Taking Control of Hepatitis C

You have just been told you are infected with the hepatitis C virus (HCV) and you probably have a lot of questions. You may wonder what HCV means to you, your family, and your future. You may feel confused and scared. It is important to know that you are not alone. There are more than 3,000 Nova Scotians known to have HCV, and there may be many more that are still not aware they have it. You have the support of many healthcare providers. There are effective treatments that may be right for you.

This booklet will give you more information about HCV, and what you need to do to keep your body healthy. We have highlighted some medical terms in the text, and defined them near the end of this booklet. This will help you understand commonly used medical terms. Information is key to helping you take control of HCV.

What is HCV?
HCV is the most common chronic viral infection in Canada. In the past, HCV was called non-A, non-B hepatitis. The hepatitis C virus was identified in 1989. In 1990, an HCV antibody test (anti-HCV) became available to identify people exposed to HCV. There is still no vaccine to prevent HCV.
Can I be treated?
Yes, there are treatments for HCV, but these treatments are not available for everyone. Only you and a member of your healthcare team can decide together if a treatment is right for you.

What causes HCV?
HCV is transmitted (passed to another person) through direct exposure to HCV-infected blood if there is an opening in the skin or mucous membrane. Transmission rarely happens from exposure to other infected body fluids, such as semen. HCV infects the liver, causing inflammation (swelling) that damages the liver tissue.

Who is at risk for getting HCV?
People who may come in contact with infected blood, instruments, or needles, such as injection drug users, healthcare workers, or public safety workers (for example, fire fighters, police officers, and paramedics) are at risk of getting HCV. Other potential risks include snorting cocaine, tattooing, and body piercing.

If you are in a long-term, monogamous relationship with a partner who has HCV, your risk of getting HCV is thought to be low. For these monogamous couples, Health Canada does not recommend using condoms to prevent transmission. However, couples should avoid sharing razors, toothbrushes, and nail clippers.

The risk of transmission is higher if you have multiple short-term sexual relationships with partners who have HCV. Your risk of getting HCV goes up significantly if you have HIV. Under these circumstances, Health Canada recommends regular condom use to lower your risk of transmission.

About 250,000 Canadians have been infected with HCV. It is estimated that up to 85% of people infected with HCV will develop a chronic infection. As many as 21% of the people infected do not know they have the virus.
What can I do to stop the spread of HCV?
Once you know that you have HCV, it is important not to spread the virus. If you use common sense and educate your loved ones about HCV, you and they can live risk-free.

Important facts to remember:
• The risk of spreading HCV through normal household contact is very low.
• Oral transmission of HCV has not been proven, so you can hug and kiss your family and friends.
• People living with an HCV-infected individual should not share personal care items such as razors, toothbrushes, and nail clippers. This lowers the risk of others being exposed to infected blood.
• There is a low risk that HCV can be transmitted through sex. There is an increased risk of many types of infections if you have multiple sexual partners. Tell your partner about your infection. If you are sexually active with multiple partners, you should always use a condom.
• There is a very low risk of the infection in long-term partners of people with chronic HCV if they have no other risk factor for infection.
• Menstrual (period) blood is known to carry HCV. Women should not have sex while they have their period.
• Women with HCV do not need to avoid pregnancy or breastfeeding. The risk of passing the virus to your baby during childbirth is about 5%. Children of mothers with HCV should be tested at least 18 months after birth. HCV positive mothers should not breastfeed if their nipples are cracked or bleeding.

What are your questions? Please ask.
We are here to help you.
Your Liver and HCV

Where is my liver?
Your liver is the largest internal organ in your body. It is located in the upper right section of the abdomen (belly), just under your rib cage.

What does my liver do?
Your liver is a complex chemical factory that works 24 hours a day. Most of the blood returning to your heart from your intestinal tract passes through your liver. This means everything absorbed into your bloodstream from the food you eat passes through your liver.

Your liver is a complex organ that is essential to life. You cannot live without it.

Your liver helps you by:
• Clearing alcohol, drugs, harmful by-products, and other toxins from your blood.
• Converting (changing) most medicines into a form your body can use.
• Making essential proteins that:
  › Carry nutrients and other substances throughout your body
  › Clot blood
  › Provide resistance to infection and bacteria
• Maintaining a healthy balance in your body of:
  › Hormones
  › Cholesterol – your liver makes it, excretes it, and converts it
  › Essential vitamins and minerals – which your liver processes
  › Glucose – your liver makes, stores, and supplies glucose (a sugar) to the rest of your body
  › Fat – your liver makes and stores fat for your body
What are the symptoms of HCV?
You can live with HCV for many years without having any major symptoms, or you might have a small loss of energy. When this happens, fatigue (tiredness), fever, nausea (feeling sick to your stomach), poor appetite, or muscle and joint pain may also happen. Symptoms can vary and can come and go over time. Whether you have no symptoms or many does not have anything to do with the amount of liver damage you have.

