

HEALTHY LIVING with Viral Hepatitis



ACKNOWLEDGEMENTS

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HEALTHY LIVING with Viral Hepatitis

Healthy Living with Viral Hepatitis is a practical guide for people infected with the hepatitis B or hepatitis C **virus**. It also includes information on the hepatitis A virus. Whether you have recently been diagnosed, have been infected with, or affected by one of these diseases for a long time, this booklet can help you learn how to live well with a **chronic** illness. You will find information on how to stay as healthy as possible and how to improve your quality of life. However, this booklet may not be applicable to persons with end-stage liver disease or liver cancer.

Healthy Living with Viral Hepatitis is also a resource tool for **health care providers**. Whether you are a nurse, physician, social worker or community worker, this booklet can equip you to help others enhance their quality of life and minimize potential health complications.

Three appendices at the back of the booklet contain additional information. Words and terms that may be unfamiliar to you are either defined directly in the text or in the glossary (see *Appendix A*). Words that appear in bold red print (like **virus**, above) are defined in the glossary. The glossary-defined words and terms appear in bold red print only the first time they are mentioned in each chapter of the booklet. *Appendix B: Where can I find out more?* provides contact information for various resources and organizations that can help you learn more about viral hepatitis. Finally, *Appendix C: My local contacts* is a tool that can help you keep track of the names and contact information of your health care providers and other local supports.

While this booklet discusses the three most common forms of viral hepatitis in Canada, its main focus is on hepatitis B and hepatitis C because of the chronic nature of these two diseases. It is not the intent of this booklet to discuss treatment options, so the treatment section gives you only a brief overview. If you want to learn more about treatment, you can explore the resources listed in *Appendix B*.

Whatever your situation is right now, *Healthy Living with Viral Hepatitis* is a basic guide to help you find the information and support you need to live well with hepatitis B or hepatitis C.

LIVERight

Liver Canada believes in taking a positive and supportive approach to helping Canadians protect and manage their liver health at every stage of life.

Our LIVERight program highlights the critical role the liver plays in protecting and nurturing the body and seeks to provide positive, preventative and practical advice for optimizing liver health throughout life.

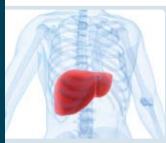
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Section 1

VIRAL HEPATITIS: THE FACTS



What does the liver do?

After the skin, the liver is the body's largest organ and is found just under the rib cage on the right side of your body. The liver is like a large filter; blood passes through it and is cleaned. The liver is also the body's major processor of nutrients found in foods. After food is digested, the nutrients from food go to the liver where important things like proteins and clotting factors that help heal cuts and other injuries, are made. The liver also keeps substances like hormones, sugar and cholesterol at balanced levels in the body. As well, the liver breaks down toxins found in alcohol and drugs.

What is viral hepatitis?

The word "hepatitis" means **inflammation** of the liver. It can be caused by a **virus**, fat in the liver, alcohol, drugs or certain medical conditions. When hepatitis is caused by a virus, the condition is called viral hepatitis.

In Canada, the three most common types of viral hepatitis are caused by the hepatitis A virus, hepatitis B virus and hepatitis C virus. These three viruses are completely unrelated. In general, hepatitis A is a relatively mild viral infection that does not cause a **chronic** disease. Hepatitis B and hepatitis C are serious viral infections that can cause chronic illness leading to liver damage and liver cancer. Although early **symptoms** of all three forms of viral hepatitis may be the same, the ways you can get these infections are different.

In this booklet, we refer to the medical condition as hepatitis A, hepatitis B or hepatitis C, and to the actual virus as hepatitis A virus (HAV), hepatitis B virus (HBV) and hepatitis C virus (HCV).

The time when you first become infected with one of these viruses is called **acute infection**. Acute infection with the hepatitis A virus in adults will almost always appear with symptoms. However, the acute infection stage of hepatitis B or hepatitis C may have no symptoms present, and you may not even know you have been infected.

Common symptoms of an acute viral hepatitis infection include:

- » fatigue (tiredness)
- » lethargy (lack of energy)
- » nausea
- » abdominal pain
- decreased appetite
- » jaundice (yellowish skin and eyes), and
- » dark urine

Hepatitis A

Hepatitis A is most common in countries where food and water may get **contaminated** due to poor hygiene practices. However, occasional outbreaks of hepatitis A do occur in Canada. Hepatitis A does not lead to a chronic illness, but is a potentially serious infection in the elderly and in persons who have **chronic** liver disease. If you were born in a country where hepatitis A is common, you have likely already been infected with HAV. The good news is once you have been exposed to HAV and have recovered, you will develop lifelong protection against it which means you will never get hepatitis A again.

I have hepatitis A. What can I expect?

Not all people infected with HAV will have symptoms. Preschool children often have no symptoms, and, in general, children will have milder symptoms than adults. Symptoms may occur 15 to 50 days from the time you first come in contact with HAV.

Typical symptoms of an **acute** HAV infection include: **fatigue**, **nausea** and vomiting, **abdominal** discomfort, **jaundice** (yellowing of the whites of the eyes and skin), dark urine, **low grade fever** and loss of appetite.

The older you are when you get HAV, the more likely that you will experience more severe symptoms. Some people feel sick for one to two weeks, while in others the symptoms may last several months. Hepatitis A rarely causes death. However, persons with pre-existing chronic liver disease, including chronic hepatitis B and C, are at increased risk of serious complications from this infection.

How did I get hepatitis A?

Hepatitis A is spread through close contact with an infected person, or by eating HAV contaminated food or drinking water. Because the virus is found in the **stool** of infected people, eating food prepared by an infected person, who does not wash his/her hands properly after using the washroom, is one way of getting the virus.

Coping with hepatitis A symptoms

- » You will feel tired and may have very little energy. You may need to take time off from daily activities, work or school to recover.
- » Nausea and vomiting may cause you to lose your appetite. Try to eat small snacks and soft foods such as soup or toast.
- » You may look "yellow". Once you become yellow, you are no longer infectious. There is no need to isolate yourself. Let people around you know it is OK to be near you.
- » Try not to drink alcohol. Your liver may not be able to process alcohol and alcohol may make your symptoms worse.
- » Talk to your doctor before taking over-thecounter medications or complementary medicine. None of the alternative therapies have proved helpful in treating hepatitis A.

You have an increased risk of hepatitis A if you:

- » travel to regions where hepatitis A is common,
- » live with someone who is newly infected with HAV,
- use injection drugs and share contaminated drug preparation/injection materials,
- » are an inmate in jail, or
- » have sex involving oral/anal contact.

Eating raw or undercooked seafood and shellfish from water polluted with sewage, or eating salad greens that are rinsed in contaminated water are other ways of becoming infected. Sharing drug-use equipment, or having sexual contact with an infected person can also give you hepatitis A.

Can I protect myself from getting hepatitis A?

There is a safe and effective vaccine that can protect you from getting hepatitis A. The vaccine is usually given in two doses six months apart. The vaccine will give you protection for up to 20 years. A combined vaccine for hepatitis A and hepatitis

B is also available. Since up to 40% of the reported cases of hepatitis A occur in travellers, it is advisable to protect yourself with HAV vaccination six weeks before you leave.

Consider these additional safety precautions:

- » Wash your hands frequently and thoroughly especially after using the washroom, before preparing food and before eating.
- » Avoid raw or undercooked food.
- » If you are travelling to countries with high rates of hepatitis A:
 - > Drink bottled or boiled water and use it for brushing your teeth
 - > Drink bottled beverages without ice
 - > Avoid uncooked food including salads
 - > Avoid food from street vendors
 - > Peel and wash fresh fruits and vegetables yourself.

How is hepatitis A treated?

There is no drug treatment for hepatitis A. The disease will eventually run its course and an infected person will recover completely although recovery time varies for each person. Recovery from this virus infection means that you are protected for life from getting it again.

Notes:

Hepatitis B

Hepatitis B is common worldwide. In regions where hepatitis B is most common such as countries in Asia and Africa, at least one in five people may be infected with this virus. Hepatitis B is a much more serious infection than hepatitis A. Although many people recover completely from HBV infection, some individuals can carry this virus for life and their liver will slowly be damaged over time. **Chronic** hepatitis B is a "silent" disease because often no **symptoms** appear until your liver is severely damaged. There is no cure for chronic hepatitis B: it can only be controlled by currently available treatments. Fortunately, a safe and effective vaccine exists that can prevent you from getting this infection.

I have hepatitis B. What can I expect?

