would not be discharged from the hospital if we did not think that you were ready. Please talk with your health care team about any concerns you have about going home.
- You will need a follow-up appointment for the Post-Liver Transplant Clinic and instructions about blood tests. Your nurse will give you this information before you leave the hospital.

Common tests

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

You may have some of these tests:

- Abdominal (stomach area) ultrasound
- Abdominal MRI scan
- Blood tests
- Chest X-ray
- Colonoscopy
- Echocardiogram
- Electrocardiogram (ECG or EKG)
- 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 give you lifelong support. Regular visits to the Post-Liver Transplant 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. If you feel like something is not right, call your primary health care provider right away. Be sure to also keep in touch with the Transplant Team.

Post-Liver Transplant Clinic

When you are discharged from the hospital and staying in Halifax, before you return home, the Post-Liver Transplant Clinic (the 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 Halifax Infirmary Emergency Department on Robie Street.

Locations:

- The Clinic is on the 4th floor of the Dickson Building, VG site, near the Kidney Transplant Clinic. This is where you will go for appointments.
- The nurses' office of the Post-Liver Transplant Clinic is on 6 South, on the 6th floor of the Victoria Building, VG site, near the Inpatient Transplant Unit.

At first, you will need to visit the Clinic once a week. You will see the Clinic nurse at each visit.

The Clinic nurse will:

- check your overall condition.
- answer any questions you have.
- help you learn about life after your transplant.
- review your medications with you.

At first, you will see the Liver Transplant Practitioner or Clinic doctor every week. Over time, you will see them less often.

During your visit they will:

- check on your progress.
- review your blood tests.*
- make changes to your medications, as needed.

*See the information on blood tests on page 57.

How do I get ready for my 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. **Do not take any anti-rejection medications until after your blood is taken.**
- Give yourself lots of time to get to the hospital for your appointment so you do not feel rushed. If you are staying at offsite patient accomodations, ask staff about the shuttle service. If someone is driving you, it can take 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.**

Follow-up after my Clinic visit

When you return to your hometown, the Clinic will give you the follow-up and care needed for your liver transplant and other related medical concerns.

The Transplant Team will:

- continue to answer any questions you have as you adjust to life after your transplant.
- continue to review your blood tests.
- make changes to your anti-rejection medications, as needed.
- call you with any medication changes made by the Clinic doctor. It is helpful to have an answering machine or voicemail. We will only leave a message on your answering machine or voicemail, or with the person who answers the phone, if you have given us permission to do so.
- send you a letter in the mail to confirm any medication changes.

Follow-up with my primary health care provider

- Your care has many parts and involves many people. **Your primary health care provider is an important member of your health care team.**
- **You should visit your primary health care provider during the first 2 weeks that you are home.** It is important to see your primary health care provider and your local specialist regularly. This will reduce the number of trips that you need to make to Halifax.
- Your primary health care provider will give you routine care. The Clinic will send a letter to your primary health care provider and local specialist after each Clinic visit. They will also be notified if there are any changes to your anti-rejection medications.
- Tell your pharmacist and dentist that you have had a transplant and are on anti-rejection medications. Your dentist will need to give you antibiotics before any dental work, including regular cleaning.
- **If it is an emergency, call your primary health care provider or go to the nearest Emergency Department.** Call the Clinic to let us know if you go to the Emergency Department or are admitted to the hospital.

Taking care of yourself

Rejection

Remember that you will always be at risk for rejection. Changing your anti-rejection medications can control most rejection episodes. Steroids may be injected through an IV to treat acute rejection. If 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**.

Signs of rejection:

- flu-like symptoms
- fever over 38° C/100.4° F
- feeling tired
- loss of appetite (not feeling hungry)
- nausea (feeling sick to your stomach) and/or vomiting (throwing up)
- abdominal pain or pain above your liver area
- dark-coloured pee
- pale or grey-coloured poop
- yellow skin and/or eyes
- changes in 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 infections.

Watch for signs of infection:

- fever over 38° C/100.4° F
- cough with sputum (phlegm)
- shortness of breath
- cold sores around your lips or mouth
- headaches
- changes in your vision
- white coating on your tongue or the roof of your mouth, pain, or trouble swallowing
- aching joints
- burning or stinging when peeing
- peeing more than usual
- tiredness
- more than the usual amount of redness, swelling, discharge, or pain around a sore or cut

MedicAlert®

MedicAlert® identification (ID) could save your life in an emergency. If you already have MedicAlert® ID, it must be updated and replaced. It is important that your MedicAlert® ID reads **"Transplant Recipient - Immunosuppression"**. Any allergies or other medical conditions should also be listed on your 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 (2 months) for delivery.