What are the symptoms of advanced liver disease due to HCV?
In the first few decades of infection, your liver-related symptoms are not present. When your liver changes more than 75%, you may have jaundice (yellow skin and eyes), ascites (fluid buildup in the abdomen), encephalopathy (severe confusion and coma due to buildup of toxins) and hemorrhage (heavy bleeding) from veins in the esophagus (throat area).

How does HCV affect the liver?
HCV infects your liver cells. This causes your liver cells to become inflamed (swollen). Over time, chronic (long-term) inflammation can cause liver cell damage and result in fibrosis (liver scarring), or even cirrhosis (advanced liver scarring).

Chronic HCV appears to be a slowly progressive disease that may gradually get worse over 10-40 years. About 20% of people with chronic HCV develop cirrhosis within 20 years. The misuse of drugs and alcohol affects how fast the inflammation changes into fibrosis or cirrhosis.

HCV is associated with an increased chance of developing hepatocellular carcinoma, a type of liver cancer. Almost all HCV-related liver cancer happens in patients with cirrhosis of the liver.

Healthy eating, achieving and maintaining a normal weight, getting proper rest, avoiding alcohol and recreational drugs (such as cocaine), as well as a responsible approach to treatment can make a large difference in managing your HCV.
How to prepare for your clinic appointments

Because appointments can be short and there is often a lot to talk about, it’s a good idea to be prepared.

To prepare, try to:

• Write down any symptoms you are experiencing, including any that may seem unrelated to the reason for your appointment.

• Write down important personal information, including any major stresses or recent life changes (marriage, divorce, death of a family member, new job, etc).

• Make a list of all medications, vitamins, and supplements (including herbal remedies) you’re taking.

• Consider taking a family member or friend along. Sometimes it can be hard to remember all the information given during an appointment. Someone who goes with you may remember something that you missed or forgot.

Notes:
How is HCV diagnosed?
A diagnosis is made through a blood test. The blood test looks for the antibodies to the virus. If this is positive, a second test is done to see if the virus is present in the blood. Here is a table of the tests commonly used to diagnose HCV and monitor liver function.

<table>
<thead>
<tr>
<th>Test</th>
<th>Definition</th>
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<tbody>
<tr>
<td>HCV antibody (Anti-HCV) (blood test)</td>
<td>Your body makes HCV antibodies to fight the virus. These antibodies stay in your system for life. This test measures whether there are HCV antibodies in your blood (screening test).</td>
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<tr>
<td>Alanine Aminotransferase (ALT) (blood test)</td>
<td>When liver cells are injured or destroyed, enzymes escape into your blood. This test measures the level of the enzyme ALT in your blood and tells if there is inflammation.</td>
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<tr>
<td>HCV RNA Viral Load (blood test)</td>
<td>This test measures the number of HCV particles in your blood.</td>
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<tr>
<td>HCV RIBA Antibody Test</td>
<td>A laboratory test to confirm HCV antibodies in your blood.</td>
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<tr>
<td>Genotyping (blood test)</td>
<td>There are different genetic strains of HCV. It is very helpful to know the genotype of your virus because different types need different lengths of treatment.</td>
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<tr>
<td>Ultrasound (imaging test)</td>
<td>Sound waves are used to create a picture of your liver. The picture shows the size and texture of your liver, and the size of bile ducts and blood vessels. This is a safe and painless way to check on your liver and its blood supply.</td>
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<tr>
<td>Fibroscan®</td>
<td>Similar to an ultrasound, a Fibroscan®, or Transient Elastography, sends a wave into the liver using an ultrasound transducer on an ultrasound probe. The speed of the wave passing through the liver is measured and converted into liver stiffness to help measure the amount of liver fibrosis. A Fibroscan® can not be done if you are pregnant or if you have a pacemaker.</td>
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How is HCV treated?

It is important to remember that no treatment will work for every single person, but treatment is very effective and cures more than 90% of those who receive it. Talk with your healthcare provider. Make sure you fully understand the goals of your treatment.

Getting treatment for HCV may depend on many factors, including:

- The amount of damage to your liver
- Any other health conditions you have
- How much HCV virus you have

Most people with acute HCV do not receive treatment because they do not know that they have the virus. If you believe you have come in contact with the hepatitis C virus, talk to your healthcare provider to get tested. Acute HCV can be found early, and may be treated with medicine to help prevent chronic HCV.

People with chronic HCV may also not know they have the virus because they do not show symptoms. If a blood test, liver biopsy, or Fibroscan® shows that you do have chronic HCV, but there is no damage to your liver, then you may not need treatment. If you have some liver damage, medicines can be used to help fight the viral infection.