What happens to you depends largely on the age at which you first become infected with HBV and how well your **immune system** copes with the virus. If you are infected as an adult, you may have a brief illness with mild or moderate symptoms such as **jaundice**, dark urine, **fatigue**, **abdominal** discomfort, and loss of appetite. As an adult, you have a 95% chance of clearing the infection completely and developing lifelong protection against this virus. The **acute infection** rarely (in less than 1% of cases) leads to severe illness that requires a liver transplant.

Most babies and children exposed to this virus never have signs and symptoms. Unfortunately, they are more likely to become carriers of HBV for life because their immune system is unable to fight and clear the virus from their body. In these cases, chronic infections are often not detected or "picked up" until much later in life when the person becomes seriously ill with liver disease.

Chronic hepatitis B infection goes through different phases that also show how well your body is coping with the virus. Although most people with chronic hepatitis B have **inactive disease** and will remain healthy, about one in four will have **active disease** that may lead to **cirrhosis**, liver failure, and liver cancer.

The term "healthy carrier" for people with inactive disease is an old and misleading concept, and this term should not be used. We now know that people who are healthy with inactive disease may still be at risk of **virus reactivation**, especially when their immune system is weakened by medicines such as chemotherapy or by other viral infections.

You will need treatment if you have ongoing active disease that causes a lot of damage to your liver, or if you are going to take medicines that will weaken your immune system.

DIFFERENT PHASES OF CHRONIC HBV INFECTION WHEN ACQUIRED EARLY IN LIFE

Immune tolerance occurs during the early years of the infection. Although you have a lot of hepatitis B virus in your body, your immune system does not recognize that your liver is infected and so does not fight the virus at all. As a result, there is little or no damage to the liver, and you are totally free of symptoms.

Immune damage occurs when your immune system starts fighting the virus which results in damage to your liver. This phase can last for months or years. The longer your immune system fights, the more damage is caused to your liver. Yet, most people will have no symptoms despite active liver damage. Only abnormal blood tests will reveal any liver damage at this stage. You may need treatment if you are in this phase.

Immune control occurs when your body finally takes control of the virus and your hepatitis B becomes inactive. However, not everyone with hepatitis B can reach this phase without treatment.

Immune reactivation happens when the virus becomes active again after a long period of inactivity. Your body can no longer control the virus either because the virus has changed or mutated, or because your immune system is weakened.

How did I get hepatitis B?

A person who has acute or chronic hepatitis B can spread the infection to other people through his/her blood and other body fluids or by sexual contact. HBV is found mainly in the blood, semen, and vaginal fluid of an infected person. Saliva is also a body fluid but the virus concentration is 1,000 to 10,000 times less than what is found in the blood. The ways in which hepatitis B is spread are similar to those for hepatitis C, but the level of risk differs somewhat.

YOU HAVE A HIGH RISK OF HBV INFECTION IF YOU:

- » have unprotected sex with an infected person;
- » have unprotected sex with multiple sexual partners;
- » have a sexually transmitted infection (STI);
- » were born to an HBV infected mother; or
- » use injection drugs and share contaminated drug preparation/injection materials.

YOU HAVE A MODERATE RISK OF HBV INFECTION IF YOU:

- » have siblings or other family members who have hepatitis B;
- » share a household with someone who has hepatitis B;
- » live or travel to regions where hepatitis B is more common;
- » are exposed to blood and body fluids because of your job; or
- » receive bite wounds containing blood from an infected person.

TRANSMISSION OF HEPATITIS B IS NOT ASSOCIATED WITH:

- » coughing, sneezing;
- » touching or shaking hands with an infected person;
- » sharing food, drinks or eating utensils;
- using toilet seats;
- » hugging and kissing; or
- » other casual contact.

Why do I need so many blood tests?

Because hepatitis B has no symptoms until your liver is badly damaged, a blood test is the only way for your **health care provider** to find out if your hepatitis B is active or inactive, and to offer treatment, if needed. To help your health care provider monitor how your disease behaves over time, you will need lifelong repeat blood tests every six to 12 months. If you are receiving treatment for hepatitis B, a blood test every three to six months is very important to tell how well you are responding.

Hepatitis B is also a "dynamic" disease, meaning it may change from active to inactive and vice versa. It is also a complex disease, and interpreting test results may be complicated. Your health care provider may require several blood test results to understand the state of your disease.

Blood tests to identify and evaluate your hepatitis B:

HBsAg (hepatitis B surface antigen) – This test measures the outer "coat" of the virus. A positive result means you have the virus and are potentially infectious. If this test continues to be positive for longer than six months, then you have chronic hepatitis B. A negative test result means you currently do not have the virus.



- Anti-HBs (antibody to hepatitis B surface antigen) This test measures the protective antibody that develops against the hepatitis B virus. A positive result means you are immune to or protected from hepatitis B, either because you have recovered completely from a past infection or because you have received vaccination. You are not infectious, and you will not get hepatitis B again. There are several hepatitis B antibodies, but only the anti-HBs antibody gives immunity.
- Anti-HBc (antibody to hepatitis B core antigen) Hepatitis B core antigen cannot be measured in the blood, but the antibody to this antigen can. A positive result means that you either are currently infected with HBV (the HBsAg test is also positive), or you have been infected in the past and have recovered (the HBsAg test is negative). A negative anti-HBc result means you have never been exposed to this virus. This is the test used by the Canadian Blood Services to screen all blood donors.
- » HBeAg (hepatitis B e antigen) This test measures a protein made by the virus as the virus grows. When this test is positive, you most likely have active hepatitis B. The more hepatitis B virus is in your blood, the more e antigen will be found, and the more infectious you are.
- Anti-HBe (antibody to hepatitis B e antigen) This test looks for the antibody to the e antigen. When your body makes an antibody to the e antigen, it means there is only a little hepatitis B virus left in your body, and therefore, your hepatitis B is presumably inactive. However, some people with a positive anti-HBe test can still have active disease.
- BBV DNA This test tells how much of the active virus is in your blood (the viral load). It is measured in international units (IU/mI) and reported in logarithms (just count how many zeros are in the test result). A viral load less than 1,000 IU/ml or 3 logs is considered not dangerous. A very high viral load (e.g. > 1,000,000 IU/ml or 6 logs) means that you are very infectious but does not always mean you need treatment immediately. HBV DNA viral load testing is a crucial tool to monitor and manage chronic hepatitis B. HBV DNA level can be used to predict the risk of cirrhosis and liver cancer development. HBV DNA test will usually need to be repeated at intervals of three to six months to monitor the progression of the disease. During treatment, HBV DNA tests are frequently needed to monitor response to treatment.
- » HBV genotyping This test can tell what type (or genotype) of HBV you have been infected with. There are eight genotypes of HBV designated from A to H. Having a certain genotype may give you a better response to treatment. This test is not widely available in Canada.

Additional tests to gauge your liver health:

Liver enzymes tests measure the amount of liver damage on the day of the tests. The AST (aspartate aminotransferase) and ALT (alanine aminotransferase) enzymes are made in the liver. When liver cells die, these enzymes leak out of the liver cells into the blood. The higher the number of enzymes, the more liver cells have died. However, these tests cannot tell the specific cause of a liver problem or the extent of the damage to the liver. Sometimes a person may have severe liver disease even with normal liver enzymes.

- Bilirubin, albumin and INR (International Normalized Ratio) These liver function tests tell how well your liver is working. When these test results become abnormal, it means that your liver is deteriorating.
- Hepatitis A If your test result is negative, you should consider getting an HAV vaccine (being immunized) to protect yourself because you do not want to put extra stress on your liver if you do get exposed to HAV at some point.
- Hepatitis C If your test result is positive, you have a co-infection. People infected with both HBV and HCV infections often have more severe liver disease. Your plan of care might be different because of co-infection. There is no vaccine for hepatitis C, so, if you are negative, make sure you take precautions to avoid risky behaviours for getting hepatitis C. (see the chapter on hepatitis C).
- Human immunodeficiency virus (HIV) If your test result is positive, you have a coinfection. People infected with HIV and HBV have a more complicated treatment plan because some medicines can treat both viruses and some cannot.
- Liver biopsy This procedure is done in a hospital. A doctor will use a needle to remove a small piece of your liver to look for inflammation and scarring (or, fibrosis). Most liver biopsy reports will give you a number for the amount of inflammation and another number for the amount of scarring. One commonly used scoring system has a scale from 0 (normal) to 4 (severe) for inflammation, and a scale also from 0 (normal) to 4 (cirrhosis) for scarring. The biopsy results help your health care providers understand the amount of damage done to your liver by the virus as well as by other causes such as fat and alcohol.
- Fibroscan (FS) A completely non-invasive diagnostic instrument to measure fibrosis (scarring) of the liver. FS uses an 'elastic wave' (transient elastography) to measure hepatic stiffness which correlates with fibrosis. FS is based on the premise that as the liver becomes more fibrotic, the tissue density increases and the liver becomes less elastic. FS is easier to perform, safer and less expensive in comparison to a liver biopsy. Measurements with the FS can be taken at multiple locations in the liver whereas a liver biopsy tissue sample is taken from one location in the liver. FS an be used to monitor progression of fibrosis in chronic hepatitis B.

