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Living With Advanced Liver Disease

This book belongs to: _____

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Living with Advanced Liver Disease

Finding out that you have advanced liver disease can be confusing and frightening.

However, there has been a lot of progress made in treating liver disease.

You have been referred to a Liver Specialist at the Queen Elizabeth II Health Sciences Centre (QEII). You and the Liver Specialist will decide on the best treatment for you.

A liver transplant is only one of many treatments that may be used to treat liver disease.

You will learn about:

- How the liver works
- Treatments that may control your liver symptoms
- How the Liver Transplant Team can support you

Please read this booklet before your appointment at the QEII. The Transplant Coordinator will talk about the information in the booklet with you.

Please bring this booklet to the Clinic with you.

Where do I go to see the Liver Specialist?

The Liver Specialist works in the Transplant Clinic. The Clinic is located on the 4th floor of the Dickson building, Victoria General site. There is a map at the end of this booklet.

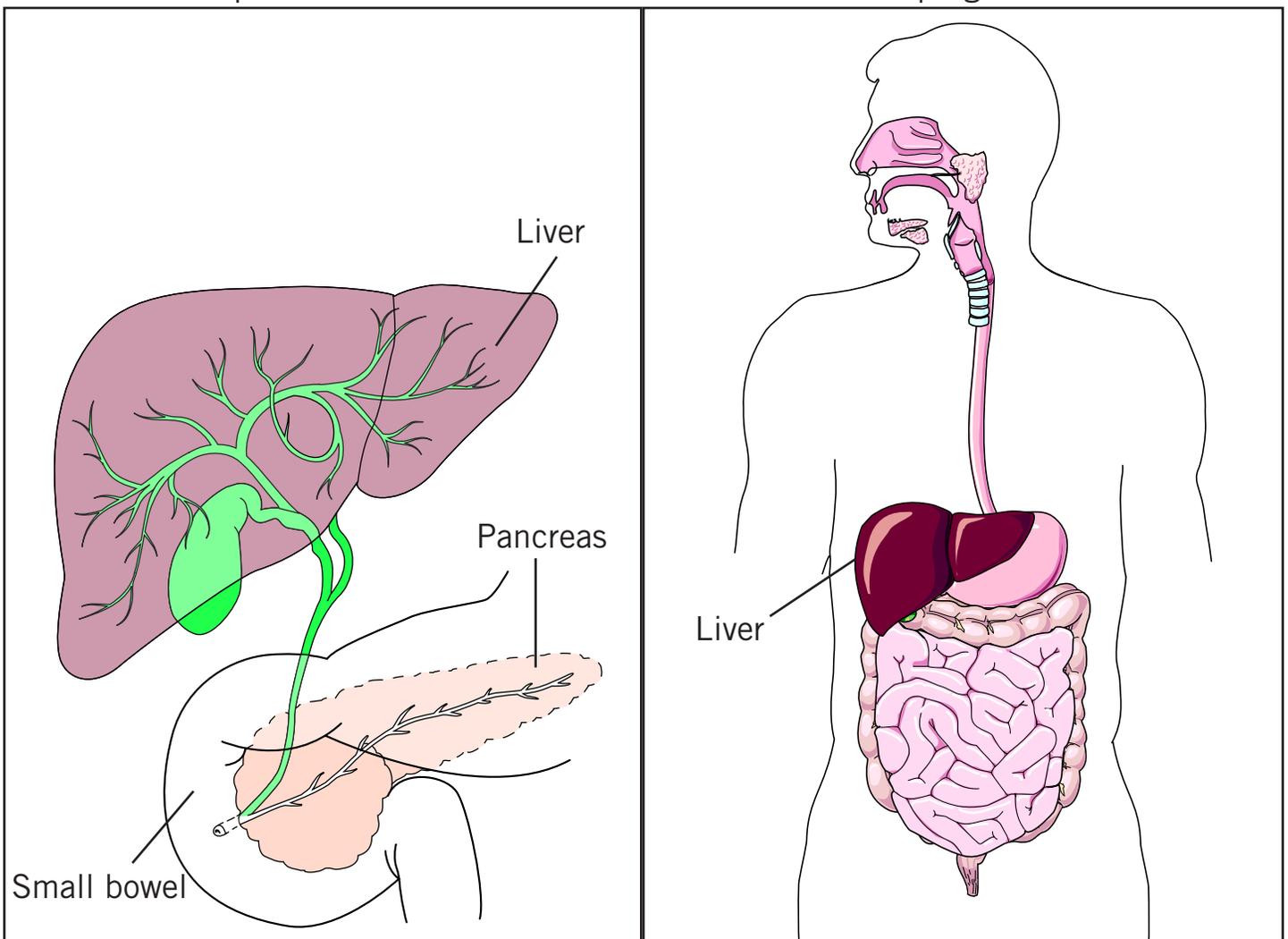
The **Transplant Coordinator** is one of the first members of the Transplant Team that you will meet. He/she is a nurse who has had a great deal of experience in caring for liver transplant patients. The Coordinator will follow your care during the assessment, the waiting period, hospital stay, and Clinic visits. He/she will put you in touch with the other team members.