Emotional and social adjustment

- This is a very exciting time in your life. Having a transplant is a precious gift, but it is also a time of loss for others. You, your donor, and your donor's family must stay unknown to each other to protect everyone involved.
- You may write a thank you letter to your donor's family for giving you a new chance at life. Tell your nurses if you would like a pamphlet on how to write this letter. You will send your letter to the Transplant Clinic Nurse, who will give it to a Coordinator to mail to the family. For more information, visit:
  - www.nshealth.ca/sites/nshealth.ca/files/patientinformation/1212.pdf
- For donations and transplants that take place in Nova Scotia after January 18, 2021, you and the donor family may be eligible to contact each other directly. Both you and the donor family must be willing to have contact and both of you must meet certain criteria. For more information on the **Direct Contact** process, please contact the Family Support Liaison.
  - Email: DonorFamilySupport@nshealth.ca
- There are many changes to get used to after a long hospital stay, and a long illness.
- You may have mood swings and trouble sleeping while you are 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 Transplant Team can help. Exercise can also lower stress. A psychologist is available to meet with you and/or your family to help you cope with these changes. You can also make arrangements for counselling in your own area.
- If there are complications after your transplant, you may feel like you have just changed one set of problems for another. You may ask "why me?" or believe that nothing in your life is going right. This is especially true if you see other transplant patients who seem to be doing well. The Transplant Team will try to help you deal with these issues and find supports.
- Sometimes people feel so much better when they return home that they wonder if they need to keep taking their medications, or following their exercise or healthy eating programs. **It is very important to talk with your health care team before you make any changes.** Your medications and lifestyle changes will help to protect your new liver and keep you as healthy as possible.

Sexual health

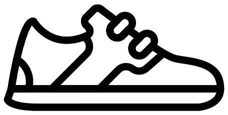
- You may go back to having sex whenever you feel well enough. You will probably have a lot more energy after your transplant.
- Everyone should be concerned about sexually transmitted infections such as HIV, herpes, and hepatitis. After a transplant, you are at a higher risk of getting an infection because your immune system is suppressed. Practice safe sex: use a condom if you have a new sexual partner or if your regular partner is at risk of an infection.
- Some medications may lower your desire and ability to be sexually active. If this happens, talk with your primary health care provider. Medications may be helpful for some people.

Pregnancy and birth control

- If you were not having periods before your transplant, you may start having them again after your transplant. You may also get pregnant. It is important to talk about birth control options with your primary health care provider.
- **Transplant recipients can have successful pregnancies.** Choosing to have a child is an important decision that you and your partner should talk about with your transplant doctor **before you get pregnant.** Some anti-rejection medications could harm a baby during pregnancy, so talk about this with your transplant doctor if you are thinking of getting pregnant. You should be doing well for at least a year after transplant before trying to get pregnant. Your obstetrician (doctor specializing in pregnancy and childbirth) will monitor the pregnancy closely in case of any problems.

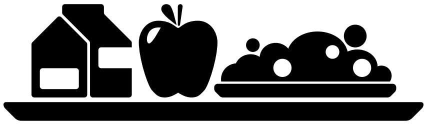
Exercise

- You may do your usual activities. Moderation is key – do not do too much. The amount of time and work needed to regain your strength depends on how healthy you were before surgery.
- Do not lift anything over 15 pounds for the first 3 months. You can then go back to normal lifting if you are not having any discomfort around your incision. Do not strain by lifting anything too heavy or too quickly.
- Exercise is a very important part of a healthy lifestyle. Your physiotherapist may give you a home exercise program or arrange for you to visit your local hospital's physiotherapy department when you return home.



Healthy eating

You need regular healthy meals to heal and build your strength. Ask to meet with a dietitian at the Clinic if you have questions or concerns about what you should be eating. Your nurse can arrange for this meeting.



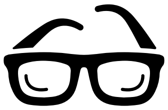
Dental care

It is very important to keep your gums and teeth healthy. Your anti-rejection medications raise your risk of mouth infections.

- Brush your teeth at least 2 times 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 regular cleaning. Clinic staff will give you an information handout to give your dentist called, *“Antibiotic Prophylactic Regimen for Dental Procedures”*. Your dentist will decide if antibiotics are needed for your dental procedure.

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 dose is steady before having your eyes checked for new glasses.
- Have your eyes checked at least every 2 years by an eye specialist. Some patients who are on prednisone for a long time can develop cataracts.



Alcohol

Do not drink any alcohol. Drinking alcohol interferes with anti-rejection medications and will hurt your liver.

Smoking

Do not smoke. Smoking will hurt your lungs, heart, and blood vessels. You are at a higher risk of getting cancer because your immune system is suppressed. Smoking raises the risk of getting cancer even more.

Skin cancer

Your medications make your skin more sensitive to damage from the sun.

Protect yourself in the sun by:

- using sunscreen with an SPF of 30 or higher.
- wearing a hat, a long-sleeved cotton shirt, and cotton pants.
- avoiding the sun between 11 a.m. and 3 p.m., when the sun’s rays are most damaging.
- wearing UV-filtering sunglasses to protect your eyes.

Watch for any signs of skin cancer:

- Check your skin every month for changes in freckles, moles, or spots. A family member or friend should check the areas that you cannot see.
- Tell your primary health care provider if you see any changes.

Follow-up care

Regular visits to your primary health care provider are an important part of taking care of yourself.

- See your primary health care provider if you have any kind of infection. Do not wait for it to clear up on its own.
- Tell your primary health care provider if you see any blood in your poop.
- If you are over the age of 50, get checked for cancer of the colon and rectum (bum).

Every year:

- Get a flu shot in the fall. Everyone living in your household should also have a flu shot. The flu shot changes each year depending on what type of flu is active in the world. You need a new flu shot every fall before the winter flu season starts.
- We recommend that anyone who has a cervix consider having a Pap test.
- If you are over the age of 40 and have breasts, schedule a mammogram.
- We recommend that anyone who has testicles and is over the age of 50 be checked for testicular cancer.
- If you have a prostate, you should also have a PSA blood test to check for prostate cancer.
- People with primary sclerosing cholangitis (PSC) and inflammatory bowel disease (IBD) should have a colonoscopy.
- Get tested to find out how well your kidneys are working. You will be asked to collect an early morning pee sample.
- Get the following blood tests:
  - TSH (to measure how well your thyroid is working)
  - a lipid profile (to check your cholesterol and triglyceride levels)
  - HgbA1C (to check your blood sugar)

Every 2 years:

- Have a bone mineral density (BMD) test to check the strength of your bones.