Can I get hepatitis B more than once?

No. You cannot get hepatitis B more than once.

Who should be tested for the hepatitis B virus?

If you have at least one risk factor (risk factors are mentioned in the section above called "How did I get hepatitis B?"), you should ask your health care provider to be tested for HBV. Also, you should be tested for hepatitis B if:

- » you were born in a region where hepatitis B is more common, including Asia, Africa, southern and eastern Europe, the Pacific Islands, the Middle East, and the Arctic;
- » one or both of your parents immigrated from a region where hepatitis B is 13 more common;

- » you live or travel to regions where hepatitis B is more common;
- » you have a family history of liver disease or liver cancer;
- » you have been in prison;
- » you are pregnant;
- » you are a man who has sex with men;
- » you have HIV;
- » you have chronic hepatitis C;
- » you receive kidney dialysis;
- » you have ever used injection drugs, even just once;
- » you have unexplained abnormal liver enzymes; or if
- » you receive medicines that suppress the immune system.

Notes:		

Hepatitis C

Like hepatitis B, hepatitis C is common worldwide. It is also a "silent" disease because, like hepatitis B, often no **symptoms** appear until the liver is badly scarred. Although hepatitis B and hepatitis C are caused by completely different **viruses**, they are similar in how they are spread and how they damage the liver.

I have hepatitis C. What can I expect?

Hepatitis C is an illness where changes happen slowly. For most people, infection will not result in any symptoms, serious disease or death.

When you have just become infected with HCV, you may have no symptoms and may not even know you have been infected. This is the **acute infection** phase and can last from six to eight weeks, or longer. If you have symptoms, they are usually mild and may include **fatigue**, **lethargy**, **nausea**, reduced appetite, **abdominal** pain and **jaundice**.

Over time, the virus may disappear on its own, and you are no longer infected. This happens to approximately 25 out of 100 HCV-infected people. If the virus does not disappear after six months, your infection is **chronic**. This happens to approximately 75 out of 100 HCV-infected people.

If your hepatitis C is chronic, in three out of four cases, you will have only very mild to moderate damage to your liver over time. However, in one out of four cases, chronic hepatitis C can lead to more serious problems including **cirrhosis**, liver failure and liver cancer over a period of 25 to 30 years.

You are more likely to develop cirrhosis if you drink alcohol, are obese, are male, became infected after age 40, have another type of liver disease or have another chronic infection, such as **HIV** or hepatitis B in addition to hepatitis C.

How did I get hepatitis C?

Hepatitis C is spread through blood-to-blood contact, which means that somehow blood infected with HCV got into your blood stream.

YOU HAVE A HIGH RISK OF HCV INFECTION IF YOU:

- use or have used injection drugs;
- » have received blood or blood products or an organ transplant before July 1990 in Canada;
- » have been in jail; or

» have been injected or scratched during vaccination, surgery, blood transfusion or a religious/ceremonial ritual in regions where HCV is common.

YOU HAVE A MODERATE RISK OF HCV INFECTION IF YOU:

- » have a sexual partner infected with hepatitis C;
- » have multiple sexual partners;
- » have a sexually transmitted infection (STI), including HIV or lymphogranuloma venereum (LGV);
- » have experienced traumatic sex or rough sex or have used sex toys or fisting that can tear body tissue;
- » have vaginal sex during menstruation;
- » have received a kidney treatment (hemodialysis);
- » have received an accidental injury from a needle or syringe;
- » have tattoos or body piercing;
- » share personal items with an HCV-infected person (e.g., razors, nail clippers, toothbrush);
- » share cocaine (snorting) equipment;
- » have another infectious disease (e.g., hepatitis B, HIV); or
- » were born to an HCV infected mother. (Pregnancy is not contraindicated, but fetal scalp monitoring or prolonged labour after rupture of membrane should be avoided. Whether C-sections prevent transmission of HCV remains unknown.)

TRANSMISSION OF HEPATITIS C VIRUS IS NOT ASSOCIATED WITH:

- » coughing, sneezing;
- » touching or shaking hands with an infected person;
- » sharing food, drinks, or eating utensils;
- » using toilet seats;
- » hugging or kissing;
- » other casual contact;
- » breastfeeding unless your nipples are cracked and bleeding; or
- » oral sex, unless blood is present.

Why do I need so many blood tests?

Since most people infected with HCV have no symptoms, a blood test is the easiest way for your **health care providers** to look for HCV, other diseases, and ongoing liver damage. The results of these tests will help you decide on your options for treatment.

Blood tests to identify and evaluate your hepatitis C:

Anti-HCV – This test looks for antibodies to HCV. If your test is positive, it means only that you have been infected with the virus at some point in time. It doesn't tell you whether your infection is new, how long you have had it, or if the infection is still present.

- HCV RNA This test can tell if you still have the virus and how much of the virus is in your blood. It is done through a very sensitive method called polymerase chain reaction (PCR), and is reported as a viral load. The viral load does not relate to how severe your disease is: in other words, having a high viral load does not mean you are sicker. This test is very important for monitoring your response to HCV treatment.
- HCV genotyping This test identifies the type (or genotype) of HCV you have. There are six genotypes of HCV, numbered from 1 to 6, and you can be infected with more than one genotype at the same time. In Canada, genotype 1 is the most common but also the most difficult to treat. Genotypes 2 and 3, which are the most easily treated, account for almost all other HCV infections in Canada.

Additional tests to gauge your liver health:

You may be asked by your health care provider to consider *more blood tests* for hepatitis A, hepatitis B and HIV. If you have hepatitis B or HIV, as well as hepatitis C, you have a **co-infection**, and the planning for your medical care will be different than if you are only infected with HCV. If you are co-infected with hepatitis B, your liver disease is often more severe and the plan of care might be different. If you have never had hepatitis A or hepatitis B, you should consider being **immunized** to protect yourself because having either of these infections puts extra stress on your liver.

Your health care providers will also want other blood tests to determine whether HCV is damaging your liver. These tests will include **liver function** and **liver enzymes tests**. Liver function tests are bilirubin, albumin and INR (International Normalized Ratio). These tests tell how well the liver is functioning. When these test results become abnormal, it means that the liver is deteriorating. Liver enzymes referred to as AST (aspartate aminotransferase) and ALT (alanine aminotransferase) are normally found in liver cells. When liver cells die, these enzymes leak out into the blood and can be measured in the blood. However, the levels of these enzymes in the blood cannot tell the specific cause of a liver problem or the extent of the damage to the liver. Sometimes a person may have severe liver disease even with normal liver enzymes.

A liver **biopsy** is another test that your health care provider may order. This is a procedure that is normally done in a hospital. A doctor will use a needle to remove a small piece of your liver to look for inflammation and scarring (fibrosis). Most liver biopsy reports will give you a number for the amount of inflammation and another number for the amount of scarring. One commonly used scoring system has a scale from 0 (normal) to 4 (severe) for inflammation, and a scale also from 0 (normal) to 4 (cirrhosis) for scarring. The biopsy results help your health care providers understand the amount of damage done to your liver by the virus as well as by fat and alcohol.

Can I get hepatitis C more than once?

You are at high risk of HCV *re-infection*, or *coinfection* with HIV, another hepatitis virus or an STI, if you:

- » share contaminated druguse/preparation equipment;
- » get tattoos, piercings, scarification or acupuncture with contaminated equipment;
- share razors, toothbrushes, nail clippers, scissors or anything that could have blood on it;
- » have rough sex where blood is present;
- » have unprotected sex;
- » already have an STI; or
- » have vaginal sex during menstruation.

