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HEALTHY LIVING

with Hepatitis C

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ACKNOWLEDGEMENTS

Project Steering Committee Members

Ms. Kazimiera Adamowski
Mr. Rob Boyd
Ms. Gail Butt
Dr. Brian Conway
Ms. Hannah Cowen
Dr. Joseph Cox
Dr. Lisa Graves
Ms. Lynn Greenblatt
Ms. Geri Hirsch
Dr. Samuel Lee
Dr. Bruce Marshall
Mr. Michael McGee
Dr. Len Moore
Ms. Josephine Muxlow
Dr. Gilles Pinette
Ms. Andrea Poncea

Contributors

Mr. Rob Boyd
Dr. Joseph Cox
Ms. Geri Hirsch
Ms. Cathy Latham-Carmanico
Dr. Samuel Lee
Ms. Deirdre Maclean
Dr. Rob Myers
Dr. Michael Vallis
Ms. Colina Yim

HEALTHY LIVING
with Hepatitis C

Healthy Living with Hepatitis C is a practical guide for people infected with the hepatitis C **virus**. Whether you have recently been diagnosed, have been infected with, or affected by the disease for a long time, this booklet can help you learn how to live well with this **chronic** liver disease. 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 and liver cancer.

Healthy Living with Hepatitis C 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 that may be unfamiliar to you are defined in a glossary (see *Appendix A*). Any word in red bold print (like **chronic**, above) is defined in the glossary, and it will be bolded only the first time it appears in the text. *Appendix B: Where can I find out more?* lists contact information for various resources and organizations that can help you learn more about hepatitis C. Finally, *Appendix C: My local contacts* provides 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 treatment briefly, this is not its focus. If you would like to learn more about treatment, you can explore the resources listed in *Appendix B*. Whatever your situation is right now, *Healthy Living with Hepatitis C* is a basic guide to help you find the information and support you need to live well with hepatitis C.

Remember hepatitis C is an illness where changes happen slowly. The disease can be managed and, in many cases, treated successfully.

LIVERight™

The Canadian Liver Foundation 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.

To learn more about LIVERight, please visit www.liver.ca.

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HEPATITIS C: THE FACTS

What is hepatitis?

"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. Early **symptoms** of all three may be the same, but the ways you can get these infections are different.

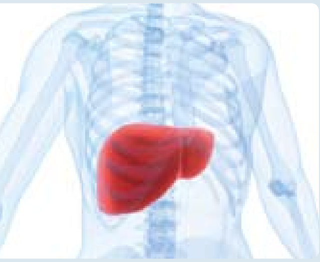
- Hepatitis A virus (HAV) is usually spread by swallowing food, water or other liquids **contaminated** with the virus; it is found in the **stool** of infected people.
- Hepatitis B virus (HBV) is spread through contact with the blood or other body fluids (such as **vaginal fluids**, **semen**) of an infected person.
- Hepatitis C virus (HCV) is spread by blood-to-blood contact with an infected person's blood.

In this booklet, we refer to the medical condition as hepatitis C and to the actual virus as hepatitis C virus or HCV.

I have hepatitis C. What can I expect?

Remember that 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, this is called **acute infection** and can last from six to eight weeks, or longer. At this early stage, you may have no symptoms and may not even know you have been infected. 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 40 out of 100 HCV-

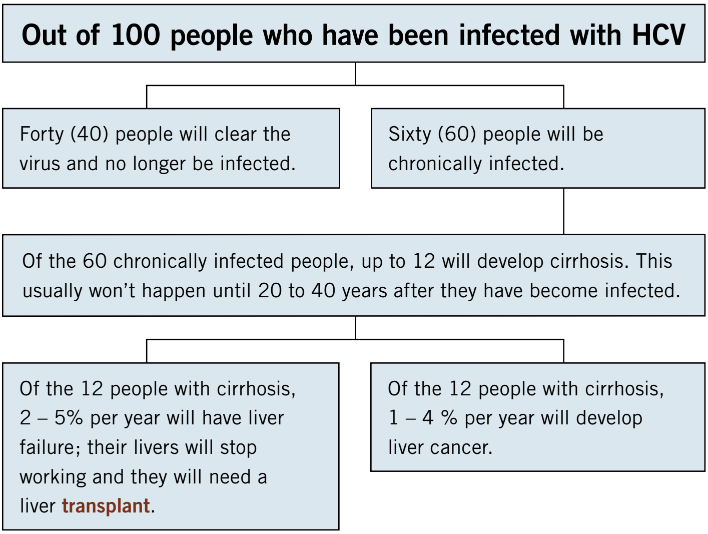


What does the liver do?