Vaccinations

Do not get any vaccinations for 6 months after your transplant. After 6 months, you may get most vaccinations. **Do not get vaccines made from live sources**. Ask your primary health care provider about what vaccinations you need.

Your environment

- **The best way to prevent most infections is to wash your hands often with soap and hot water**. Wash your hands before and after you touch food, after you use the bathroom, after touching any animals, 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, as it is hard to clean all the germs off of them.
- Take steps to prevent food poisoning. Look at dates on food you buy at the store, and be careful not to keep leftovers too long.

Around the house:

- If you are planning major renovations, demolition could expose you to mould and possible fungal infections.

Pets

After your transplant, your immune system will be suppressed. Your pet could make you sick.

- Keep your pet healthy, clean, and groomed.
- Wear gloves when cleaning your pet's body fluids (like vomit, poop, pee, and spit) and when changing cat litter boxes. Clean these fluids up with a disinfectant. If possible, have someone else do this cleaning.
- Some animals are more likely to carry diseases. This means they are more likely to make you sick. Stay away from:
  - stray or wild animals
  - animals with diarrhea (loose, watery poop)
  - sick animals
  - exotic animals, including turtles and monkeys

Outdoor activities

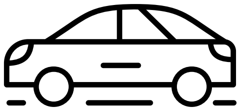
- Wear gloves to protect yourself from fungi (fungus) when gardening or digging soil.
- Talk with the Transplant Team before taking part in any sports. Pace yourself so that you do not get too tired, especially right after your transplant.
- West Nile virus is spread to humans by infected mosquitos. Because your immune system is weaker, you are more likely to get sick if you are bitten by an infected mosquito. Stop mosquitoes from biting you by wearing pants and long-sleeved shirts when mosquitoes are out. Use insect repellent with DEET. Get rid of standing water because that is where mosquitoes breed.

Going back to work

Talk with your transplant doctor about when you should go back to work. They will suggest the best time for you to go back based on how physical your job is, your age, your overall health, and job stress. Most people are able to go back 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 pain killers.** You must wear a seatbelt. Try putting a towel under the seatbelt if it bothers your incision.
- If you gave up your driver's license before your transplant, ask your primary health care provider or Clinic staff about getting it back.



Travelling

- It is OK for you to travel after your transplant. Always talk about your travel plans with Clinic staff or your primary health care provider. Make arrangements well in advance.
- You can often arrange to have blood tests in the area you are visiting. The transplant doctors may be able to give you the name of a transplant 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 bag.
- Keep your medications in their original containers.
- Carry enough medication for at least an extra week, in case your return is delayed.
- Always take health insurance and cancellation insurance.
- Ask Clinic staff or your primary health care provider 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 in the country you plan to visit.
- If you are crossing time zones, talk with Clinic staff about how this will affect the times when you take your medications.
- Be prepared to return home if you get sick on your trip.

The self-medication program

Introduction

You must 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 a medication calendar for you to follow. Please tell your nurse if you have any vision, hearing, or memory problems.

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
- Possible side effects of each medication
- How to get your supply of each medication

You will be given a supply of medications and a medication record. While you are in the hospital, you will learn how to get your medications ready on your own and take them at the right times. During your hospital stay, the 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 told by your doctor.
- Do not stop taking any medication without asking your primary health care provider, Clinic nurse, or pharmacist first.
- Take your medications at the same time each day.

What to do if you forget a dose of your anti-rejection medication:

For medications you take 2 times a day:

  - › If you miss a dose and remember it, take the medication.
  - › If it is after the halfway point, skip this dose and take the next dose at the regularly scheduled time.

For medications you take once a day:

  - › Take your dose as soon as you remember it.

- If you are vomiting, you are probably throwing up your medications. If you vomit **within** half an hour (less than 30 minutes) of taking a dose of anti-rejection medication, repeat that dose of medication after your stomach settles.
- If you vomit **more than** half an hour (more than 30 minutes) after taking a dose of anti-rejection medication, do not repeat that dose unless you saw the pills come up. Take your usual dose at the next regularly scheduled time. **Do not double dose.** If your nausea continues, contact your primary health care provider.
- If you have diarrhea that lasts more than a couple of days, contact the Transplant Team and your primary health care provider.
- 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 primary health care provider about the medications you are taking.
- Carry a list of your medications with you at all times.
- **Some over-the-counter medications may affect your anti-rejection medications.** Do not take any over-the-counter medications, like cold medications, without talking to your primary health care provider, pharmacist, or Clinic staff first.
- Do not take any other medications, like vitamins or herbal remedies, without talking to your primary health care provider or pharmacist first.

How to get your anti-rejection medications

Nova Scotia, PEI, and Newfoundland

- If you live in Nova Scotia, PEI, or Newfoundland, your anti-rejection medications are provided through a government-funded program. **They are not available in your local drugstore**. We will give you instructions on how to get your medications before you leave the hospital.

New Brunswick

- If you live in New Brunswick, you can get your anti-rejection medications from your local drugstore. Before you are discharged from the hospital, please make sure that you know how to get your medications.