Although your body's **immune system** makes antibodies to HCV, these antibodies do not protect you. The virus changes so quickly that it escapes your body's defences. This means that you cannot have lifelong protection from hepatitis C. Also, no hepatitis C vaccine exists at this time. If you are treated for HCV and get rid of the virus, you can still be infected again. However, what you do, or do not do, can affect your level of risk for getting hepatitis C again.

Am I alone?

No. As of December 2007, approximately 242,500 persons in Canada were chronically infected with HCV, and an estimated 7,900 persons were newly infected in 2007.

About one third of the people with chronic hepatitis C do not know they are infected and cannot take steps to protect their health and prevent the spread of HCV to others. Many have no symptoms, and so do not know that they need to be tested and, if possible, treated.

Who should be tested for the hepatitis C virus?

Anyone who is worried about having done something that could have put them at risk – even once or a long time ago – should go to a clinic or their health care provider to be tested for HCV.

Anyone with signs or symptoms of having hepatitis C, such as nausea, fatigue, reduced appetite, jaundice, dark urine or abdominal pain should consider being tested for HCV.

Anyone who has resided in countries where hepatitis C is common (e.g., Egypt, southern Italy, India, Pakistan, Vietnam) and has been exposed to blood products, medical procedures, or vaccinations should consider being tested for HCV.

Notes:

Section 2

HOW CAN I LIVE HEALTHY WITH HEPATITIS?

In most cases, both hepatitis B and hepatitis C are illnesses where changes happen slowly, and you may not have symptoms for a long time, if ever.

What can I do now about my health and health care?

Take charge of your health and your health care by learning all you can about your viral infection. **Health care providers** may be experts in some areas and not others, so you may find that you need to approach different people for different things to help you. Get involved in decisions about your health care — ask questions and make suggestions. Remember, your health care providers are experts in their jobs, but you know your body the best.

If you do not have a health care provider, you may find other people or groups can help you. Check out community and regional health centres, street health clinics, outreach services, immigrant health centres, public health clinics or your *Centre local de services communautaires (CLSC)* if you live in Quebec. Once you find a good source of care, try to stay with it, as it will make your health care planning much easier.

What healthy choices can I make?

Your liver has many jobs — from cleaning your blood to turning the food you eat into energy for your body. It can stand a fair amount of stress, even if you have chronic hepatitis B or hepatitis C. You can reduce the stress on your liver by controlling three of its major enemies: alcohol, smoking and too much weight. How you control these three things can seriously affect how your disease progresses in your body.

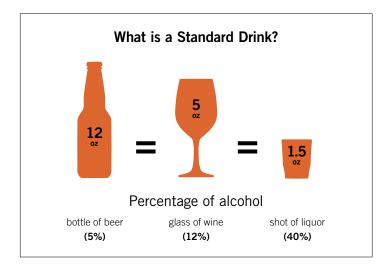
Tips for making the most of your health care appointments

- » Bring with you a list of all the medicines you are taking. Include medicines prescribed by doctors, over-the-counter medicines (these do not need a prescription), herbal remedies, nutritional supplements, vitamins and minerals, and any alcohol or street drugs you are taking.
- » Keep track of your tests and results.
- » Keep a record of your symptoms.
- » Write down questions as you think of them and bring them with you.
- » Bring along a family member, friend or someone who can give you support.
- » Bring a pen and paper so you can write down important information.
- » Ask about the risks, benefits and any side effects before you take any medicine, have a test, take a treatment or have an operation.
- » Never leave an appointment without understanding what was discussed and what your next steps are.

Avoid or limit alcohol

The use of alcohol can cause further damage to your liver more quickly. Two or more drinks a day can increase the rate of scarring in your liver and may speed up the development of **cirrhosis** and liver cancer. If you have hepatitis B or hepatitis C and are receiving treatment, drinking alcoholic beverages will make treatment less effective. Every time you choose *not* to have a drink, you are doing something good for your liver.

What is a "drink"? A drink is a standard "shot" of one and a half ounces of liquor or spirits, a five-ounce glass of wine or a 12-ounce bottle of beer. One type of alcoholic drink is not safer than another. If you have hepatitis B or hepatitis C, or any other form of liver disease, it is best to avoid alcohol completely.



Avoid or limit tobacco

Tobacco harms your lungs and contains several cancer-causing agents. More cancercausing agents are contained in many of the chemicals added to tobacco products when they are made. Smoking increases the risk of liver cancer if you have hepatitis B or hepatitis C. If you have lung disease and your liver disease worsens and causes cirrhosis and liver failure, your chances of a successful **liver transplant** will be much more limited. If you smoke, try to stop. If you need help, talk to your health care provider.

Eat healthy

Healthy eating gives your body and mind the fuel they need to do their work. Your liver processes everything you eat, so eating healthy can help keep your liver healthy. Follow the guidelines in *Eating Well with Canada's Food Guide* (http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php) to give your body the right balance of carbohydrates, protein and fat.

There are no special foods or dietary requirements for living with hepatitis *B* or hepatitis *C* unless you have complications from cirrhosis. If you have severe cirrhosis, and your liver is not working properly, you may need a special diet such as a low-sodium diet to prevent water build up in your body. In this case, talk with your health care provider.

Like everyone else, it is important that you keep your body weight within a normal range for your height to stay healthy. The body mass index (BMI) is a number calculated from

your weight and height that gives you an idea of your body fatness. A BMI between 18 and 25 is healthy, 25 to 30 suggests you are overweight, and over 30 means you are obese.

Besides your BMI, carrying extra inches around your waist is another way of telling whether you are at a higher risk for diseases such as fatty liver disease, heart problems, high blood sugar, and high blood pressure. A waist circumference of 102 cm (40 in) or



more in men, and 88 cm (35 in) or more in women is not healthy. If you are considering dieting to gain or lose weight, talk to your health care provider.

What else can I do to stay healthy?

You can do many things every day that will help to protect your liver from damage and keep you feeling good. Here are some activities and behaviours to think about.

Try to avoid illness

Other viruses, such as hepatitis A and HIV, can make your liver worse. If you have hepatitis C, make sure you are vaccinated against hepatitis A and hepatitis B. If you have hepatitis B, get **immunized** for hepatitis A, but no vaccine for hepatitis C exists. Talk to your health care provider about getting immunized against other diseases such as the flu.

Avoid street drugs

The use of street drugs is not good for your health and can harm your liver. Heavy or moderate use of **marijuana** products may increase scarring of your liver. Injecting, inhaling or smoking drugs with shared equipment may infect you with another type of viral hepatitis or HIV. You can be infected with more than one type of hepatitis C at the same time, and some types are harder to treat than others.

If you do use street drugs, make sure you have your own sterile drug-use equipment (such as syringes, cookers, filters, water, tourniquets, pipes and straws) and never share any of it. Inject yourself rather than having someone else inject you. Do not assume that you are safe from infection if you smoke or snort drugs. Smoking crack or crystal meth can cause swelling and burns on the lips and gums that can lead to bleeding; snorting drugs can cause bleeding in the lining of the nose.

If you need help...

A variety of treatment and support-group programs exist that can help you deal with problems of addiction. Some are based on an **abstinence** approach, while others encourage **harm reduction**. Consider which approach is best for you. For more information, contact your health care provider, employee assistance program, social worker, patient support group, public health unit or the Canadian Liver Foundation (http://www.liver.ca/Home.aspx).

Practising safer sex means:

- » having a lot of condoms easily available and using them when having sex (if you use drugs or alcohol, you may do things that increase your risk of unsafe sex practices);
- » always using a condom when giving or getting oral sex and making sure you do not have Vaseline® or other oil-based products on your lips (it may cause the condom to break); and
- » always using a water-based lubricant with your condoms to reduce the risk of breaks or tears to your skin and to the condoms.

Practise safer sex

Hepatitis B is much more easily spread between sexual partners than hepatitis C. If you have hepatitis B, your sexual partner(s) must be tested and vaccinated against hepatitis B, if they are not already **immune**.

Sexual transmission of hepatitis C in a monogamous, longterm relationship is rare. However, practising safer sex by using condoms helps protect your partners from getting HCV, and protects you from being exposed to other types of viruses and sexually transmitted infections (STIs). If you have an STI, especially those that cause ulcers or sores (such as, herpes and syphilis), you have a greater risk of giving or getting hepatitis C, since blood may be present when you have sex.



If you use street drugs or alcohol, you need to be particularly careful. Drug or alcohol use can cause you to do things you normally would not do – that is, take more risks – around sex, drug use and other things.