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. Most of the damage to the body caused by hepatitis C occurs to the liver. The liver is like a large filter; blood passes through it and is cleaned. The liver is also the body's major factory. After food is digested, it goes to the liver where important things like proteins and clotting factors that help heal cuts and other injuries, are made. The liver also keeps things like hormones, sugar and cholesterol at balanced levels. As well, the liver breaks down **toxins** found in alcohol and drugs.

infected people. If the virus does not disappear after six months, your infection is chronic. This happens to approximately 60 out of 100 HCV-infected people.

If your hepatitis C is chronic, in most cases you will have only very mild to moderate damage to your liver over time. In a few cases, however, chronic hepatitis C can lead to more serious problems including **cirrhosis**, liver failure and liver cancer.



Out of 100 people who have been infected with HCV

Forty (40) people will clear the virus and no longer be infected.

Sixty (60) people will be chronically infected.

Of the 60 chronically infected people, up to 12 will develop cirrhosis. This usually won't happen until 20 to 40 years after they have become infected.

Of the 12 people with cirrhosis, 2 – 5% per year will have liver failure; their livers will stop working and they will need a liver **transplant**.

Of the 12 people with cirrhosis, 1 – 4 % per year will develop liver cancer.

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 **human immunodeficiency virus (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 HAVE:

- used injection drugs;
- received blood or blood products or an organ transplant before July 1990;
- received kidney treatment (**hemodialysis**);
- been in jail;
- received an accidental injury from a needle or syringe;

- been injected or scratched during vaccination, surgery, blood transfusion or a religious/ceremonial ritual in countries of the world where HCV is common;
- received tattoos or body piercing;
- shared personal items with an HCV-infected person (e.g., razors, nail clippers, toothbrush);
- shared intranasal (snorting) and inhalation drug use equipment;
- another infectious disease (e.g., hepatitis B, HIV);
- undiagnosed liver disease;
- children born to HCV infected mothers.
  (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.)

YOU HAVE A *MODERATE* RISK OF HCV INFECTION IF YOU HAVE:

- had a sexual partner infected with hepatitis C;
- had multiple sexual partners;
- had a **sexually transmitted infection (STI)**, including HIV or lymphogranuloma venereum (LGV);
- experienced **traumatic sex** or **rough sex** or have used sex toys or fisting that can tear body tissue;
- had vaginal sex during menstruation.

TRANSMISSION OF HEPATITIS C VIRUS IS *NOT* ASSOCIATED WITH:

- coughing;
- sharing food and water supplies;
- sharing eating utensils;
- hugging or kissing;
- shaking hands;
- using toilet seats;
- other casual contact;
- breastfeeding unless nipples are cracked and bleeding;
- 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 health care providers to look for HCV and other diseases. The results of these tests will help you decide on your options for treatment.

- The *Anti-HCV 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 show whether your infection is new, how long you have had it, or if the infection is still present.

- The *HCV RNA tests* can tell if you still have the virus and how much of the virus is in your blood. They are used to qualify and quantify the viral material in your blood. A qualitative test gives you a positive or negative result, and is the most sensitive test with a very low cut-off value. A positive test result means that you still have the virus infection. A quantitative test tells you how much of the virus (**viral load**) is in the blood. However, the level of virus in your blood does not relate to how severe your disease is. In other words, a person with a high viral load does not mean he/she is more sick. Both test methods are also used for monitoring response during treatment. It may take several weeks for the results to be reported back to your health care provider.

- The *HCV genotyping test* can tell what type (or **genotype**) of HCV you have. There are six common 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.

- 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 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 and can be measured in the blood. However, they 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?

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.

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

- share drug-use 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;
- have vaginal sex during menstruation.

Am I alone?

No. As of December 2002, about 251,000 people in Canada were chronically infected with hepatitis C. About 5,000 individuals are newly diagnosed each year.

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 (e.g., nausea, fatigue, reduced appetite, jaundice, dark urine, 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.

HOW CAN I LIVE HEALTHY WITH HEPATITIS C?

In most cases, hepatitis C is an illness 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 hepatitis C. 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, 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.