Storing your medications

- Keep all medications out of the reach of children and pets.
- Do not store medications in damp areas, such as the bathroom.
- Do not store medications in direct sunlight.
- Do not store pills or tablets in the fridge.
- Do not take any medications in foil packages out of the package until you are ready to take them.
- Do not keep old medications or medications that you no longer need. Take these to your local drugstore. They will get rid of them safely.
- Do not share your medications 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 need to take other medications to prevent infections or control high blood pressure or diabetes. You may also need to keep taking the medications that you took before your transplant, such as thyroid medication.

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

What are your questions?

Please ask. We are here to help you.

Medication record

Name of medication	Dose	How often	Reason for taking this medication	Times							

It is very important to contact your primary health care provider if you have any side effects from your medications. It is dangerous to stop any medication on your own.

Acyclovir

Generic name: Acyclovir

Brand name: Zovirax®

What is acyclovir?

- Acyclovir is a drug used to prevent or treat infections caused by viruses, like chicken pox, shingles, and cold sores.

How do I use acyclovir?

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

What are the possible side effects of acyclovir?

Note: This is not a complete list of all possible side effects.

Side effects can happen with all medications. Talk with a member of your health care team if you do not feel well while taking acyclovir. Below is a list of side effects to be aware of:

Stomach upset (indigestion, reflux): Taking this medication with food may help prevent stomach upset.

Blood problems: Acyclovir can lower red blood cells, white blood cells, and platelets (part of the blood that helps blood to clot). This can make you feel tired and raise your risk of infections, bruising, and/or bleeding problems. The Transplant Team will watch closely for any signs of these problems and will change how much acyclovir you take, if needed. Please tell a Clinic nurse, your pharmacist, or your primary health care provider if you have any unusual tiredness, bruising, or infections.

Kidney problems: Rarely, acyclovir can cause kidney problems. The Transplant Team will watch closely for these problems and will change how much acyclovir you take, if needed.

Rash: Contact your primary health care provider, Clinic nurse, or pharmacist if you develop a rash.

Cyclosporine

Generic name: Cyclosporine

Brand name: Neoral®

What is cyclosporine?

- Cyclosporine is an anti-rejection drug that weakens your immune system. A drug that weakens your immune system is called an immunosuppressant.
- It is taken to prevent your body from rejecting your transplanted liver.

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 with your primary health care provider, Clinic nurse, or pharmacist first.
- Take cyclosporine with a glass of water.
- Cyclosporine can be taken with or without food.
- **Avoid grapefruit and grapefruit juices** because they may affect how cyclosporine works.
- On days when you are going to get blood tests to check your drug levels, it is important that you wait 2 hours after taking cyclosporine to have your blood drawn.
- Cyclosporine may cause problems if you take it with other medications. Talk with your primary health care provider, pharmacist, or Clinic nurse before taking any new medications, including prescription, non-prescription, natural products, or supplements.
- Your drug levels and bodily functions will be monitored to make sure you are taking the correct dose. If you are not sure how much medication to take, think you may be having a side effect, are started on a new medication and need information on drug interactions, or have missed a dose and are not sure what to do, contact your primary health care provider, pharmacist, or Clinic nurse.
- Store cyclosporine at room temperature away from heat, light, and moisture.

What are the possible side effects of cyclosporine?

Note: This is not a complete list of all possible side effects.

Side effects can happen with all medications. Talk with a member of your health care team if you do not feel well while taking cyclosporine. Below is a list of side effects to be aware of:

Higher risk of infection: This risk is present with all medications that suppress the immune system. Report the first signs and symptoms of infection (like fever, sore throat, chills, fast pulse, etc.) to your primary health care provider **right away.**

Higher risk of cancer: This risk is present with all medications that suppress the immune system. Report any lumps or changes in skin colour or moles to your primary health care provider.

Stomach upset, loss of appetite, nausea, vomiting, diarrhea: These symptoms usually go away soon after you start taking cyclosporine. Having a lot of diarrhea can lower how much of the drug you absorb. **Talk with your primary health care provider or pharmacist if it continues and before you take any medications to treat these symptoms.**

High blood pressure or cholesterol: Cyclosporine can make your blood pressure and cholesterol levels higher. If this happens, your amount of cyclosporine or type of medication may need to be changed.

Kidney problems: The Transplant Team will watch closely for these problems and will change how much medication you take, if needed.

More hair growth: How much this happens is different for everyone.

More growth of the gums: Good mouth hygiene and regular dental check-ups can lower and control this problem. Tell your dentist if you are taking cyclosporine.

If you are of child-bearing age: Do not get pregnant while you are taking cyclosporine. It may cause harm to an unborn baby. Ask your primary health care provider or pharmacist to help you choose the right birth control method for you. If you are planning to get pregnant, talk with the Transplant Team months before, as some of your medications may need to be changed.

Mycophenolate mofetil

Generic name: Mycophenolate mofetil (MMF)

Brand name: CellCept®

What is MMF?

- MMF is an anti-rejection drug that weakens your immune system.
- It is taken to prevent your body from rejecting your transplanted liver.

How do I use MMF?

- Do not stop taking MMF on your own. Talk with your primary health care provider, Clinic nurse, or pharmacist first.
- Take this medication at the same time each day.
- MMF can be taken with or without food, but it is best absorbed on an empty stomach. Take your medication the same way each day.
- MMF may cause problems if you take it with other medications. Talk with your primary health care provider, pharmacist, or Clinic nurse before taking any new medications, including prescription, non-prescription, natural products, or supplements.
- Your blood cell counts will be checked regularly. The amount of MMF you take may have to be adjusted depending on the results of your blood cell count.
- If you are not sure how much medication to take, or if you think you may be having any side effects, talk with a Clinic nurse or your pharmacist.
- Keep MMF in its packaging until you are ready to take it.
- If you have started taking a 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 a Clinic nurse or your pharmacist.
- Store MMF at room temperature away from heat, light, and moisture.