How does the liver work?

The liver is the largest organ in your body. It weighs between 1-2 kilograms (3-4 pounds). It is mainly behind the ribs on the upper right side of your abdomen. Your liver does many important jobs to keep you healthy.

Your liver:

- Changes your food into energy. This is needed for life and growth.
- 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 stream.
- Makes a yellowish-green fluid called bile. Bile helps you digest fats and also allows you to absorb some important vitamins.
- Regulates your hormones (sex, thyroid, and adrenal).
- Makes proteins needed for the blood to clot and to help fight infection.



How do I take care of my liver disease symptoms?

- **Fatigue**

Your liver disease may make you feel tired. Poor nutrition, lack of 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 your important activities when you have the most energy.

- **Jaundice (the skin and/or eyes are yellow)**

Yellow pigments called bilirubin may collect in the skin and eyes when there is too much in the blood. Your urine (pee) may be darker and your bowel movements pale in colour. This happens when your liver can't get rid of bilirubin. Some people never experience jaundice, some have it all the time, or it comes and goes. Everyone is different.

- **Dry and itchy skin**

To control itch:

- › Use creams and lotions to prevent dry skin.
- › Do not scratch your skin. This will make your skin itch more.
- › Always pat your skin dry. Do not rub.
- › Do not wear fabrics that may irritate (bother) your skin.
- › Ask your doctor about medications that may help, if the itchiness does not go away. Your doctor may prescribe Questran® (cholestyramine powder).

- **Mental changes**

With advancing 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 mental changes may get worse if you have:

- › A decrease in body fluids caused by the fluid pills.
- › Extra animal proteins in your diet. You will still need to get enough calories. Your dietitian can help you plan your meals.
- › Bleeding from the bulging veins in your swallowing tube (esophagus) or stomach.
- › An infection.
- › Constipation. Your doctor may prescribe a laxative called Lactulose. You will have 2-3 bowel movements a day which help prevent the toxins from building up in your blood.

Do not drive if you are confused. Your reaction time will be slower than normal which puts you at risk of getting into an accident.

Your family and/or friends must learn to recognize the early signs of confusion. If you are confused, go to your doctor right away for treatment.

- **Abdominal swelling**

The blood protein albumin is made in the liver. When the liver is not working well, it will not be able to make enough albumin. Albumin helps to hold fluid in the blood vessels. When the albumin is low, fluid may pass into your abdomen, legs, or other parts of the body.

With advanced liver disease, the kidneys get confusing messages from the liver and start keeping extra salts and fluid in the body. When this extra fluid collects in the abdomen, it is called “ascites”.

You may need:

- › A low salt diet.
- › Fluid pills such as spironolactone, amiloride HCl, or furosemide.
- › Blood tests to make sure the levels of potassium and creatinine stay normal in your blood while you are taking the fluid pills. The creatinine level shows us how your kidneys are working.
- › To check your weight once a week or more often 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) to create a different pathway for the blood that flows through your liver.

• Bleeding

The pressure in the liver veins may get too high if the liver can't handle the blood that normally flows through it. Your body will try to lower the pressure by creating varices (bulging veins) which show up in the stomach and swallowing tube. If these varices bleed, a person can vomit (throw up) bright red blood or it may look like dark coffee grounds. Sometimes there may also be black bowel movements (stools).

Varices may be treated with:

- › Medications such as nadolol can lower the pressure inside the blood vessels going to the liver.
- › A gastroscop is a tube with a light at the tip. Your doctor may insert (put) it into your swallowing tube and stomach to look for varices and find the cause of any bleeding. Sclerotherapy (injecting medication into the bleeding area) or banding (applying an elastic band around the varix) to prevent or stop the bleeding are both done through a gastroscop.

You need medical help right away if you vomit or spit up blood at any time.

- **Bruising**

Your blood may not clot normally if your liver is damaged. You will need to have your blood tested often. The platelet level (normal value 150-350) and International Normalized Ratio (INR) (normal value 1.0) will be measured. If needed, ask your Coordinator for information about your blood tests. You may **bruise easily, have nosebleeds, or small red dots** on your skin, especially on your arms and legs.