Tips for making the most of your health care appointments

- Tell your health care provider about 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.

What healthy choices can I make?

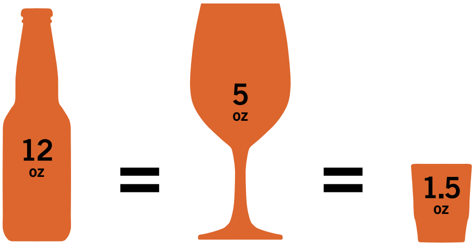
Your liver has many jobs — from cleaning your blood to turning the food you eat into energy for your body. It can stand a fair amount of stress, even if you have chronic hepatitis C. You can reduce the stress on your liver by controlling three of its major enemies: alcohol, smoking and too much weight.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

Avoid or limit alcohol

The use of alcohol can cause HCV to damage your liver more quickly and will make your treatment less effective. Two or more drinks a day can increase the rate of scarring in your liver and may speed up the development of cirrhosis and possible liver cancer. 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 C, or any other form of liver disease, it is best to abstain from alcohol.

What is a Standard Drink?



Percentage alcohol

bottle of beer	glass of wine	shot of liquor
(5%)	**(12%)**	**(40%)**

Avoid or limit tobacco

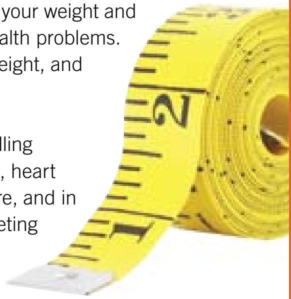
Tobacco contains several cancer-causing agents. More cancer-causing agents can be found in many of the chemicals added to tobacco products when they are made. Smoking increases the risk of liver cancer if you have hepatitis C. Also, tobacco harms your lungs. If you have lung disease and your hepatitis C 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. Because the liver processes everything you eat, eating well can help keep your liver healthy. The Dietitians of Canada suggest that most people with HCV do not need a special diet. Follow the guidelines in *Eating Well with Canada's Food Guide* (**http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index_e.html**) to give your body the right balance of carbohydrates, protein and fat. If you have cirrhosis or poor liver function, 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. A body mass index (BMI) is a number calculated from your weight and height. It gives you an idea of your body fatness, which may lead to health problems. A BMI between 18 and 25 is healthy, 25 to 30 suggests you are overweight, and over 30 means you are obese.

Besides the BMI, excess 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, etc. In men, a waist circumference of 102 cm (40 in) or more, and in women 88 cm (35 in) or more, 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?

There is a lot you can do every day that will help to protect your liver from damage and keep you feeling good. Here are some things to think about.

Try to avoid illness

Other viruses, such as hepatitis A or B, can damage the liver. Talk to your health care provider about getting immunized for these diseases and others (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 hepatitis C, hepatitis B or HIV. Remember, 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 (e.g., syringes, cookers, filters, water, tourniquets, pipes, straws) and never share any of it. Inject yourself rather than have 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, HCV support group, public health unit or the Canadian Liver Foundation.

Practising safer sex means:

- having a lot of condoms easily available (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® on your lips (it may cause the condom to break);
- using water-based lubricant with your condoms to reduce the risk of breaks or tears to your skin and to the condoms.

Practise safer sex

If you are in a **monogamous**, long-term relationship, sexual transmission of hepatitis C is rare. If this is not your situation, you should use condoms during sex. Condoms help protect your partners from HCV, and protect you from being exposed to other types of HCV and sexually transmitted infections. If you have an STI, especially those that cause ulcers/sores (e.g., herpes or 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 illness** can create anxieties, and the added stress can affect your overall health. Explore 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.

You can improve your health just by being active 30 minutes a 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/.**

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 with other symptoms of HCV 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. It can also contribute to the fatigue that some people with hepatitis C feel. 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 have trouble sleeping at night, try taking breaks or naps when you feel tired during the day.

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

If you have advanced liver disease or cirrhosis, you will need to avoid certain medicines including aspirin, sleeping pills and non-steroidal **anti-inflammatory** pills. 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. The Canadian Liver Foundation has compiled a list of herbal remedies that can damage your liver. Visit the CLF website at **www.liver.ca** for more information.

