

Living With Advanced Liver Disease

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- A liver transplant is one of many treatments for advanced liver disease. This pamphlet is for people who are being considered for a liver transplant.
- You have been referred to a doctor called a **liver specialist** at Nova Scotia Health. You and your liver specialist will work together to decide the best treatment for you.
- The Transplant Coordinator will follow your care during your assessment and while you are on the waitlist. They will put you in touch with other Transplant Team members.
- You will learn about:
 - › How the liver works
 - › Treatments that may control your symptoms
 - › How the Transplant Team can support you
- **Please read this pamphlet before your appointment with the liver specialist.**

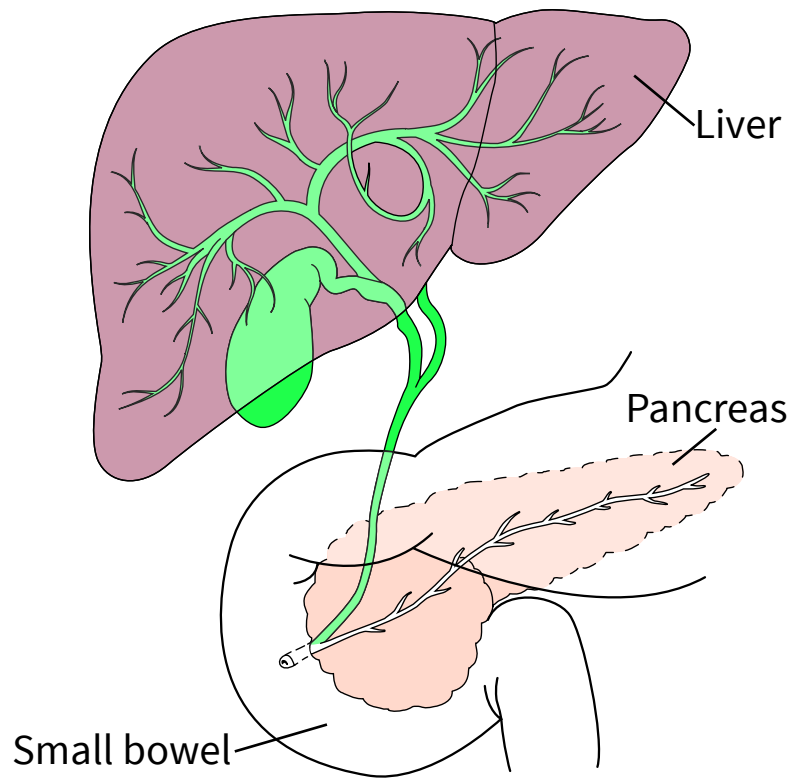
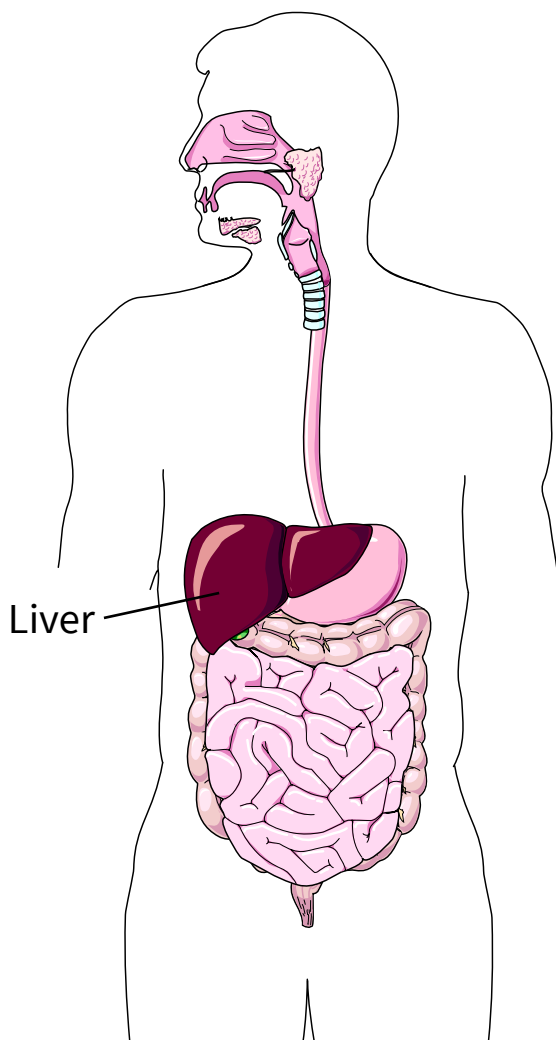
Where do I go for my appointment?

