
Understanding Cirrhosis of the Liver:

FIRST STEPS FOR THE NEWLY DIAGNOSED



Cirrhosis Basics

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I WAS TOLD I HAVE CIRRHOSIS

Have you just found out you have cirrhosis? You probably have a lot of questions about your diagnosis. You may be feeling stressed, overwhelmed or worried. It's normal to feel this way. It can be difficult to receive a new diagnosis. Learning about your condition can help you take control of your health and make the best choices for you.

This booklet will help you understand cirrhosis caused by viral hepatitis. Keep in mind that this is only one source of information. Many people can help you learn about cirrhosis and how to take care of yourself. Doctors, nurses, pharmacists and other healthcare workers can help you to make decisions, connect you to other services and provide support. Don't be afraid to ask for more information or help.





WHAT IS CIRRHOSIS?

Cirrhosis is a form of damage to the liver. The liver is about the size of a football. It's on the right side of the body and it's protected by the rib cage. It has over 500 functions and is very important. You cannot live without your liver.

When the liver is damaged, it develops scars as it tries to fix the damage. Early stages of scarring are called fibrosis. Someone has cirrhosis when serious and extensive injury or scarring has developed in the liver. The scarring can stop the liver from working properly.

Cirrhosis is a very slow-acting disease. It can take up to 30 years to develop. The amount of time it takes for cirrhosis to develop depends on a few factors, including the cause of the cirrhosis, a person's general health, lifestyle and genetics.

Cirrhosis is a serious condition. If left untreated, it can lead to liver failure, liver cancer or death. Only a small number of people with cirrhosis will develop these serious problems. The good news is that there are things you can do to manage cirrhosis and improve your health.

WHAT CAUSES CIRRHOSIS?

Cirrhosis is caused by long-term injury to the liver. Many things can cause it. This booklet has been written for people who have cirrhosis caused by viral hepatitis.

Viral hepatitis is a disease in which the liver becomes damaged after getting infected by a really small germ called a virus. Viruses that infect the liver are known as hepatitis viruses. You may have heard of hepatitis A, hepatitis B and hepatitis C. (Hepatitis D and E also exist.)

Each hepatitis virus has its own characteristics and passes between people in different ways. These viruses are also treated in different ways and some are easier to eliminate than others. For more information about hepatitis viruses, talk to a healthcare professional and check out www.catie.ca.

There are many other causes of cirrhosis, including:

- alcoholism
- NASH (non-alcoholic steatohepatitis) or NAFLD (non-alcoholic fatty liver disease)
- metabolic diseases or inherited diseases (Hemochromatosis, Wilson's disease, etc.)
- severe reactions to prescribed drugs or prolonged exposure to toxins or chemicals

Symptoms, Monitoring your Liver and Treatment

WHAT ARE THE SYMPTOMS OF CIRRHOSIS?

Blood from the stomach and intestines passes through your liver, where it is filtered and processed before heading to other parts of your body. When scar tissue begins to replace healthy tissue in the liver, it is harder for blood to flow normally through the liver and for the liver to work in its usual way. Cirrhosis is a silent disease, and people who have it sometimes don't have symptoms until there's been a lot of injury to the liver. Injury may be occurring even if a person has few or no symptoms.

The symptoms of early liver cirrhosis (sometimes called **compensated** cirrhosis) include:

- fatigue and loss of energy
- unexplained loss of appetite and weight loss
- nausea
- abdominal pain
- pinhead-sized spots on the skin from which tiny blood vessels spread out in a circle (spider angiomas)
- redness of the palms of the hand (palmar erythema)

In some people, cirrhosis progresses over time and the liver's ability to work normally decreases. How quickly this happens varies from person to person and depends on a few things, including the person's general health, their gender, the cause of the cirrhosis, the stage of the disease when they were diagnosed, their diet and their alcohol intake.

In a small number of people with cirrhosis, the liver gets so damaged it can no longer work properly. (This serious type of damage is called **decompensated** cirrhosis.)