Treatments are changing quickly; therefore talk about treatment options with your healthcare professional often. There is a cure for hepatitis C. Read about treatment options on the following pages.
Treatment Options and Genotype

Chronic HCV has 6 different genotypes (‘types’). The genotype strand of chronic HCV you have may determine your treatment options. It may be important for your healthcare provider to know the genotype of your chronic HCV before making any recommendations.

6 different genotype strands:

- Genotype 1a & 1b
- Genotype 2a, 2b, 2c, & 2d
- Genotype 3a, 3b, 3c, 3d, 3e & 3f
- Genotype 4a, 4b, 4c, 4d, 4e, 4f, 4g, 4h, 4i, & 4j
- Genotype 5a
- Genotype 6a

What treatments have been approved for HCV in Canada?

- **Harvoni®**
  - Oral pill taken once per day with or without food
  - Genotype 1

- **Sovaldi® and ribavirin**
  - Oral medication taken once per day
  - Genotypes 1, 2, 3 and 4

- **Holkira™ Pak**
  - Oral combination of one pill taken once per day, as well as another pill taken twice per day; can be prescribed with ribavirin as well
  - Genotype 1

- **Zepatier®**
  - Oral pill taken once a day with or without food – some patients may also need ribavivarin and an additional pill daily
  - Genotypes 1 and 4

- **Epclusa®**
  - Oral pill taken once a day with or without food
  - Genotypes 1, 2, 3, 4, 5 and 6

There are a number of treatments for HCV and they are changing quickly.
Your healthcare provider needs to know all of your medications, including prescribed, over-the-counter, or herbal remedies, in order to assess any drug-to-drug interactions with hepatitis C treatment.

Your liver care team will give you available options based on a number of factors:

- Degree (amount) of liver scarring
- Genotype
- How well you responded to previous HCV treatment
- Medication insurance coverage, Nova Scotia Pharmacare, or assistance programs

**How can treatment help me?**

HCV treatments can remove (or clear) the hepatitis C virus from your blood. With the latest treatments, this happens in more than 90% of those treated. The treatment can stop the virus from damaging your liver and lower the risk of spreading the virus.

**Do I need a test to measure the amount of scarring in my liver before starting treatment?**

You may be asked to have a Fibroscan® (similar to an ultrasound) before you start treatment. A Fibroscan® tells how much damage there is in your liver and can help you decide when to start treatment.

**If I want to start treatment, what should I do next?**

Speak with a member of your healthcare team if you want to start treatment for HCV. It is a good idea to talk about any concerns you have before you start treatment. Your healthcare provider and you will decide if treatment is right for you. Together, we will also check your insurance coverage or assistance programs for medicine costs.
What should I know about my treatment?
- You will have several lab tests while you are on the medicines to check for side effects, to make sure that the medicines are safe and working for you.
- You may need to be available for follow-up visits with your healthcare provider. This will help in managing any side effects.
- **You or your partner cannot become pregnant while taking the medication ribavirin.** Ribavirin can cause serious birth defects. If you are taking ribavirin, you must use 2 forms of birth control: one for you, and one for your partner. An example is a condom for the man, and a diaphragm or birth control pill for the woman. You must keep using 2 types of birth control the whole time you are on combination treatment and for 6 months after your last dose.

What else do I need to know about treatment?
The treatment for HCV is expensive. Many insurance companies cover the medicines. If you are on provincial social assistance, some of the medicines are also covered. If you need help with the medicine costs, please let your healthcare provider know.

What are some side effects of HCV treatment?
There are minimal side effects associated with treatment. However, some possible side effects may include:
  › Feeling tired
  › Nausea or vomiting (throwing up)
  › Feeling anxious, irritable, depressed, or moody (when using ribavirin)
  › Headaches and muscle aches
  › Sun-sensitivity

What lifestyle changes should I make?
Maintaining a healthy lifestyle and normal weight, eating a well-balanced diet, and avoiding alcohol will help. Getting enough rest and moderate exercise can also lead to a feeling of well-being.
Alcohol and your liver

When you drink alcohol, it is absorbed directly into your bloodstream through your stomach and small intestine. When alcohol absorbs into your bloodstream, it can move quickly throughout your body where it affects the function of each cell that it enters. Your liver is the only organ that is used to detoxify (get rid of) alcohol. When there is too much alcohol for your liver to handle at one time, the normal functions of your liver are stopped, which can lead to a chemical imbalance in your body. If your liver is continually being used for detoxification of alcohol, this can lead to liver cells becoming changed or destroyed, which can cause fat deposits, inflammation, or permanent scarring.

What is a healthy, well-balanced diet?

Eating a healthy diet means choosing a variety of foods from the 4 food groups according to Canada’s Food Guide to Healthy Eating.