- Your appointment will be at:
Transplant Clinic
4th floor, Dickson Building
Victoria General (VG) site, QE II

There is a map at the end of this pamphlet.

How does the liver work?

- The liver is the largest organ in your body. It weighs 1 to 2 kilograms (3 to 4 pounds). It is mostly behind your ribs on the upper right side of your abdomen (stomach area).
- Your liver does many important things to keep you healthy. It:
 - › changes the food you eat into energy.
 - › stores sugar, iron, vitamins, and minerals so your body can use them when needed.
 - › breaks down and removes medications, alcohol, and other harmful substances from your blood.
 - › makes a yellowish-green fluid called **bile**. Bile helps you digest fats and absorb (take in) vitamins.
 - › regulates your hormones.
 - › makes proteins needed to clot (thicken) your blood and help fight infections.



Liver diseases

- There are more than 100 liver diseases. Your primary health care provider (family doctor or nurse practitioner) or liver specialist will talk with you about your liver disease.

How do I manage my symptoms?

Fatigue (tiredness)

- You may feel tired because of:
 - › Your liver disease
 - › Not getting enough sleep
 - › Not eating healthy foods
 - › Being less active
- **It is very important to:**
 - › Eat healthy foods
 - › Exercise to keep your muscles strong
 - › Pace your activities during the day
 - › Plan important activities for when you have the most energy
 - › Ask others for help, if needed

Jaundice (yellow skin and/or eyes)

- When your liver is not working well, too much bile may build up in your blood. **Bilirubin** (yellow pigments in the bile) may build up in your skin and eyes.
- Your pee may be dark yellow or brown, and your poops may be pale (a light colour).
- Each person is different. You may never have jaundice or have it all the time, or it may come and go.

Dry, itchy skin

- To help with itching:
 - › Use creams and lotions to prevent dry skin.
 - › **Do not** scratch your skin. This will make it more itchy.
 - › **Do not** rub your skin. Always pat it dry.
 - › **Do not** wear fabrics that may irritate (bother) your skin.
- If the itching does not go away, ask your primary health care provider about medications that may help.

Changes in your thinking

- With advanced liver disease, certain toxins (poisons) may build up in your body. This can affect your thinking. You may be irritable, drowsy, or confused. This is called **hepatic encephalopathy**.
- These changes may get worse if you have:
 - › Less body fluids, caused by your fluid pills
 - › Bleeding from the bulging veins in your esophagus (tube that connects your throat to your stomach) or stomach
 - › An infection
 - › Constipation (not being able to poop).
- Your primary health care provider may prescribe a laxative like Lactulose or RestoraLAX®). This will help you poop 2 to 3 times a day, which will help prevent toxins from building up.
- They may also prescribe a medication called **rifaximin**. This helps to remove bacteria from your stomach.

Do not drive if you are confused. Your reaction time will be slower than usual. This can put you at risk of having an accident.

- Your support persons must learn the early signs of confusion (like trouble focusing, being disoriented, memory issues, and mood changes).
- **If you are confused, call your primary health care provider or go to the nearest Emergency Department right away.**

Abdominal (stomach area) swelling

- Your liver makes a blood protein called **albumin**. When your liver is not working well, it is not able to make enough albumin.
- Albumin helps to hold fluid in your blood vessels. When you do not have enough albumin, fluid may pass into your abdomen, legs, or other parts of your body.
- With advanced liver disease, your kidneys get confusing messages from your liver. They start to keep extra salt and fluid in your body. When this extra fluid collects in your abdomen, it is called **ascites**.