- **Decrease in muscle strength**

Keep up your muscle mass and strength by:

- › Eating small meals more often
- › Eating foods high in calories
- › Exercising regularly

- **Infections**

You may be more likely to get an infection.

Signs of infection:

- › Fever
- › Chills
- › Stomach pain
- › New episode of confusion

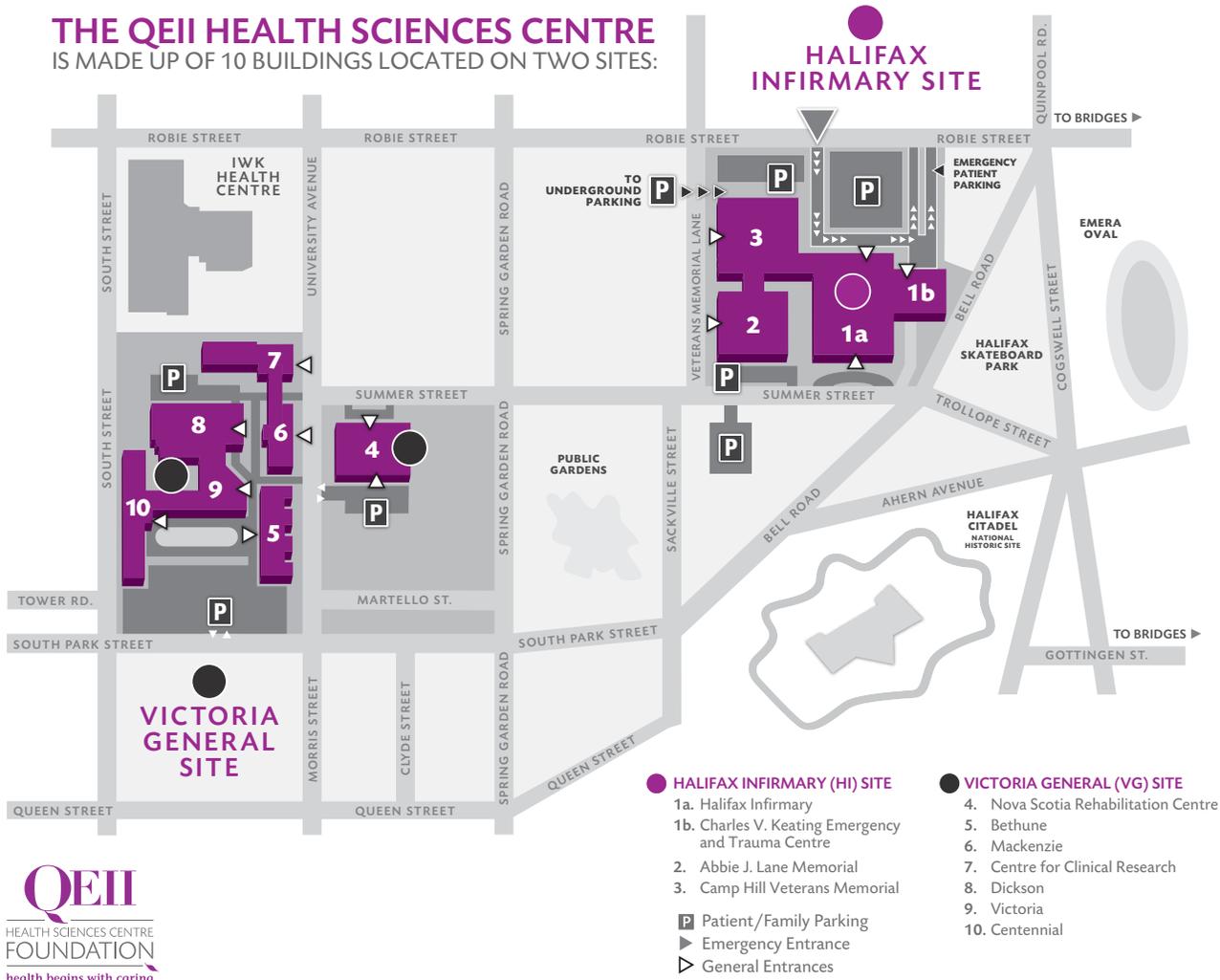
- **Changes in sexual function**

Women may have irregular periods or even stop getting their periods. Liver disease can cause lower sexual desire and/or the ability to be sexually active. You, your partner, and doctor should talk about this.

- **Liver spots**

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

THE QEII HEALTH SCIENCES CENTRE
IS MADE UP OF 10 BUILDINGS LOCATED ON TWO SITES:



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