Symptoms of more serious cirrhosis include:

- continuous weight loss
- extreme fatigue
- yellowing of the skin (**jaundice**) or eyes that doesn't go away
- itchy skin
- dark, tea-coloured urine
- difficulty falling asleep and/or staying asleep; sleep patterns are reversed for some people: they stay awake through the night and sleep during the day
- frequent bacterial infections in fluid that can accumulate in the belly (**spontaneous bacterial peritonitis**)
- bleeding gums or gums that get bruised easily
- swelling or ruptured veins (**varices**) in the esophagus (food pipe) and stomach. (Some symptoms of this are black or bloody stools and dark vomit that looks like coffee grounds. If you notice this, you need to get medical attention right away. Bleeding varices are a very serious and potentially life-threatening medical problem.)
- painful swelling of the legs (**edema**) and abdomen (**ascites**) due to an imbalance of fluid
- shortness of breath, although this is not a common symptom
- confusion, forgetfulness, personality changes, changed sleep habits or other changes in mental function (**hepatic encephalopathy**)

If you have cirrhosis and you notice any of these symptoms, you should mention them to your care provider as soon as possible. They might be a sign that your cirrhosis is getting worse.

HOW DOES CIRRHOSIS AFFECT MY BODY?

Some of the effects of cirrhosis on the body are directly related to the liver's function. For example, jaundice develops because the liver can't properly break down bilirubin. Bilirubin is a by-product of the breakdown of red blood cells; it is excreted into bile and changes the colour of stools. If it builds up in the body it can also lead to yellowing of the skin. Bleeding gums, nosebleeds and bruising happen more easily than usual because the liver stops making enough platelets to help with blood clotting. Finally, brain fog and other serious mental changes linked to hepatic encephalopathy can happen when the injured liver cannot clear the toxin ammonia from the blood.

Other symptoms develop because blood vessels in the scarred liver get narrower or become blocked. This can lead to swelling of the liver and the spleen. These blockages also cause blood and fluids to back up in the body, like water that cannot empty through a blocked drain. The backed-up blood increases pressure within the blood vessels that flow through the liver (called portal hypertension). Blockages also mean that blood is re-routed around the liver through smaller veins in the body. This causes the blood vessels in the food pipe and upper stomach to bulge (varices) and break more easily.

HOW DO I KNOW HOW SERIOUS MY CONDITION IS?

Scarring in the liver that is caused by ongoing damage is talked about using F scores. These refer to the amount of fibrosis found in the liver, with F0 meaning no damage and F4 meaning cirrhosis. Your healthcare team look at your F scores, any symptoms you may be experiencing and blood test results to figure out how severe your condition is and to determine possible treatment.

WHAT TESTS DO I NEED TO HAVE?

Several different tests monitor your liver and help you and your healthcare provider understand how cirrhosis is affecting it. You may have some of the following types of tests:

- **Blood tests** assess injury or inflammation in the liver and how well your liver is working. These tests have names like AST, ALT, GGT, INR, albumin and bilirubin.
- **Imaging tests** determine whether the liver is an abnormal shape or size and also measure how well blood is flowing through it. Ultrasounds look at the shape and size of your liver, as well as checking for fluid in the liver and monitoring for cancer. If anything out of the ordinary is found, other tests like MRIs and CT scans can be used for further testing.

You may also have tests to monitor the scarring (fibrosis) on your liver. There are two common tests:

- **FibroScan** measures liver stiffness using sound waves—a scarred liver is stiffer than a healthy one. This is a quick, painless procedure.
- **Liver biopsy** involves inserting a needle into the body to take a small piece of the liver. The piece is then studied under a microscope to look for damage.

Talk to your healthcare provider about the tests you'll need, how often you'll need them, what to expect during each test and how to prepare for each one.



ARE TREATMENTS AVAILABLE?

Yes! Treatments are available. One goal of treatment is to target the cause of the cirrhosis. For example, if your cirrhosis is caused by viral hepatitis, treatment of the infection will be an important part of your care. Treatments for hepatitis C cure almost everyone. Treatments for hepatitis B do not cure the infection, but they can help to keep the virus under control.