- Ascites may be treated by:
 - › eating less salt and making sure you eat enough protein. A dietitian will talk with you about this.
 - › taking fluid pills (like spironolactone, amiloride HCl, or furosemide).
 - › having regular blood tests to make sure the levels of potassium and creatinine in your blood are normal while you are taking fluid pills. Your creatinine level tells us how your kidneys are working.
 - › carefully watching for weight gain or loss. Weigh yourself often. This is to make sure you are not keeping or losing too much fluid.
 - › a procedure called **paracentesis** to remove some of the fluid in your abdomen.
 - › a procedure called a **TIPS** (transjugular intrahepatic portosystematic shunt). This will make a different path for the blood that flows through your liver.

Bleeding

- If your liver cannot handle the blood that normally flows through it, the pressure in your liver veins may get too high. Your body will try to lower the pressure by making **varices** (bulging veins) in your esophagus and stomach.
- If the varices bleed, you may vomit (throw up) bright red blood or what looks like dark coffee grounds. Your poop may also be dark or black.
- Your doctor may use a gastroscope (a tube with a light at the tip) to look for varices in your esophagus and stomach. This will help them to find the cause of any bleeding. They can use the gastroscope to prevent or stop the bleeding by:
 - › **Sclerotherapy** (injecting medication into the bleeding area). Medications like **nadolol** can help to lower the pressure in the blood vessels going to your liver.
 - › **Banding** (putting an elastic band around each varix).

Bruising

- If your liver is damaged, your blood may not clot normally. You may bruise easily, have nosebleeds, or have small red dots on your skin (especially on your arms and legs).
- You will need to have your blood tested often to measure your:
 - › **Platelet level:** Normal value is between 150 to 350
 - › **INR (International Normalized Ratio):** Normal value is 1.0

Less muscle strength

- Keep up your strength and prevent muscle loss by:
 - › Eating small meals more often
 - › Eating healthy foods that are high in calories
 - › Exercising regularly

Infection

- You may be more likely to get an infection.

Signs of infection:

- › Fever (temperature above 38 °C or 100.4 °F)
- › Chills
- › Stomach pain
- › New confusion

If you have any of these signs of an infection, call your primary health care provider. If you cannot reach your primary health care provider, go to the nearest Emergency Department right away.

Sexual changes

- Liver disease can cause you to have less interest in sex and/or be less able to have sex. If you and your partner have questions, talk with your primary health care provider.
- If you usually get your period (menstruate), you may have irregular periods or stop getting your period.

Liver spots

- These are small, dark areas on your skin that look like spiders. They often appear on the chest, abdomen, or back. They may also appear on the arms and face.

What will happen at my first appointment?

- Your liver specialist and Transplant Coordinator will:
 - › go over your liver problems with you to confirm what type of liver disease you have.
 - › check the stage of your liver disease.

If your liver disease is at an early stage:

- › Your primary health care provider and a specialist in your area will manage your care.
or
 - › Your liver specialist and Transplant Coordinator will follow your care.
- Your primary health care provider and a specialist in your area will be important partners in helping you manage your liver disease.
- Your liver specialist and the Transplant Clinic team will assess you to check the stage of your liver disease. You may need many tests. After your assessment, you and your liver specialist will plan your future care.
- Your tests may show that damage caused by your liver disease can be treated with medications.
- If your tests show severe (very bad) liver disease that cannot be treated with medications:
 - › You will meet with the Transplant Team.
 - › A liver transplant may be the best treatment for you.
 - › You may be put on the transplant waitlist once all tests are done, or it may be best to wait a bit longer. While you are waiting, your medications will be changed as needed.