- Grain products (6-8 servings each day) (for example, bread, cold or hot cereal, pasta, rice)
- Vegetables and fruit (7-10 servings each day) (for example, apples, carrots, cranberry juice, V-8® juice, salad)
- Milk products (2-4 servings each day) (for example, milk, yogurt, cheese)
- Meat and alternatives (2-3 servings each day) (for example, beef, poultry, fish, eggs, beans, peanut butter)

Here are some simple ways that you can make healthier choices to help you feel your best:

- Ask for 1% or skim milk instead of cream in your coffee or tea.
- Look for a “healthy section” on the menu when at a fast food restaurant or ask your server.
- Look for words like ‘grilled’ and ‘baked’ instead of ‘fried’ and ‘breaded’ when eating at restaurants.
- Snack on baked chips or pretzels instead of regular chips or cheese puffs.
- Drink water or black coffee instead of pop.
- Choose non-hydrogenated margarines such as Becel® instead of butter.
- Choose lower-sodium products when available (such as soups, sauces, and crackers).
• Leave canned veggies on the shelf and buy frozen instead.
• Pick lean or extra-lean meats instead of regular cuts (look for white parts – less white on the meat means less fat).
• Try to eat fish at least 2 times per week.
• Try to get at least 30 minutes of activity (exercise) per day.

What about herbal medicines?
Generally, there is little scientific proof to support claims about herbal (or “alternative”) medicines. Herbal medicines may interact with hepatitis C medicines. Possible side effects, exact ingredients, potency (strength), effectiveness, and directions for use may be hard to know. Some herbs and high doses of some vitamins are toxic to your liver, or may cause serious problems to your general health if not taken properly. Tell your healthcare provider about any herbal medicine you are thinking of taking.
Key terms:

**Acute hepatitis C**: This is an inflammation of the liver caused by HCV. It can start suddenly or over time, and rarely lasts longer than 1 or 2 months. Usually, there is little immediate damage to the liver. In rare cases, acute hepatitis C can cause severe, even life-threatening liver damage but often there are no symptoms.

**Antibodies**: Our bodies make these proteins as a natural defense to infections. They attach to the virus and try to destroy it.

**Chronic hepatitis C**: Patients with chronic HCV have the disease for life if it is left untreated. Over a period of time, inflammation continues.

- Stage 1 inflammation: very little inflammation and no liver function damage. The hepatitis C virus invades the liver cells and infects them.
- Stage 2 fibrosis: the infected liver cells get inflamed. Liver cells die and turn into scar tissue.
- Stage 3 bridging fibrosis: among the healthy and inflamed parts of the liver, cell strands of scar tissue form.
- Stage 4 cirrhosis: damage of the liver with a lot of liver cell destruction. Cell damage causes scar tissue in the liver (fibrosis), leading to cirrhosis. In such cases, liver function is lowered. This can lead to liver failure.

**Cirrhosis**: A type of permanent and progressive liver damage. Usually, the liver will try to regenerate (grow back) itself. Any chronic liver disease can lead to scarring. Once present, cirrhosis is permanent, but its progress can be stopped.

**Fibroscan**: A safe and painless way to find out the stage of fibrosis in the liver by measuring the liver’s stiffness with an ultrasound.

**Fibrosis**: Scar tissue that is made after an infection or injury. It can happen in the liver because of long-term inflammation.

**Genotype**: Classification of a virus based on the specific genetic strands of the virus.

**Glucose**: A simple sugar that your cells need for energy. Glucose passes directly into the bloodstream from the small intestine and is stored in the liver as glycogen.

**Infection**: An invasion of body tissues by germs (such as viruses and bacteria).

**Inflammation**: A reaction of your body (such as heat, swelling, redness, or pain) to injury or disease. Inflammation may result from physical damage, infection, or surgery.
**Liver biopsy:** A small piece of tissue is taken out and looked at under a microscope to measure the effects of a disease. A special needle is passed through the skin into the liver to take out a very small piece of tissue.

**Liver enzymes:** A chemical substance made up of protein, which is made by living cells such as ALT (SGPT) and AST (SGOT). Enzymes change the rate of chemical reactions in other substances.

**Platelets:** Disc-shaped structures that float in the blood plasma or fluid and are key to the clotting process.

**Virus:** A type of germ that may cause an infection. It is made of genetic material wrapped up in a protein coat.

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**Online resources**

- www.youtube.com/watch?v=y6osMO5xnag (video)
- http://liver.ca/liver-disease/types/viral_hepatitis/Hepatitis_C.aspx
- www.liverfoundation.org
- www.catie.ca/en/basics/hepatitis-c
- www.cdc.gov/hepatitis/hcv/
- www.who.int/mediacentre/factsheets/fs164/en
- http://harmreduction.org/issues/hepatitis-c