

Living With Advanced Liver Disease

This guide belongs to:

Living With Advanced Liver Disease

It can be confusing and scary to find out that you have advanced liver disease. You have been referred to a Liver Specialist at the Queen Elizabeth II Health Sciences Centre (QEII).

A liver transplant is one of many treatments that may be used to treat advanced liver disease. You and the Liver Specialist will decide on the best treatment for you.

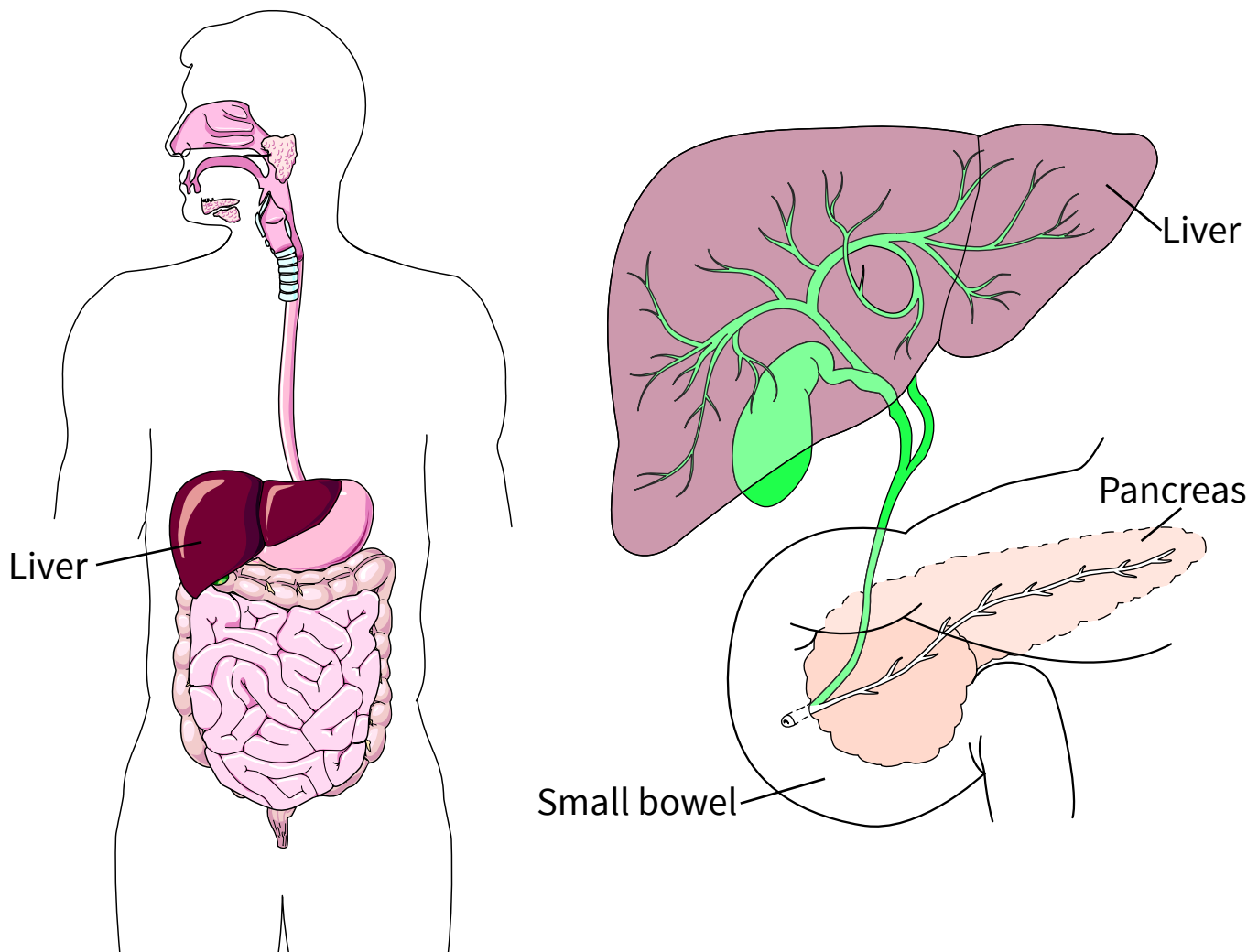
- There are many other people on your Transplant Team. The **Transplant Coordinator** is one of the first team members you will meet. They are a nurse with a lot of experience caring for liver transplant patients.
- The Transplant Coordinator will follow your care during the assessment, the waiting period, and clinic visits. They will put you in touch with your other team members.
- **You will learn about:**
 - › How the liver works
 - › Treatments that may control your symptoms
 - › How the Liver Transplant Team can support you
- Please read this guide before your appointment with the Liver Specialist. The Transplant Coordinator will talk about the information in this guide with you.
- **Please bring this guide with you to your appointment.**

Where do I go for my appointment?