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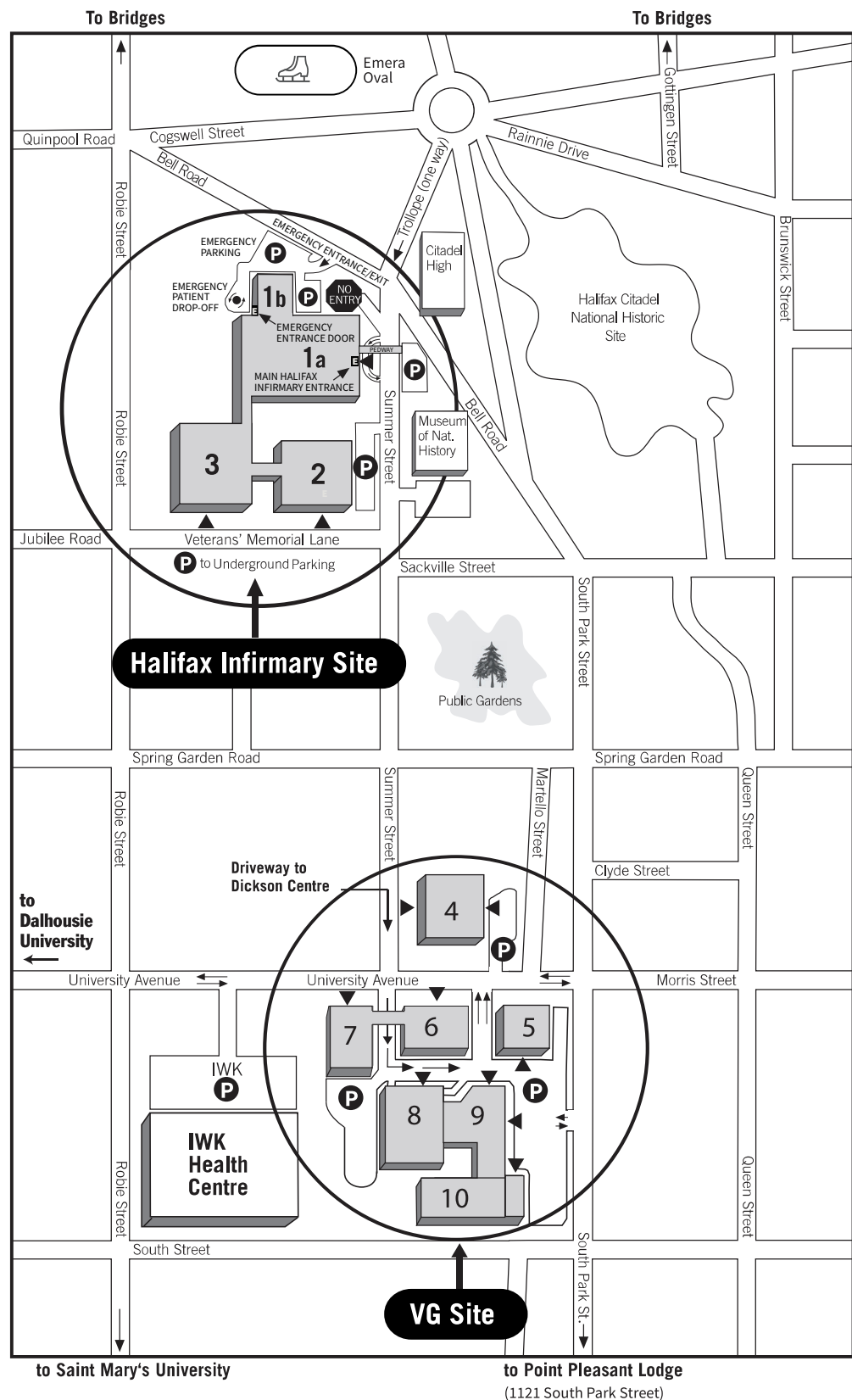
QEII Health Sciences Centre

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

- P** Patient Parking
▶ Entrance Doors

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



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