Reduce stress

Living with a **chronic** infectious disease can create anxiety, and the added stress can affect your overall health. Find ways to reduce stress, such as adjusting your work schedule or daily activities; pick up a hobby that you enjoy; take up regular exercise; or do something calming such as having a bath, massage or meditating. Do not isolate yourself. Go out and have fun. Do something special for yourself every day.

Get moving

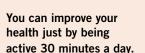
Being active helps your body stay healthy. It helps you manage stress, feel better, and reach and maintain a healthy weight. Being active can also help symptoms like joint pain and **fatigue**. Being active in a way that you enjoy is important. Your choice will depend on how fit you are and how your body reacts to exercise.

Before starting a new exercise program, speak with your health care provider. Whichever activity you choose, start slowly and work your way up. Exercise is about putting time aside just for you, every day.

Get adequate sleep

Not getting enough sleep can make you feel less well overall and can also contribute to general fatigue. If you are not getting any exercise during the day, start being more active

so you will feel physically tired at the end of the day. Do not eat or exercise too close to bedtime. Try relaxation tapes, meditation or deep muscle relaxation to help with sleep. Reading in bed can help relax your mind. If you still have trouble sleeping at night, try taking breaks or naps when you feel tired during the day.



You can even break the 30 minutes into three 10-minute periods throughout the day. For help in getting started, see *Canada's Physical Activity Guide to Healthy Active Living* at http://www.phac-aspc. gc.ca/pau-uap/paguide/index. html

Are prescription medicines and over-the-counter drugs OK?

If you have advanced liver disease or cirrhosis, you should avoid certain medicines including aspirin, sleeping pills and non-steroidal **anti-inflammatory drugs**. Always avoid mixing drugs, especially with alcohol. This includes mixing prescription drugs, over-the-counter drugs, street drugs and alternative medicines. Before taking any medicine, talk to your health care provider to be sure that it is safe for you.

The safety of many herbal therapies has not been established. Some herbal remedies that can be harmful to the liver can be found at the Canadian Liver Foundation web site (http://www.liver.ca/Liver_Health/Medications_and_the_Liver.aspx).

What about toxic substances or fumes?

Many chemicals in our environment have the *potential* to put stress on your liver. However, definite liver damage due to exposure to such chemicals has not been proven. Some chemicals are more **toxic** than others, and if you are exposed to them frequently and in high concentrations, they may be dangerous to your liver. Therefore, it makes sense to try to avoid chemicals such as carbon monoxide, solvents, benzene, carbon tetrachloride and other dry cleaning fluids.

What if I have a mental illness?

If you are taking medicine for a mental illness, make sure that your doctor knows about all your medicines to be sure that the combination of what you are taking is safe. This is particularly important if you are starting treatment. Interferon is one of the treatment drugs for both hepatitis B and hepatitis C, and it can make an existing mental illness worse. As long as your mental illness is being managed, you can receive treatment.

What about my family and friends?

If you have been diagnosed with hepatitis B or hepatitis C, you may worry about passing on the virus to someone else. If you have had hepatitis B or hepatitis C for a long time and did not know it, you may be concerned that you have accidentally infected someone else. Talk to your health care provider about steps you can take to protect your family and friends. It is important to remember that hepatitis B and hepatitis C are not spread by casual contact, such as shaking hands, talking, sharing food and utensils, sneezing or hugging.

To decrease the risk of HBV or HCV infection to others:

- on ot share razors, toothbrushes, nail clippers, scissors or anything else that could have your blood on it;
- » cover any open wounds or sores with a bandage;
- get rid of articles contaminated with your blood (such as, tampons, sanitary napkins, tissues, bandages and needles) by placing them in a protective container;
- » if you inject, snort or smoke drugs, do not share needles, straws or other equipment (like cookers, filters, water) with anyone else;
- » use condoms if you are not in a long-term monogamous relationship; and
- » do not breastfeed if your nipples are cracked or bleeding. (If you have hepatitis B, breastfeeding is safe if the baby has received both protective antibody called immunoglobulin, and the first dose of hepatitis B vaccine within the first 12 hours of life).

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TAKING CARE OF MY FEELINGS

Learning that you have viral hepatitis can cause a lot of different feelings including relief, disbelief, anger, fear, guilt, blame, denial, shame and anxiety. These feelings are a natural part of learning to live with a **chronic** disease. However, if your feelings about having an infectious disease are getting "stuck" or are overwhelming you, talk to a **health care provider** who can help you work through those feelings.

Where can I find support?

Talk to your health care provider (who can also give you a referral to another professional), supportive family members, friends or members of your faith community. Find out if there is a patient support group in your area and check out online support groups (see Appendix B: Where can I find out more?). Remember, you are not alone.

Having some of the symptoms below for more than two weeks may mean that you are depressed:

- » fatigue or a loss of energy, mentally or physically;
- » change in appetite;
- » gain or loss of weight;
- » sleeping all the time or unable to sleep;
- » overwhelming feelings of sadness or fear, or no feelings;
- » decreased interest or pleasure in daily activities;
- » trouble concentrating, remembering or making decisions;
- intense feelings of guilt, helplessness, hopelessness, worthlessness, isolation, loneliness or anxiety;
- more frequent use of alcohol, tobacco or other drugs; and
- » crying a lot or having mood swings.

What if I am depressed?

Depression is one of the most common mental health problems for Canadians in general and is often reported by persons diagnosed with hepatitis C. If you think you have depression, talk to your health care provider.

Interferon treatment for hepatitis B and hepatitis C can sometimes cause depression or make an existing depression worse. If you have a history of depression and are considering treatment using interferon, your doctor may start you on **antidepressant drugs** before or during treatment.

What about my relationships?

Not only do relationships add pleasure to our lives, they can often help us deal with problems. So taking care of your relationships is an important part of taking care of your feelings.

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Will hepatitis change how I feel about myself?

It is important to ask yourself how *you* feel about having hepatitis. Do you feel differently about yourself because you have a chronic illness?

Having a chronic illness can make you feel bad or worried. Such feelings can affect how you act around other people, and they, in turn, may pick up on how you feel and act differently toward you. If you are concerned that the level of distress you feel is more than usual, ask your health care provider for advice.

Will hepatitis change how others feel about me?

Most healthy people can understand things like the flu or cancer, but many do not understand or know enough about hepatitis B and hepatitis C. Some people think they can "catch" the virus from you or that all liver diseases are caused by alcohol or other drug use. They may blame you for having the infection and change the way they act around you. Or, they may be excessively worried about you and treat you as if you could break.

If you are worried about what others think about you, try talking to them. They may just have questions for you or not understand the illness. You may be surprised by how many people are willing to be supportive once they are better informed. And keep in mind that people move in and out of our lives for various reasons – this is normal.

What do they think of me?

If you suspect someone thinks differently about you because you have hepatitis, try asking the person some questions:

- » Do you know anyone else who has hepatitis?
- » Do you know how someone gets hepatitis B or hepatitis C?
- » Are you interested in knowing more about my illness?
- » How do you think your life would be affected if you had hepatitis B or hepatitis C?

Whom should I tell that I have hepatitis?

With a few exceptions, the decision to tell others that you have hepatitis B or hepatitis C rests with you. You make the decision as to whom you tell, when to tell and what you say.

Who is required to know about my hepatitis?

Your local public health department. Your health care provider is required to report your infection to the local public health department. The public health department is required to keep this information confidential. They may contact you to ask for more details or to provide you with information about community health services that can help you. Some provinces and territories require that you tell an insurance company about your infection when you apply for life insurance. In addition, your province or territory may have other rules about whom you must tell about your infection. If you have questions about this, discuss them with a lawyer.

Who should know about my hepatitis?

- Your doctor. It is important to tell all of your doctors. If your doctors know about your hepatitis B or hepatitis C, they will be better able to help you with your health care needs. It is especially important if you have cirrhosis and are going for surgeries. Cirrhosis gives you a higher risk of complications during and after surgery, so you need a special plan of care. If you have hepatitis B, remind your doctor about the infection if you are going to receive medicines that lower your immune system, such as the newer medications for arthritis.
- » Your dentist. It is particularly important to inform your dentist if you have advanced liver disease and a blood-clotting problem. Your dentist will need to check your blood before performing any dental surgeries.
- Anyone who has been exposed to your blood or might be in the future. If there is a risk of someone getting the virus from you (such as your acupuncturist), then it is important to tell him or her. Also, to avoid getting reinfected and to help prevent infecting others, find out how your personal service providers (such as you hairdresser, barber, manicurist, tattooist or acupuncturist) sterilize their equipment.