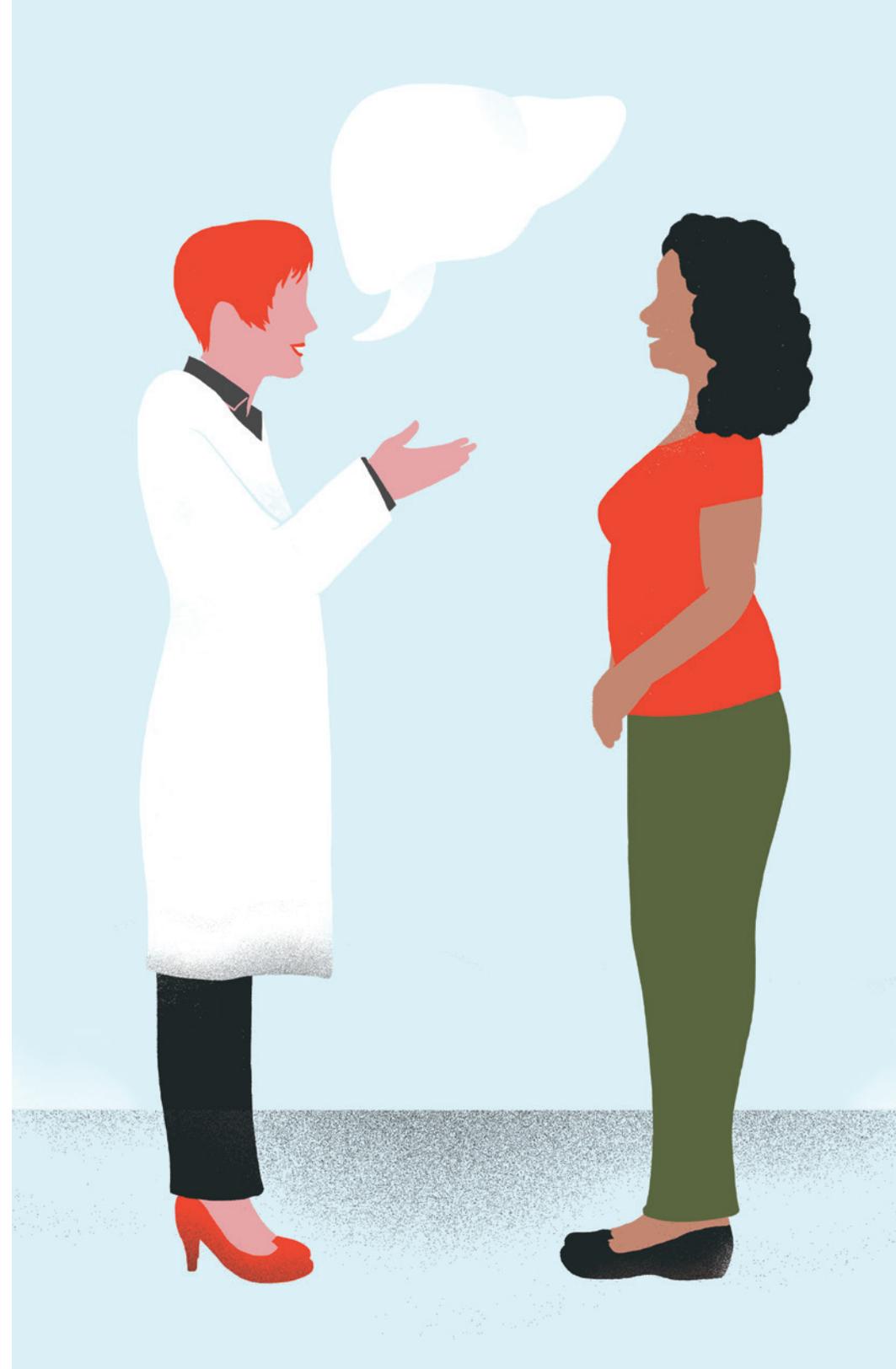
Another goal of treatment is to manage the symptoms and complications of cirrhosis. Medications taken by people with cirrhosis include the following:

- Blood-pressure medications, such as beta-blockers, are used to lower pressure in blood vessels that carry blood through the liver.
- Diuretics (water pills), such as hydrochlorothiazide or furosemide, are used to reduce the swelling from ascites and edema.
- The laxative lactulose helps to clear the toxin ammonia from your system. This keeps your mind clear and prevents confusion or brain fog. Talk to your healthcare provider about figuring out a way of taking it that works for you and doesn't disrupt your day-to-day activities.

Varices in the food pipe (esophagus) and stomach, which are a serious complication of cirrhosis, can usually be treated. Doctors can use various procedures to repair them and can prescribe medicines afterwards to maintain treatment. Surgery, including liver transplant, may be an option in serious cases of cirrhosis.

DO I NEED A TRANSPLANT?

Not everyone who has cirrhosis needs a transplant. Many people can live for a long time with cirrhosis of the liver. Transplants are usually considered only when liver damage is severe and life threatening. Keep in mind that liver transplants are expensive, few organs are available and transplants are not always successful. Candidates must meet very strict criteria to qualify for a transplant. Many factors are considered, including your age, whether you smoke and your alcohol consumption. You will only know if you need a transplant after talking to your healthcare provider.