What are the possible side effects of MMF?

Note: This is not a complete list of all possible side effects.

Side effects can happen with all medications. Talk with a member of your health care team if you do not feel well while taking MMF. Below is a list of side effects to be aware of:

Higher risk of infection: This risk is present with all medications that suppress the immune system. Report the first signs and symptoms of infection (like fever, sore throat, chills, fast pulse, etc.) to your primary health care provider **right away.**

Higher risk of cancer: This risk is present with all medications that suppress the immune system. Report any lumps or changes in skin colour or moles to your primary health care provider.

Stomach upset, loss of appetite, nausea, vomiting, diarrhea: These symptoms usually go away soon after you start taking MMF. Having a lot of diarrhea can lower how much of the drug you absorb. **Talk with your primary health care provider or pharmacist if it continues and before you take any medications to treat these symptoms.**

Headache, light-headedness, dizziness, weakness: If these symptoms continue, or if you faint, see your primary health care provider right away.

Blood problems: MMF can lower red blood cells, white blood cells, and platelets. This can make you feel tired and raise your risk of infections, bruising, and/or bleeding problems. The Transplant Team will watch closely for any signs of these problems and will change how much MMF you take, if needed. Please tell a Clinic nurse, your pharmacist, or your primary health care provider if you have any unusual tiredness, bruising, or infections.

If you are of child-bearing age: Do not get pregnant while you are taking MMF. It may cause harm to an unborn baby. Ask your primary health care provider or pharmacist to help you choose the right birth control method for you. If you are planning to get pregnant, talk with the Transplant Team months before, as some of your medications may need to be changed.

Prednisone

Generic name: Prednisone

Brand name: none

What is prednisone?

- Prednisone is an anti-rejection drug that weakens your immune system.
- It is taken to prevent your body from rejecting your transplanted liver.

How do I use prednisone?

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

What are the possible side effects of prednisone?

Note: This is not a complete list of all possible side effects.

Side effects can happen with all medications. Talk with a member of your health care team 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 feel depressed, while others may feel very happy or energetic. Prednisone can also make psychiatric (mental health) disorders worse. If you have a psychiatric disorder and think it is getting worse, or if you think you may be having mood problems, contact your health care professional **right away.**

Higher risk of infection: This risk is present with all medications that suppress the immune system. Report the first signs and symptoms of infection (like fever, sore throat, chills, fast pulse, etc.) to your primary health care provider **right away.**

High blood pressure or cholesterol: Prednisone can make your blood pressure and cholesterol levels higher. If this happens, your amount of prednisone or type of medication may need to be changed. Eating well and exercising can help.

Stomach upset: Taking this medication with food may help prevent stomach upset.

Fluid retention: Prednisone can make your body hold onto fluid, causing edema (swelling). If you notice swelling in your hands, feet, or legs, contact the Clinic.

Weakened bones: Over time, prednisone can weaken bones and may cause osteoporosis. Make sure you have enough calcium in your diet to help lower the risk of this side effect.

High blood sugar: Prednisone can make your blood sugar higher and some people may develop diabetes. Eating well and exercising can help.

Ranitidine

Generic name: Ranitidine/Famotidine

Brand name: Zantac®/Pepcid®

What is ranitidine?

- Ranitidine is a type of antacid that lowers how much acid the stomach makes.
- It is taken to prevent heartburn, stomach upset, and stomach ulcers.

How do I use ranitidine?

- Do not stop taking ranitidine on your own. Talk with your primary health care provider, Clinic nurse, or pharmacist first.
- Ranitidine can be taken with or without food.
- Ranitidine may cause problems if you take it with other medications. Talk with your primary health care provider, pharmacist, or Clinic nurse before taking any new medications, including prescription, non-prescription, natural products, or supplements.
- If you are not sure how much medication to take, or if you think you may be having any side effects, talk with a Clinic nurse or your pharmacist.
- If you have started taking a new medication and worry it might have an effect on ranitidine, or you forgot to take your medication and are not sure what to do, talk to a Clinic nurse or your pharmacist.
- Store ranitidine at room temperature away from heat, light, and moisture.

What are the possible side effects of ranitidine?

Note: This is not a complete list of all possible side effects.

Side effects can happen with all medications. Talk with a member of your health care team if you do not feel well while taking ranitidine. 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: Rarely, ranitidine can lower white blood cells and platelets. This can raise your risk of infections, bruising, and/or bleeding problems. The Transplant Team will watch closely for any signs of these problems and will change how much ranitidine you take, if needed. Please tell a Clinic nurse, your pharmacist, or your primary health care provider if you have any unusual bruising, bleeding, or infections.

Rash: Contact your primary health care provider, Clinic nurse, or pharmacist if you develop a rash.

Sirolimus

Generic name: Sirolimus

Brand names: Rapamune®

What is sirolimus?

- Sirolimus is an anti-rejection drug that weakens your immune system.
- It is taken to prevent your body from rejecting your transplanted liver.

How do I use sirolimus?