Should I tell family and friends?

Both hepatitis B and hepatitis C are infectious diseases and you may worry about passing on the virus to someone else. If you have hepatitis B, you must ask all your immediate family members including siblings and parents to be tested and **immunized** if needed. Hepatitis B is much more easily spread especially among household members, and is preventable by vaccines. You are protecting your family by telling them. If you have a steady sexual partner, he/she must also be tested and immunized.

The decision to tell your family can be complicated. It may help to look at each relationship separately.

- » Do your *parents* cope well with stressful information? Will you feel reassured or worried if you tell them?
- » Can you think of any reason not to tell your partner about your hepatitis?
- » Even though the rate of transmission of HCV by sexual contact is considered to be very low, sexual partners must decide for themselves about routine condom use.
- » If, and what, you tell your children will depend on how old they are and how well they deal with difficult situations. In general, if children understand what is happening, they can adjust.

The decision to tell your friends about your infection can be difficult . Hepatitis B and hepatitis C are not spread by casual contact such as touching or shaking hands, sharing cups or toilets, sneezing or coughing. Think about how telling your friends might impact your relationships. Consider how close you are, how well your friends keep things private and how open they are with you about things going on in their own lives. You may be reluctant to tell someone for fear they will reject you or treat you differently. Sometimes this happens but often friends will want to offer support.

Should I tell anyone at work?

For most people, there is no reason to tell anyone at work about having a viral infection. However, if what you do at work could put others at risk of coming in contact with your blood (for example, you are a health care provider), you must speak with your employer, your workplace health advisor, your occupational health and safety representative, or your professional or occupational association if you have one. You can also call the public health department in your area for advice.

Time to adjust

Like you, your family and friends may need time to adjust to how they feel about you having hepatitis. They will have their own concerns about your well being and their risk of contracting the virus from you. Their concerns may be similar to yours.

Let your family and friends know that just because you have an illness, it does not change who you are as a person and you are still able to support them. If your illness does limit the things you can do, talk about it with them; let them know what you can and cannot do. Make sure you, your family and friends get plenty of information about your disease.

If you do tell your employer or colleagues and then you feel you are being unfairly treated in the workplace, you can ask for help from your Human Resource services, supervisor, union representative or local Canadian Human Rights Commission office. It is illegal in Canada to discriminate against people because they have an infectious disease.

How do I tell people I have hepatitis?

If you decide to tell someone you have hepatitis B or hepatitis C, find the right place for the conversation. It can be easier to talk about something important if you are in a quiet place that is comfortable and has few distractions. It is probably best to wait until both you and the other person are calm. If you present the information in a calm and non-alarming manner, it is more likely to be received in the same way.

Whom should I tell?

Consider these questions:

- » Am I required by law to tell?
- » Has this person been exposed to my blood? May they be?
- » Will telling allow the person to provide me with better care or support?
- » Will telling affect our relationship?
- » How well does this person keep personal information private?

TAKING CARE OF MY SYMPTOMS

Most people with **acute** hepatitis B or acute hepatitis C have no **symptoms**. If you do have symptoms, they will likely be mild and may include **fatigue**, **lethargy**, **nausea**, reduced appetite, **abdominal** pain and **jaundice**.

Most people with **chronic** hepatitis B or chronic hepatitis C also have no symptoms. But you may have, or may develop symptoms and feel unwell. Your symptoms may be very similar to those for other illnesses or they may be difficult to identify and describe. For this reason, it can sometimes be hard for **health care providers**, family members and friends to understand your symptoms. If this happens, encourage them to learn more about your illness.

The most commonly reported symptom of chronic hepatitis C is fatigue. If you have chronic fatigue, you may feel tired or have no energy, or you may be so tired you have trouble getting through the day. You may also feel not energized or refreshed when you get up in the morning. Regular exercise is the best way to deal with this symptom. Healthy eating can also help you feel less fatigued. The feeling of fatigue may also improve following successful HCV treatment.

Other symptoms some people have are listed on the following page, along with tips for dealing with them. If you have these symptoms and plan to use over-the-counter medicines to treat them, speak to your health care provider before taking anything.

What are some of the *less common* symptoms of chronic hepatitis?

Rarely, other parts of the body are affected by HCV, including the skin, kidneys, blood vessels, thyroid gland, nerves and lungs. If they are affected, the resulting conditions are probably related to the hepatitis C virus itself or to your **immune system's** reaction to the virus. These problems may cause skin rashes, arthritis, weight gain or loss, kidney problems and numbness and tingling in your arms and legs. If you have these symptoms, you should discuss them with your health care provider.

What are the symptoms of advanced liver disease (cirrhosis)?

If your liver gets very scarred and starts to work poorly, you may start to have a variety of symptoms. But many people who have **cirrhosis** live for years without ever developing a problem. In fact, one in four people with hepatitis B cirrhosis, and one in 20 people with hepatitis C cirrhosis will develop one or more of the following problems:

- Fluid retention means that fluid may collect in your legs or abdomen. You may experience swelling of your ankles and abdomen, which can make you feel less hungry due to the pressure of the fluid on your stomach, or shortness of breath due to the pressure of the fluid on your lungs. This happens when your kidneys are absorbing too much salt and water. Your health care provider will tell you to cut down on the amount of salt you eat, and may start you on water pills.
- Internal bleeding is usually caused by swollen veins in the esophagus or stomach. Signs of bleeding can be vomiting blood (looks bright red or dark like coffee grounds) or passing stool with blood in it (looks like black, tar-like material). If you have this kind of bleeding, get medical attention immediately. You can die from too much bleeding.
- » Hepatic encephalopathy happens when the liver is so damaged it can no longer clean out harmful things from your body. Your brain starts to be affected and you can become very confused, sleepy or even go into a coma. Being **constipated**, having other infections, taking sleeping medicines or being **dehydrated** can lead to this condition.
- » Other symptoms of end-stage liver disease include jaundice, severe fatigue, muscle wasting, and easy bruising or bleeding. If you have any of these symptoms, let your health care provider know right away. These symptoms may mean a liver transplant should be considered due to the seriousness of your liver disease.

Symptom	What It Feels Like	Tips for Dealing with This Symptom
Nausea	Feeling sick to your stomach, like you want to throw up.	Try drinking frequent sips of water. Try eating small amounts of crackers or dry toast. Try beverages that contain ginger.
Reduced appetite	Not feeling hungry or not wanting to eat. This symptom may go along with depression, mood swings and a lack of sleep.	Eat smaller more frequent meals that are high in protein (meat, cheese or eggs). Try fruit and veg- etables as snacks. Exercise regularly.
Sore muscles and joints	Aches and pains like you get with the flu, but there are no visible changes in your joints, such as swelling, tenderness or redness.	Try regular exercise and get ade- quate sleep. Talk to your health care provider before taking any medi- cines. Many arthritis pills are bad for you if you have advanced disease.
Abdominal discomfort over the liver	Aching in the stomach area, either a feeling of pressure or a dull ache.	Be sure to talk to your health care provider to exclude other causes such as gallstones.
"Brain fog"	Difficulty concentrating or remembering things. Feeling "spaced out."	Try not to get frustrated if you can- not remember something. To help, write down important information.

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TAKING CARE OF MY FUTURE

Generally, **chronic** hepatitis causes changes in your body slowly over time. Most people diagnosed with hepatitis B or hepatitis C have many years of a healthy life ahead of them. However, having a chronic disease can create changes in your life. For example, if you have hepatitis B and are in need of long-term treatment, finding the money to pay for the drugs can be a challenge if you do not have a drug plan. Now is the time to think about what those changes may be.

Find out ahead of time about your options for dealing with life changes. It takes time to get support systems in place. It is best to be prepared and to know what you need to do before you really need the help. Think about what your income and housing needs might be in a few years, and how you will meet them. Ask your **health care provider**, employer, social assistance worker, social worker, community worker or someone in your support group to help you find the resources you need.

What if I want to keep working?

Having hepatitis or even **cirrhosis** may not prevent you from working. In fact, you should continue to work for as long as you can or want to. Some employers offer flexible work schedules or provide job-sharing and part-time work. This means you can still work and earn some money, but you work fewer hours. Many employers belong to an Employee Assistance Program (EAP) and provide free counselling services to employees. Contact your benefits advisor at your workplace for details on how to access this support.

What if I may not be able to afford my house or apartment?

If your financial circumstances change, rent and mortgage payments may become difficult to manage. If you think that your housing situation will be affected because your income will be less, check into your options before you need them. Your banker or financial advisor may be able to provide options to you.