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 have HCV and are taking medicine for a mental illness, speak to your health care provider. You will want to make sure that your doctor knows about all your medicines to be sure that the combination of what you are taking is safe. It is particularly important if you are starting treatment for hepatitis C. Interferon is one of the treatment drugs that can make an existing mental illness worse. As long as your mental illness is being managed, you can receive some forms of hepatitis C treatment.

What about my friends and family?

If you have been diagnosed with HCV, you may worry about passing on the virus to someone else. If you have had hepatitis C for a long time and did not know it, you may be concerned that you have accidentally infected someone else. It is important to remember that HCV is spread *only* through contact with infected blood. Hepatitis C is not spread by casual contact, such as shaking hands, talking, sharing food and utensils, sneezing or hugging.

To decrease the risk of HCV infection to friends and family:

- » do not 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 (e.g., tampons, sanitary napkins, tissues, bandages, needles) by placing them in a protective container;
- » if you inject, snort or smoke drugs, do not share needles, straws or other equipment (e.g., containers, cookers, filters, water) with anyone else;
- » do not breastfeed if your nipples are cracked or bleeding;
- » use condoms if you are not in a long-term monogamous relationship. (This will protect your partners from hepatitis C and will also reduce your risk of getting other infections such as hepatitis B, HIV and other STIs. The risk of sexual transmission of HCV is very low, but it may happen if a woman is having her period, a person has sores from an STI, or the sex is rough producing cuts or sores.)

Notes:

TAKING CARE OF MY FEELINGS

Learning that you have HCV 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 HCV are getting "stuck" or are overwhelming you, talk to a health professional who can help you work through those feelings.

Where can I find support?

Talk to your health care provider (who can also provide a referral to another professional), supportive family members, friends or members of your faith community. Find out if there is a hepatitis C support group in your area and check out online support groups. Remember, you are not alone.

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.

Hepatitis C treatment can sometimes cause depression or make an existing depression worse. If you have a history of depression and are considering hepatitis C treatment, your doctor may start you on **anti-depressant drugs** before or during treatment.

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;
- sleep all the time or cannot 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;
- cry a lot or have mood swings.

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.

Will hepatitis C change how I feel about myself?

It is important to ask yourself how *you* feel about having hepatitis C. 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 C 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 HCV. 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 HCV 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 are thinking about you, try talking to them. They may just have questions for you or not understand hepatitis C. 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 C, try asking the person some questions:

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

Who should I tell that I have hepatitis C?

With a few exceptions, the decision to tell others that you have 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 C infection?

- *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 C infection?

- *Your doctor.* It is important to tell all of your doctors. If your doctors know about your hepatitis C, they will be better able to help you with your health care needs. Your doctors are required by law to keep your information private.

- *Your dentist.* It is particularly important 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 (e.g., an 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 hairdresser, barber, manicurist, tattooist or acupuncturist) sterilize their equipment.

Should I tell family and friends?

The decision to tell your family can be complicated. It might 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*? 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 adjust.

It can also be difficult to decide whether or not to tell friends. Think about how telling your friends might impact your relationships. You might 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 that they will reject you or treat you differently. Sometimes this happens; but many times, friends will want to offer support.

Time to adjust

Like you, your family and friends may need time to adjust to how they feel about you having hepatitis C. 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 hepatitis C 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 hepatitis C.

Should I tell anyone at work?

For most people, there is no reason to tell anyone at work about having hepatitis C. However, if what you do at work could put others at risk of contact with your blood, you might choose to tell them about your hepatitis C.

If you are not sure whether to tell your employer, talk privately with your health care provider, your workplace health advisor or 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.

Whom should I tell?

Consider these questions:

- Am I required by law to tell?
- Has this person been exposed to my blood? Might 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?

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

How do I tell people I have hepatitis C?

If you decide to tell someone you have 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 a calm and non-alarming way.

Notes:

Section 4

TAKING CARE OF MY SYMPTOMS

Most people with *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 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 hepatitis C.

The most commonly reported symptom of chronic HCV 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.

If you have chronic hepatitis C, you may also have other symptoms, some of which are listed on the following page, along with tips for dealing with them. If you have these symptoms, and *especially if you 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 C?

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, of all people who have chronic hepatitis C infection, *less than 5%* of these people will develop one 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, and you may feel less hungry due to the pressure of the fluid on the stomach, or shortness of breath due to the pressure of the fluid on the 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 (this can be bright red or dark and look like coffee grounds) or passing stool with blood in it (this can be bright red or dark, tar-like material). If you have this kind of bleeding, get medical attention immediately.