- It is very important that you take this medication at the same time each day.
- Do not stop taking sirolimus on your own. Talk with your primary health care provider, Clinic nurse, or pharmacist 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 blood tests to check your drug levels, take your sirolimus after your blood is taken.
- Sirolimus may cause problems if you take it with other medications. Talk with your primary health care provider, pharmacist, or Clinic nurse before taking any new medications, including prescription, non-prescription, natural products, or supplements.
- If you are not sure how much medication to take, or if you think you may be having any side effects, talk with a Clinic nurse or your pharmacist.
- If you have started taking a new medication and worry it might have an effect on sirolimus, or you forgot to take your medication and are not sure what to do, talk to a Clinic nurse or your pharmacist.
- Store sirolimus at room temperature away from heat, light, and moisture.

What are the possible side effects of sirolimus?

Note: This is not a complete list of all possible side effects.

Side effects can happen with all medications. Talk with a member of your health care team if you do not feel well while taking sirolimus. Below is a list of side effects to be aware of:

Higher risk of infection: This risk is present with all medications that suppress the immune system. Report the first signs and symptoms of infection (like fever, sore throat, chills, fast pulse, etc.) to your primary health care provider **right away.**

Higher risk of cancer: This risk is present with all medications that suppress the immune system. Report any lumps or changes in skin colour or moles to your primary health care provider.

Stomach upset, loss of appetite, nausea, vomiting, diarrhea: These symptoms usually go away soon after you start taking sirolimus. Having a lot of diarrhea can lower how much of the drug you absorb. **Talk with your primary health care provider or pharmacist if it continues and before you take any medications to treat these symptoms.**

High blood pressure or cholesterol, or harm to the kidneys: You will be monitored for these effects. If this happens, your amount of sirolimus or type of medication may need to be changed.

Fluid retention: Sirolimus can make your body hold onto fluid, causing edema. If you notice swelling in your hands, feet, or legs, contact the Clinic.

Mouth sores: If you notice painful sores in your mouth, contact the Clinic.

Poor wound healing: You may notice that it takes longer for wounds (like cuts or scratches) to heal while taking sirolimus.

If you are of child-bearing age: Do not get pregnant while you are taking sirolimus. It may cause harm to an unborn baby. Ask your primary health care provider or pharmacist to help you choose the right birth control method for you. If you are planning to get pregnant, talk with the Transplant Team months before, as some of your medications may need to be changed.

Sulfamethoxazole-trimethoprim

Generic names: Sulfamethoxazole-trimethoprim, co-trimoxazole

Brand names: Septra®, Bactrim™, Apo-Sulfatrim®

What is sulfamethoxazole-trimethoprim?

- Sulfamethoxazole-trimethoprim is an antibiotic used to prevent or treat infections caused by bacteria.
- It is taken to prevent or treat bacterial infections, including one caused by Pneumocystis jirovecii pneumonia.

How do I use sulfamethoxazole-trimethoprim?

- **If you are allergic to "sulfa drugs" or sulfonamides, tell your primary health care provider before you start taking sulfamethoxazole-trimethoprim**.
- If you are glucose-6-phosphate dehydrogenase (G6PD) deficient, contact the Clinic before you start taking sulfamethoxazole-trimethoprim.
- Do not stop taking sulfamethoxazole-trimethoprim on your own. Talk with a primary health care provider, Clinic nurse, or pharmacist first.
- Sulfamethoxazole-trimethoprim can be taken with or without food.
- Sulfamethoxazole-trimethoprim may cause problems if you take it with other medications. Talk with your primary health care provider, pharmacist, or Clinic nurse before taking any new medications, including prescription, non-prescription, natural products, or supplements.
- If you are not sure how much medication to take, or if you think you may be having any side effects, talk to a Clinic nurse or your pharmacist.
- If you have started taking a new medication and worry it might have an effect on sulfamethoxazole-trimethoprim, or you forgot to take your medication and are not sure what to do, talk with a Clinic nurse or your pharmacist.
- Store sulfamethoxazole-trimethoprim at room temperature away from heat, light, and moisture.

What are the possible side effects of sulfamethoxazole-trimethoprim?

Note: This is not a complete list of all possible side effects.

Side effects can happen with all medications. Talk with a member of your health care team 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 medication with food may help prevent stomach upset.

Blood problems: Sulfamethoxazole-trimethoprim can lower red blood cells, white blood cells, and platelets. This can make you feel tired and raise your risk of infections, bruising, and/or bleeding problems. The Transplant Team will watch closely for any signs of these problems and will change how much sulfamethoxazole-trimethoprim you take, if needed. Please tell a Clinic nurse, your pharmacist, or your primary health care provider if you have any unusual tiredness, infections, bruising, or bleeding.

Kidney problems: Rarely, sulfamethoxazole-trimethoprim can cause kidney problems. The Transplant Team will watch closely for these problems and will change how much medication you take, if needed.

Potassium problems: Sulfamethoxazole-trimethoprim can cause your potassium levels to go up. Rarely, this can lead to heart problems, especially if your body has trouble getting rid of potassium. Your primary health care provider will watch closely for these problems and will change how much medication you take, if needed.

Rash: Contact your primary health care provider, Clinic nurse, or pharmacist if you develop a rash.

Tacrolimus

Generic names: Tacrolimus, FK506

Brand names: Advagraf®, Prograf®

What is tacrolimus?

- Tacrolimus is an anti-rejection drug that weakens your immune system.
- It is taken to prevent your body from rejecting your transplanted liver.

How do I use tacrolimus?