Where can I find financial assistance?

- » Employment Insurance (EI): Eligibility for EI varies between provinces and territories. Check with your benefits advisor at work or contact Service Canada.
- » Disability programs: Programs may be available to you through your employer or through the Canada Pension Plan (CPP) or Quebec Pension Plan (QPP). Check with your benefits advisor at work or contact Service Canada or Régie des rentes.
- » Social assistance: Each province and territory has different qualifications and supports for welfare and other income supports. For more information, contact your local benefits office.

If you are living on a fixed or low income, different types of subsidized or geared-to-income rental housing may be available in your community. Talk to the person who helps with your social benefits to get information on what is available and appropriate for you in your community. Look into these options before you need them as **social housing** programs often have waiting lists.

What if I need help but want to stay at home?

If you become very sick or have difficulty getting dressed, walking or bathing, you may be able to have a nurse or home care provider come to your home so you do not have to go to hospital. A nurse may be able to arrange for other supports to allow you to stay at home. Talk to your health care provider who can arrange home care services.

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IS TREATMENT FOR ME?

You may not now, or ever, need treatment for your viral hepatitis. But if you do, effective treatments are available for both chronic hepatitis B and chronic hepatitis C.

Treatment for chronic hepatitis B

Currently two types of treatment exist: interferon which is a medication administered by a needle, and antiviral medicines that are taken as a pill. Current approved hepatitis B oral medications include lamivudine, adefovir, telbivudine, tenfovir, and entecavir. These treatments do not provide a cure, but they offer control of the virus so that further damage to your liver can be prevented.

Treatment for chronic hepatitis C

Since 2010, enormous progress has been made in treatment of chronic hepatitis C. New therapies called direct acting antivirals (DAAs) are pills that act on the virus itself to eradicate it from the body, unlike older medicines like interferon injections which work by stimulating an immune response. These new treatments are very effective and can achieve cure rates of over 90%. In most situations now, there is no need for interferon, which was responsible for many of the side effects previously associated with HCV treatment. The new treatment combinations require shorter treatment durations (between 8 to 24 weeks), have reduced side effects and appear to be effective at all stages of the disease.

If you and your health care provider think treatment is right for you, consider and discuss the following questions.

What is the current treatment? What are the options for treatment?

- » What does treatment involve?
- » How long does treatment take?
- » How do I prepare for treatment?

How effective is treatment?

- » How does my genotypeaffect my chances for effective treatment?
- » How does infection with other viruses (such as HIV) affect my chances for effective treatment?
- » How will I know if treatment has been successful?
- » Does successful treatment mean a "cure"?

What are the side effects of treatment?

- » Will treatment disrupt my life?
- » Can I still work during treatment?
- » What if I become depressed during treatment?
- » What can I do if I develop side effects while on treatment?

Am I a candidate for treatment?

- » How do alcohol and other drugs affect my ability to be treated?
- » How does mental illness affect my ability to be treated?
- » Are there any diseases that will prevent me from being treated?
- » Can I become pregnant and/or breastfeed during treatment?
- » Am I ready and motivated to take treatment? Is this the right time for me?
- » Do I have the necessary supports in place?

How do I get treatment?

- » Who provides treatment and where is it done?
- » How do I pay for treatment?
- » Do I need a liver biopsy before treatment?
- » How will I be looked after during treatment?

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Section 7

WHAT ABOUT ALTERNATIVE THERAPIES?

Some practices and products that claim to help you live better with **chronic** viral hepatitis are not considered "regular" medicine. These "alternative" therapies or medicines are most often not available from your traditional **health care provider** (your doctor), but can be obtained from naturopaths, oriental medicine providers, holistic medicine providers or nutritionists.

As of late 2006, no alternative therapy has been proven safe and effective for treating hepatitis B or hepatitis C. This includes all herbal remedies, **homeopathic** medicines,

vitamins, minerals, traditional medicines, probiotics and other products reviewed by Health Canada.

Do alternative therapies work? Are they safe?

Most alternative therapies have not been tested in the same way as regular medicines. The information about alternative therapies mostly comes from the experience of individual therapists and their patients. As a result, the safety and effectiveness of alternative therapies is not certain. Like any medicine, alternative therapies may not react well with your other medicines. Remember, some herbal remedies may even be toxic to the liver. Treat alternative therapies like you would any other drug; be sure to tell your health care provider what you are taking.

How do I choose an alternative therapy?

Learn as much as you can about how alternative therapies are used as well as their possible benefits and risks. Be careful of claims that one therapy can "cure" a wide range of unrelated diseases (such as, cancer, diabetes and acne). No one product or treatment can treat every disease and condition. Also, beware of a claim that a therapy has no side effects. It may mean that no one has carefully looked for them in patients.

Things to consider as you look for an alternative therapy:

- » What do I expect from this therapy? Are my expectations reasonable?
- » What scientific studies have been conducted on the safety and effectiveness of the therapy?
- » What are the common and serious side effects of this therapy?
- » Will the therapy interfere with my daily activities?
- » Has Health Canada approved this therapy? If not, why not?
- » Will this therapy react badly with any prescription or over-the-counter medicines that I take? With my viral hepatitis treatment?
- » How long will it take before I see results from the alternative therapy?
- » How much does it cost? Is it covered by the provincial or territorial health plan?
- » What are the ingredients?

How do I choose an alternative therapist?

Choose an alternative therapy provider the same way you would choose any other health care provider. Most alternative therapists are not regulated by provincial or territorial laws, so you will want to learn as much as possible about their training and qualifications. You may also want to know how long the therapist has been working and if he/she belongs to any professional association. Look for a therapist with a good understanding of viral hepatitis and its symptoms.

How should I choose an alternative therapy product?

Health Canada has developed Natural Health Products Regulations, which apply to herbal remedies, homeopathic medicines, vitamins, minerals, traditional medicines, probiotics, and other products like **amino acids** and **essential fatty acids**. Look for a Drug Identification Number (DIN), a Natural Product Number (NPN) or a DIN-HM (for homeopathic remedies) on the product label. If you see one, you know the product has been assessed for its quality, safety and efficacy by Health Canada.

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Appendix A

GLOSSARY

Abdomen (abdominal): The middle front part of the body between the ribs and legs; it includes the stomach and liver.

Abstinence approach: An approach to help people stop using drugs or alcohol completely.

- Active disease: A disease that is in a state of inflammation causing damage to the liver.
- Acupuncture: A treatment where small needles are stuck into the skin at specific points, usually to help relieve pain.
- Acupuncturist: A person who is trained in acupuncture.
- Acute infection: An illness/infection that comes on quickly and usually does not last too long.
- Amino acids: A building block of proteins used by the body.
- Antibody (antibodies): Blood proteins the body makes in response to an antigen.
- Anti-depressant drugs: Drugs prescribed to treat depression.
- Antigen: A part of the virus or toxin that stimulates your immune system to produce antibodies.
- Anti-inflammatory drugs: Drugs that help settle down inflammation or swelling.
- Antiviral medicines: Drugs that work against viruses.
- **Biopsy**: The removal of a small sample of tissue to look for signs of disease.
- Brain fog: Difficulty concentrating or remembering things; feeling "spaced out", "unclear" or "foggy".
- Cholesterol: A fat-like substance made by the body and found naturally in animal foods, such as meat, fish, poultry, eggs and dairy products.
- **Chronic**: Something that continues over a long period of time.
- Chronic illness/infection: An illness that lasts for at least several months, sometimes for several years or a lifetime.
- **Cirrhosis**: Very bad scarring of the liver that affects how the liver works.
- **Co-infection**: Being infected with more than one virus at a time.
- **Constipation** (constipated): Having difficult or less frequent bowel movements because the stool is hard and dry.
- **Contaminated**: Something that contains, or has touched, bacteria or a virus.
- Dehydration (dehydrated): Not having enough fluids in the body.