- **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. 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 advanced 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. In some cases, 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 lots of water in sips. Try eating small amounts of crackers or dry toast.
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 meals that are high in protein (meat, cheese or eggs). Try fruit and vegetables as snacks. Exercise regularly.
Sore muscles and joints	Aches and pains like you get with the flu. No visible change in your joints such as swelling, tenderness or redness.	Try regular exercise and get adequate sleep. Talk to your health care provider before taking any medication. Many arthritis pills are bad for you if you have advanced disease.
Abdominal discomfort over the liver	Aching in the **abdomen**, 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 cannot remember something. To help, write down important information.

Notes:

Section 5

TAKING CARE OF MY FUTURE

Generally, chronic hepatitis C causes changes in your body slowly over time. Most people diagnosed with hepatitis C have many years of a healthy life ahead of them. However, having a chronic disease like hepatitis C can create changes in your life. 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 can take 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?

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.

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.

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 by a reduced income, check into your options before you need them. Your banker or financial advisor may be able to provide options to you.

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. The 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.

Notes:

IS TREATMENT FOR ME?

You may not now, or ever, need treatment. But if you do, effective treatment for chronic hepatitis C is available. In fact, about one half of those with the most common genotypes of HCV in Canada reach a point where the hepatitis C virus can no longer be found in their blood. At present, this is achieved through a combination of two medicines: pegylated interferon and ribavirin. If you and your health care provider think treatment might be right for you, consider and discuss the following questions.

What is the current treatment for hepatitis C?

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

How effective is treatment?

- How does my genotype affect my chances for effective treatment?
- How does infection with other viruses (e.g., HIV or hepatitis B) 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 does 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?

WHAT ABOUT ALTERNATIVE THERAPIES?

Some practices and products that claim to help you live better with hepatitis C 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 2007, no alternative therapy has been proven safe and effective for treating 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 are not certain. Like any medicine, alternative therapies may not react well with your other medicines. 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 (e.g., cancer, diabetes, 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.

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 might also like to know how long the therapist has been working and if he/she belongs to any professional organizations. Look for a therapist with a good understanding of hepatitis C 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.

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 regular HCV therapy or 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?

Notes:

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.

Acupuncture: A treatment where small needles are stuck into the skin at specific points, usually to help relieve pain.

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.

Antibodies: Proteins the body makes to help fight infection.

Anti-depressant drugs: Drugs prescribed to treat depression.

Anti-inflammatory drugs: Drugs that help settle down inflammation or swelling.

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”.

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 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).

Human immunodeficiency virus (HIV): The virus that causes AIDS. It attacks the immune system, making it harder for the body to fight disease.

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.

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.

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: Yellowish skin or eyes.

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 when cells are damaged. These tests measure the amount of liver enzymes in the blood.

Liver function tests: Tests to determine how well the liver is working. These tests include INR (blood clotting factor), albumin (protein) and bilirubin.

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.

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: 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.

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.

Notes:

WHERE CAN I FIND OUT MORE?

There are many useful resources available on hepatitis C. Some to consider include:

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

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/

> *Complementary and Alternative Medicine (CAM)*
> **http://hc-sc.gc.ca/iyh-vsv/med/nat-prod_e.html**
>
> For a list of approved natural health products
> **http://www.hc-sc.gc.ca/dhp-mps/prodnatur/applications/licen-prod/lists/listapprnhp-listeapprpsn_e.html**

Public Health Agency of Canada (PHAC)
http://www.phac-aspc.gc.ca/hepc/

Canadian AIDS Treatment Information Exchange (CATIE)
http://www.catie.ca

Canadian Association of Hepatology Nurses (CAHN)
http://www.livernurses.org/

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

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)
Hepatitis C: A Nursing Guide
http://www.cna-aiic.ca/

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

College of Family Physicians of Canada (CFPC)
Primary Care Management of Hepatitis C: Physicians´ Desk Reference
http://www.cfpc.ca

National Association of Friendship Centres (NAFC)
Hepatitis C Information Manual
http://www.nafc-aboriginal.com/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 EI 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

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		
HCV support group		

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

Healthy Living with Hepatitis C

To obtain additional copies, please contact:

Canadian Liver Foundation
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**

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Ce document est également disponible en français.

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