- Do not stop taking tacrolimus on your own. Talk with your primary health care provider, Clinic nurse, or pharmacist first.
- Take tacrolimus at the same time each day.
- Tacrolimus can be taken with or without food, but it is best absorbed on an empty stomach. Take your medication the same way each day.
- Your blood counts will be checked regularly. The amount of tacrolimus you take may have to be adjusted based on the results of your blood count.
- On days when you are going to get blood tests to check your drug levels, do not take your tacrolimus before your test. Bring it with you so you can take it after your blood is taken.
- Tacrolimus may cause problems if you take it with other medications. Talk with your primary health care provider, pharmacist, or Clinic nurse before taking any new medications, including prescription, non-prescription, natural products, or supplements.
- If you are not sure how much medication to take, or if you think you may be having any side effects, talk with a Clinic nurse or your pharmacist.
- If you have started taking a new medication and worry it might have an effect on tacrolimus, or you forgot to take your medication and are not sure what to do, talk to a Clinic nurse or your pharmacist.
- Store tacrolimus at room temperature away from heat, light, and moisture.

What are the possible side effects of tacrolimus?

Note: This is not a complete list of all possible side effects.

Side effects can happen with all medications. Talk with a member of your health care team if you do not feel well while taking tacrolimus. Below is a list of side effects to be aware of:

Higher risk of infection: This risk is present with all medications that suppress the immune system. Report the first signs and symptoms of infection (like fever, sore throat, chills, fast pulse, etc.) to your primary health care provider **right away.**

Higher risk of cancer: This risk is present with all medications that suppress the immune system. Report any lumps or changes in skin colour or moles to your primary health care provider.

Stomach upset, loss of appetite, nausea, vomiting, diarrhea: These symptoms usually go away soon after you start taking tacrolimus. Having a lot of diarrhea can lower how much of the drug you absorb. **Talk with your primary health care provider or pharmacist if it continues and before you take any medications to treat these symptoms.**

Headache, light-headedness, dizziness, weakness: If these symptoms continue, or if fainting happens, see your primary health care provider right away.

High blood pressure, blood sugar, or cholesterol: Your primary health care provider will check for these possible effects. If you have any of these symptoms, your primary health care provider may change the amount of medication you take.

Kidney problems: Tacrolimus can cause kidney problems. The Transplant Team will watch closely for these problems and will change how much medication you take, if needed.

Slight hand trembling (shaking): This may happen depending on how much tacrolimus is in your blood. Trembling usually goes away over time.

If you are of child-bearing age: Do not get pregnant while you are taking tacrolimus. It may cause harm to an unborn baby. Ask your primary health care provider or pharmacist to help you choose the right birth control method for you. If you are planning to get pregnant, talk with the Transplant Team months before, 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 prevent or treat infections caused by viruses.
- It is taken to prevent or treat viral infections, such as the one caused by cytomegalovirus (CMV).

How do I use valganciclovir?

- Take valganciclovir according to your primary health care provider's directions.
- Do not stop taking valganciclovir on your own. Talk with your primary health care provider, Clinic nurse, or pharmacist first.
- Valganciclovir can be taken with or without food.
- Valganciclovir may cause problems if you take it with other medications. Talk with your primary health care provider, pharmacist, or Clinic nurse before taking any new medications, including prescription, non-prescription, natural products, or supplements.
- If you are not sure how much medication to take, or if you think you may be having any side effects, talk with a Clinic nurse or your pharmacist.
- If you have started taking a new medication and worry it might have an effect on valganciclovir, or you forgot to take your medication and are not sure what to do, talk to a Clinic nurse or your pharmacist.
- Store valganciclovir at room temperature away from heat, light, and moisture.

What are the possible side effects of valganciclovir?

Note: This is not a complete list of all possible side effects.

Side effects can happen with all medications. Talk with a member of your health care team 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. This can make you feel tired and raise your risk of infections, bruising, and/or bleeding problems. The Transplant Team will watch closely for any signs of these problems and will change how much valganciclovir you take, if needed. Please tell a Clinic nurse, your pharmacist, or your primary health care provider if you have any unusual infections, tiredness, bruising, or bleeding.

Kidney problems: Rarely, valganciclovir can cause kidney problems. The Transplant Team will watch closely for these problems and will change how much medication you take, if needed.

Rash: Contact your primary health care provider, Clinic nurse, or pharmacist 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 to 75 minutes.

Abdominal ultrasound/ultrasound with Doppler studies: a quick, painless 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: a special kind of X-ray that measures the thickness of your bones, usually of the hip and spine.

Bone scan: 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: 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: 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. This test checks if you have any ulcers of blood vessels that are too big. 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. A tube will be passed 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 will not hurt your new liver. The sample shows if there is any rejection, infection, or changes in your liver enzymes caused by medications. 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

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

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

Alkaline phosphatase: 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): an enzyme made by the liver released into the blood when the liver is injured.

Bilirubin: a digestive enzyme made by the liver.

Cholesterol: 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: a protein waste substance removed from the body by the kidneys. A higher level of creatinine could mean dehydration (not enough fluids), kidney disease, or a possible side effect of some anti-rejection medications.

Glucose (sugar): this test measures how well the body uses sugar after eating. A higher level of glucose could mean that a person has developed diabetes.

Hemoglobin: part of red blood cells that carries 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 be a possible side effect of 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 may clot easily. A lower level could be caused by some antibiotics and anti-rejection medications.