- **Esophagus**: The tube that runs from the throat to the stomach; food travels down the esophagus.
- **Essential fatty acids**: A group of fats the body needs to stay healthy, which must be taken in the form of food or supplements.
- Fatigue: Feeling very tired or weary; exhaustion.
- Fluid retention: Having too much fluid collect in the tissues of the body; often causes swelling.
- **Genotype**: A way of describing small differences that occur in the genetic makeup of the hepatitis B virus and the hepatitis C virus.
- **Harm reduction**: Techniques that help people change the way they use alcohol or drugs to cause them less harm.
- **Health care provider(s)**: The professionals who help people take care of their health. They can include doctors, nurses, nurse practitioners, counsellors and social workers.
- Hemodialysis: A way of cleaning the blood, with the help of a special machine, once the kidneys can no longer do the job.
- **Hepatic encephalopathy**: Confusion or changes to the way a person acts or thinks that is caused by the liver failing to properly clean the blood before it goes to the brain.
- **Homeopathy** (homeopathic): Treating a disease by taking (usually through the mouth or skin) small amounts of substances (such as herbs or drugs).
- Hormones: Chemicals released by cells that affect cell metabolism.
- **Human immunodeficiency virus (HIV)**: The virus that causes AIDS. It attacks the immune system, making it harder for the body to fight disease.
- **Immune**: Having or producing antibodies capable of defending your body against bacteria, viruses, and substances that are harmful to the body.
- **Immune system**: The complex way the body's parts work together to fight disease. The immune system's job is to look for, and get rid of, bacteria and viruses that do not belong in the body.
- **Immunity**: Resistance of an organism to infection or disease.
- Immunization (immunized): A way of making a person's immune system able to recognize and prevent infection. A person is usually immunized, or vaccinated, using a needle, but sometimes the vaccine can be swallowed.
- **Inactive disease**: The disease is not progressing or increasing; or the progress is slow.
- **Inflammation**: The body's response to injury or infection causing pain, redness, heat, and swelling in the area.
- **Internal bleeding**: Bleeding inside the body that may not be obvious because the blood cannot be seen.
- Intranasal: Inside the nose.

Jaundice: Yellowing of the whites of the eyes and skin.

- Lethargy: When a person does not want, or feel able, to do much of anything.
- Liver enzyme tests: Liver enzymes (AST and ALT) are made in the liver cells and leak out in the blood when liver cells are damaged. These tests indicate the amount of inflammation in the liver.
- Liver function tests: Tests to determine how well the liver is working. These tests include INR (blood clotting factor), albumin (protein) and bilirubin.
- **Low-grade fever**: A continuous or fluctuating oral temperature that is above 37° C (98.6°F) but lower than 38° C (100.4° F).
- Marijuana: A psychoactive drug produced from parts of the Cannabis plant. It is also called cannabis, weed, ganja or hashish.
- Monogamous: Sex with only one partner.
- Mucosa: The lining inside the body such as the lining of the mouth.
- **Muscle wasting**: Shrinking or weakening of the muscles that can make a person feel less strong and appear skinny.
- Nausea: Feeling sick to the stomach or the need to throw up.
- **Probiotics**: Non-food items that contain bacteria or yeast that are believed to help the body, particularly with digesting food.
- **Proteins**: One of three major sources of food energy that are contained in meat, eggs, dairy products and some vegetables.
- **Risk factors**: Habits, traits or conditions in a person or the environment that are associated with increased chance of disease.
- Scarification: Making cuts and scratches in the skin to produce scars, usually for decoration.
- **Social housing**: Housing that is owned by a government or a not-for-profit organization rather than a private landlord.
- Sterile (sterilize): Something that has no bacteria, viruses or any other substance that can cause disease.
- **Stool**: The waste the body expels through the bowels; a bowel movement.
- Sexually transmitted infection (STI): A disease that is transmitted person to person, through sex, including vaginal, anal and oral sex.
- **Symptoms**: The body's signs that a person has an illness.
- **Toxic**: Capable of causing injury especially by chemical means.
- **Toxins**: A poisonous substance produced by living cells and organisms or found in the environment.

Transplant: Replacing a damaged organ, such as a heart, liver, or lung, with a healthy one taken from another person's body.

Traumatic (rough) sex: Sex that results in breaking or tearing the body's tissues that put a person at risk of infection.

Virus: A form of life too small to see, even with a microscope, that causes disease.

Virus reactivation: When the virus becomes active from an inactive state.

Vitamins: Vitamins are organic compounds required as nutrients in tiny amounts by an organism.

Notes:	

WHERE CAN I FIND OUT MORE?

For more information and resources on all forms of liver disease including viral hepatitis, or to obtain additional copies of this booklet, please contact:

Canadian Liver Foundation (CLF) Toll-free number: 1-800-563-5483 Email: clf@liver.ca http://www.liver.ca

There are many other useful resources available on hepatitis A, B and C. Some to consider include:

Canadian Hemophilia Society (CHS) Toll-free: 1-800-668-2686 Email: chs@hemophilia.ca http://www.hemophilia.ca

Health Canada (HC)

http://www.hc-sc.gc.ca/

Safe Use of Natural Health Products http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/med/nat-prod-eng.php

Health Promotion Approach: Natural Health Products and Complementary and Alternative Health care http://www.hc-sc.gc.ca/dhp-mps/pubs/complement/index-eng.php

Public Health Agency of Canada (PHAC)

http://www.phac-aspc.gc.ca/hepc/ Primary Care Management of Chronic Hepatitis: Professional Desk Reference – 2009 http://www.phac-aspc.gc.ca/hepc/pubs/pdf/hepc_guide-eng.pdf Hepatitis C – get the facts http://www.phac-aspc.gc.ca/hepc/pubs/getfacts-informezvous/pdf/hepc-brochure-eng.pdf

To obtain additional copies of this booklet, or for more HIV and hepatitis C information or resources, please contact:

CATIE (Canadian AIDS Treatment Information Exchange) Email: info@catie.ca (CATIE Ordering Centre Number: ATI-30024) http://www.catie.ca/ http://www.hepcinfo.ca/

Canadian Association of Hepatology Nurses (CAHN) http://www.cahn.ca/

Canadian Association for the Study of the Liver (CASL) http://www.hepatology.ca Management of Chronic Hepatitis B: Consensus Guidelines 2007 Management of Chronic Hepatitis C: Consensus Guidelines 2007

Canadian Centre on Substance Abuse (CCSA) http://www.ccsa.ca

Canadian Human Rights Commission (CHRC) http://www.chrc-ccdp.ca

Canadian Institutes of Health Research (CIHR) http://www.cihr-irsc.gc.ca/e/4601.html

Canadian Mental Health Association (CMHA) http://www.cmha.ca/bins/index.asp

Canadian Nurses Association (CNA) http://www.cna-aiic.ca/ Hepatitis C: A Nursing Guide http://www.cna-nurses.ca/CNA/documents/pdf/publications/Hep_C_2002_e.pdf

Centre for Addiction and Mental Health (CAMH) http://www.camh.net

College of Family Physicians of Canada (CFPC) http://www.cfpc.ca

Dietitians of Canada http://www.dietitians.ca

National Association of Friendship Centres (NAFC) Hepatitis C Information Manual http://nafc.ca/PDF/HepCManual.pdf

Service Canada http://www.servicecanada.gc.ca

Disability programs: *These may be available to you through your employer or through the Canada Pension Plan (CPP) or Quebec Pension Plan (QPP)* 1-800-277-9914 (English), 1-800-277-9915 (français) Régie des rentes Quebec 1-800-463-5185

Employment Insurance (EI): Eligibility of El varies among provinces/territories. Check with your benefits advisor at work or contact: 1-800-206-7218 (English), 1-800-808-6352 (français)

Social assistance (welfare)

Each province and territory has different qualifications and supports for social assistance (welfare or other income supports). For more information, contact your local social benefits office.

Society of Obstetricians and Gynaecologists of Canada (SOGC)

The Reproductive Care of Women Living With Hepatitis C Infection http://www.sogc.org/guidelines/public/96E-CPG-October2000.pdf

Notes:			

Appendix C

MY LOCAL CONTACTS

	Name	Telephone
Doctor		
Nurse		
Social worker		
Community support – outreach worker		
Community health centre		
CLSC (QC)		
Canadian Liver Foundation		
Drop-in clinic		
Public health department		
Support group		

	Name	Telephone
Social assistance worker		
Disability worker		
Employment Insurance (EI) office		
Employee Assistance Program (EAP) counsellor		
Pharmacist		
Dietitian		
Alternative therapist		



Healthy Living with Viral Hepatitis

To obtain additional copies, please contact

Liver Canada

National Office, 2235 Sheppard Avenue East, Suite 1500, Toronto, ON M2J 5B5 Tel: 416-491-3353 Toll-free: 1-800-563-5483 Fax: 416-491-4952 Email: clf@liver.ca www.liver.ca

This publication is also available online at www.liver.ca.

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Ce document est également disponible en français.