Your appointment will be at the Transplant Clinic. The clinic is on the 4th floor of the Dickson building, Victoria General (VG) site of the QEII. There is a map at the end of this guide.

How does the liver work?

- The liver is the largest organ in your body. It weighs between 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 jobs to keep you healthy. Your liver:
 - › 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 bloodstream.
 - › 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 your blood and help fight infection.



Liver diseases

There are over 100 known liver diseases. Your primary health care provider or Liver Specialist will talk with you about your liver disease. You will get a pamphlet about your liver disease during your Clinic visit. Please write down the name of your liver disease and causes: _____

How do I manage my symptoms?

Fatigue (tiredness)

- Your liver disease may make you feel tired. Poor nutrition, not getting enough sleep, and being less active may also cause fatigue.
- **It is very important to:**
 - › Exercise to keep your muscles strong.
 - › Eat healthy meals.
 - › Pace your activities during the day.
 - › Ask others for help.
 - › Plan important activities for when you have the most energy.

Jaundice (yellow skin and/or eyes)

- When your liver is not working well, too much bile may collect in your blood. The yellow pigments (called bilirubin) in the bile may collect in your skin and eyes.
- Your pee may be darker and your poops may be pale.
- Each person is different. You may never have jaundice, have it all the time, or it may come and go.

Dry, itchy skin

- **To control itch:**

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

Changes in your thinking

- With advanced liver disease, certain toxins may build up in your body and affect your thinking. You may get 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 (swallowing tube) or stomach
 - › An infection
 - › Constipation (not being able to poop). Your primary health care provider may prescribe a laxative called Lactulose or RestoraLAX®. This will help you poop 2 to 3 times a day, which help prevent toxins from building up in your blood.

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

- **Your loved ones must learn to recognize the early signs of confusion. If you are confused, visit your primary health care provider right away for treatment.**

Abdominal (stomach area) swelling

- Albumin (a blood protein) is made in the liver. When your liver is not working well, it will not be 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 salts and fluid in your body. When this extra fluid collects in your abdomen, it is called ascites.
- **If you have ascites, you may need:**
 - › To eat less salt and make sure you eat enough protein. A dietitian will talk with you about this.
 - › Fluid pills (like spironolactone, amiloride HCl, or furosemide).
 - › 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.
 - › To weigh yourself once a week, or more 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 create a different pathway 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 creating varices (bulging veins) in your stomach and esophagus.
- 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 and black.
- **Varices may be treated with:**
 - › Medications like nadolol. These can lower the pressure in the blood vessels going to your liver.
 - › A gastroscop (a tube with a light at the tip). Your doctor may insert (put in) the gastroscop in your esophagus and stomach to look for varices and find the cause of any bleeding. They can use the gastroscop to prevent or stop the bleeding by:
 - › Sclerotherapy (injecting medication into the bleeding area)
 - › Banding (applying an elastic band around each varix)

If you vomit or spit up blood at any time, go to the nearest Emergency Department right away.

Bruising

- Your blood may not clot normally if your liver is damaged. 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 150 to 350
 - › International Normalized Ratio (INR): Normal value is 1.0
- If needed, ask your Transplant Coordinator for information about having your blood tested often.

Less muscle strength

- **Keep up your strength and do not lose muscle 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 38.5° C/101.3° F)
 - › Chills
 - › Stomach pain
 - › New confusion

Sexual changes

- Liver disease can cause you to have less desire for 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 have a vagina, you may have irregular periods or stop getting your period.

Liver spots

- These are small, red areas on your skin that look like spiders. They are usually on the chest, abdomen, or back, but may also be on the arms and face.

Write down your symptoms of liver disease: _____

At your first appointment, your Liver Specialist and Transplant Coordinator will:

- › go over your liver problems to confirm your liver disease diagnosis.
- › check the stage of your liver disease.

Your Liver Specialist and Transplant Coordinator may recommend:

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

- The Liver Specialist in the Transplant Clinic 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.

OR

- The Liver Specialist in the Transplant Clinic will assess you to see how advanced your liver disease is. You may need many tests. After your assessment, you and the Liver Specialist will plan your future care.
- Your tests may show that damage caused by your liver disease can be healed with medications.
- If your tests show severe (very bad) liver disease that cannot be healed with medications:
 - › You will meet the Transplant Team.
 - › A liver transplant may be the best treatment for you.
 - › You may be placed on the waitlist for a transplant as soon as possible, or it may be best to wait a little longer. During this waiting period, your medications will be changed as needed.

QEII Health Sciences Centre

is made up of 10 buildings located on two sites

- | Halifax Infirmary Site |
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| <ol style="list-style-type: none"> 1a. Halifax Infirmary 1b. Emergency Dept. 2. Abbie J. Lane Memorial Building 3. Camp Hill Veterans' Memorial Building |
| VG Site |
| <ol style="list-style-type: none"> 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.