CAN I BE CURED OF CIRRHOSIS?

In general, the liver damage seen with cirrhosis is permanent. Scarring cannot be fully reversed, but it can lessen (regress) with time, similar to the way a scar on the skin fades. That's why it's important to find out if you have cirrhosis early and to do as much as you can to keep your liver healthy.

The good news is that healthy parts of the liver can regenerate. With proper treatment and care, people with cirrhosis can sometimes see improvements in their liver health, depending on what caused the damage. For people with viral hepatitis, the health of their liver might improve if their infection is treated and they receive appropriate care.

It's important to stay connected to your healthcare provider even after you've been treated for viral hepatitis. Even after your infection is treated you are still at risk for liver cancer. You will need to have ongoing screening for this.

Managing your Health

WHAT STEPS CAN I TAKE TO STAY HEALTHY?

By reading this booklet you're already taking steps toward taking better care of your health. There are many other steps you can take to stay healthy. Here are a few:

- Stay connected to your healthcare provider. They can help you understand your condition and manage symptoms and complications. They may also help connect you to supports in your community.
- Try to avoid or cut back on smoking, alcohol and street drugs. These are all hard on your liver, increase liver damage and may make your cirrhosis progress faster. For example, cigarettes have many toxins and carcinogens (chemicals that can cause cancer) in them and these get in your blood when you smoke. When you have cirrhosis your liver doesn't work as effectively to clear the cigarette toxins from your blood. This increases the risk of further injury to your liver. If you're finding it hard to avoid tobacco, alcohol or street drugs, start by trying to change how much you're using and how you use. For example, reduce the number of drinks you have in a day. Making changes like this may also mean making changes to your social life. Talk to your healthcare provider about getting help and support.
- Eat as well as you can. Healthy nutrition is a big part of taking care of your liver. Start by talking to your healthcare provider about any special dietary needs you may have. If you have severe hepatic encephalopathy you may have to cut down the amount of protein you eat to reduce levels of the toxin ammonia in your body. It's important to keep in mind that although too much protein can lead to problems, too little can lead to malnutrition. Talk to your healthcare provider about finding the right balance and eating enough calories in general. There are also other steps you can take; for example, salt can contribute to high blood pressure, so it's good to reduce the amount of salt in your diet.



- Eating well can be hard when you have limited resources; take the steps you can. Read food labels and try to choose options with less salt (called sodium) or less sugar (called simple carbohydrates). Also try to eat more fruits and vegetables. Many community health centres and community organizations have staff, such as dieticians and nutritionists, whom you can talk to about your options.
- Protect yourself from other viruses. Having more than one virus can make your liver damage worse. You can get vaccines to prevent hepatitis A and B and influenza. Talk to your healthcare provider about your options. There is no vaccine for hepatitis C or HIV, but you can take steps to avoid getting these infections.
- If you're using street drugs, use new equipment each time and don't share your supplies, such as pipes, syringes, needles, filters, cookers, vitamin C powder or citric acid, alcohol swabs, ties or tourniquets and water. This will reduce your risk of passing on viruses or getting re-infected if you've already gone through treatment.

- Keep track of the prescription and non-prescription medicines you are taking, including herbal medicines, vitamins and supplements. Some medicines can be very hard on your liver. If you can, bring a list of what you are taking (or bring all the bottles) and have your doctor or pharmacist check for any potential problems.
- Talk to your healthcare provider about which painkillers are safe to use. This includes drugs like acetaminophen (Tylenol), Aspirin and ibuprofen (Advil).
- Take care of yourself by trying to get regular exercise, drinking enough water and getting enough sleep.
- Talk about your feelings with someone you trust. Living with a chronic condition like cirrhosis can be stressful. Many people find it helpful to share their emotions with someone.