Potassium: an electrolyte (salt) in the body. It helps change carbohydrates into energy, builds protein, and helps the heart muscle and nerves work.

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

White blood cell count (WBC): measures the number of 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.

QEII Health Sciences Centre

is made up of 10 buildings located on two sites

Halifax Infirmary Site

1a. Halifax Infirmary
1b. Emergency Dept.

2. Abbie J. Lane Memorial Building

3. Camp Hill Veterans' Memorial Building

VG Site

4. Nova Scotia Rehabilitation Centre

5. Bethune Building

6. Mackenzie Building Laboratories

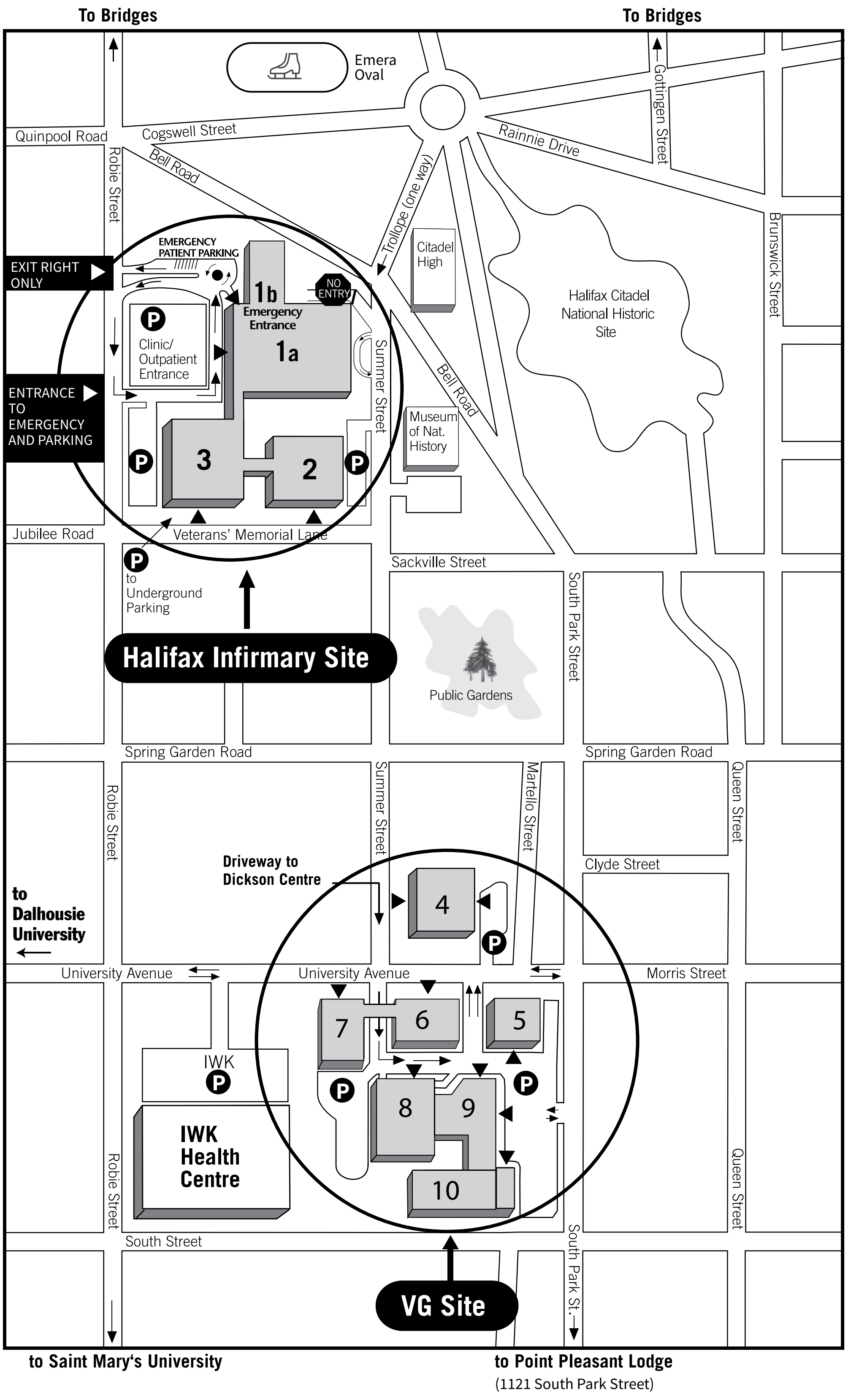
7. Centre for Clinical Research

8. Dickson Building

9. Victoria Building

10. Centennial Building

Ⓟ	Patient Parking
▶	Entrance Doors



Please do not wear scented products when you come to the QEII.

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Important phone numbers

We want you to become an independent member of your community. Your primary health care provider and health care workers can answer many of your questions.

Local numbers

Hospital: ____________________

Pharmacy: ____________________

Primary health care provider: ____________________

Family or friend to contact in an emergency: ____________________

Queen Elizabeth II (QEII) 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:

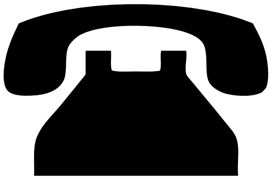
- 902-473-7986

Transplant Unit Manager/Transplant Clinic Manager:

- 902-473-7008

Patient Representative:

- 1-844-884-4177
- www.nshealth.ca/contact-us/patientfamily-feedback-commentaires-des-patients-et-des-familles



Questions for my health care team:

Notes:

Notes:

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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

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

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