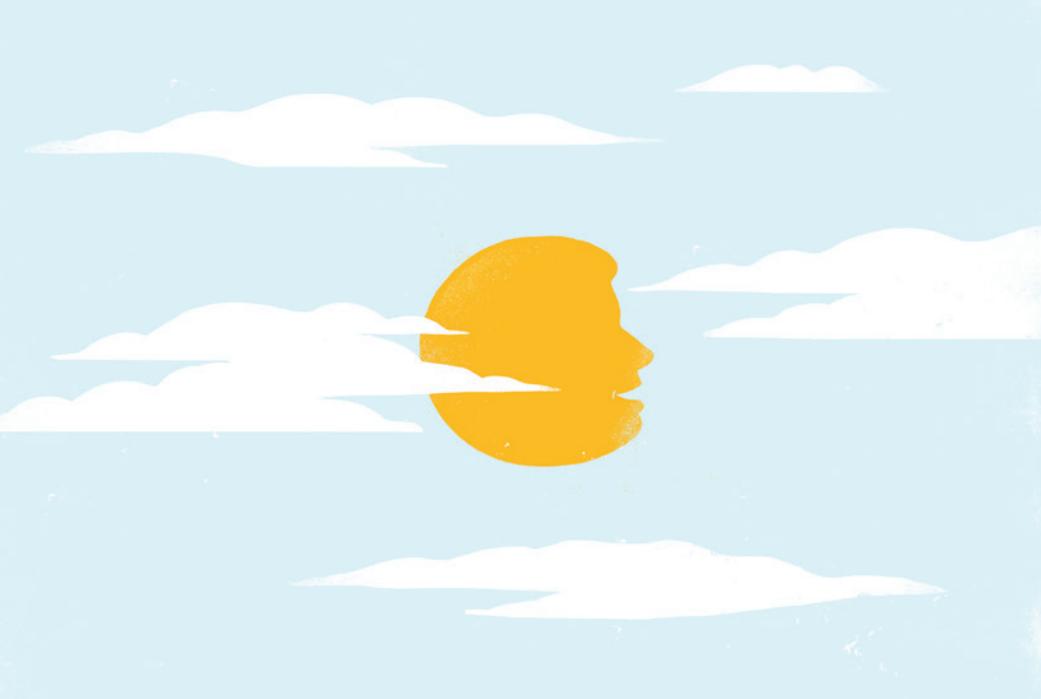
HOW DO I MANAGE THE SYMPTOMS?

Cirrhosis and its complications can lead to many different symptoms, including nausea, abdominal pain, sore muscles and brain fog. Talk to your healthcare provider about any symptoms you are experiencing as they can recommend things to help. Also, keep in mind that sometimes symptoms can be a sign of a serious problem that needs attention.

WHAT CAN I DO IF I OFTEN FEEL SAD, DOWN OR DEPRESSED?

Feelings of depression—which include hopelessness, fatigue, anxiety and lack of interest in daily life—are common in people with cirrhosis, especially those people with hepatitis C. These changes can be part of the cirrhosis or they may have some other cause. If your feelings have changed and are not getting better, talk to your healthcare professional or someone you trust. Many options exist for handling depression. You're not alone.





Resources

CATIE is Canada's source for HIV and hepatitis C information.

Learn more at

www.catie.ca

The Canadian Liver Foundation is a national non-profit organization committed to promoting liver health and providing hope to people living with liver disease. Learn more about liver health at

www.liver.ca

CAN I STILL DO MY USUAL DAILY ACTIVITIES?

Yes, many people with cirrhosis continue to live near normal lives. If symptoms of cirrhosis or the side effects of treatment are interfering with your usual activities, including work, talk to your healthcare provider about what you can do to manage them.

If you drive and are experiencing confusion or fatigue as symptoms of your cirrhosis, you need to talk to your healthcare provider about whether it is safe to continue driving. Think about asking a friend or a family member to accompany you to and from your appointments, whether you take the bus, walk or use another method to get there.

CAN I TRAVEL LOCALLY OR FARTHER?

Talk to your healthcare provider if you plan on travelling by airplane, as untreated varices can be dangerous and lead to life-threatening bleeding. They may also suggest wearing support socks or stockings to help with blood flow and swelling in your legs.



CAHN is a national professional organization that represents and supports nurses across Canada who practice in hepatology.

www.cahn.ca  [/Livernurses](https://www.facebook.com/Livernurses)



CATIE is Canada's source for HIV and hepatitis C information. CATIE connects people living with HIV or hepatitis C, at-risk communities, healthcare providers and community organizations with the knowledge, resources and expertise to reduce transmission and improve quality of life.

www.catie.ca   [/CATIEinfo](https://twitter.com/CATIEinfo) 1-800-263-1638

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DISCLAIMER

Information in this brochure is not medical advice. Decisions about treatment should always be made with the advice of a doctor. Treatment changes, so talk to a doctor to get the latest information. The opinions in this brochure may not be the views of CAHN, CATIE, or any partners or funders.

Information on safer drug use is not meant to promote the use or possession of illegal drugs.

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