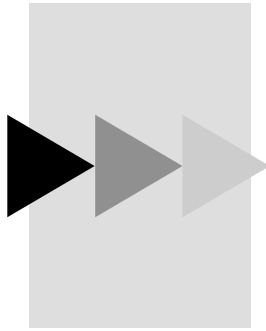


HEPATITIS C

An Information Booklet



*for People Infected with
the Hepatitis C Virus,
and for their Families
and Friends*

ACKNOWLEDGEMENTS

Teresa Lukawiecki M.S.W. and **Seeven Vydelingum Ph.D.** prepared the First Edition (April 1995) of this document for the Canadian Hemophilia Society (CHS).

The CHS is grateful to the **Manitoba Chapter of the Canadian Hemophilia Society**, and **Schering Canada Inc.** for providing the funding for the revision and reprint of the Second Edition (December 1996).

For the Third Edition (March 1999), the CHS acknowledges the collaboration of **Dr. G.Y. Minuk**, hepatologist and member of the CHS Medical & Scientific Advisory Committee, as well as the members of the **CHS HCV Task Force**.

The Fourth Edition (March 2003) was edited and revised by **Gregory Taylor M.S.W., RSW**, Vancouver General Hospital Hemophilia Program.

Jane Wilson conducted a language review for this Fifth Edition (March 2004).

The CHS would like to acknowledge the collaboration of **Dr. Kevorg Peltekian**, hepatologist and member of the CHS Medical and Scientific Advisory Committee. **Ian Deabreu, Michael King, James Kreppner** and **Bruce Rempel** provided invaluable input in their capacity as the CHS HCV Booklet Revision Advisory Group. Members of the **CHS HCV/HIV Task Force** also provided their support. **Paul Rosenbaum** completed the creative work associated with this booklet. The production of this booklet was coordinated by **Jeff Rice**, Coordinator of Regional Resources and Hepatitis C Programs with the CHS.

A special thank you is extended to **Dr. Frank Anderson** and **Natalie Rock B.S.N., RN**, Vancouver Hospital Gastroenterology, for contributing their time to help ensure an accurate portrayal of Hepatitis C disease and its management.

Health Canada provided funding for the 1999, 2003, and 2004 editions. The views expressed herein are solely those of the authors and do not necessarily reflect the official policy of Health Canada.

The Canadian Hemophilia Society would also like to acknowledge the assistance of the following people: **Tom Alloway, Lorraine Calderwood-Parsons, David Page, John Plater, Vic Parsons, Robert St. Pierre, Tom Smith**, members of the **Ontario Hepatitis C Committee**, members of the **CHS Medical and Scientific Advisory Committee**, volunteers and staff of the CHS nationwide, and our families.

The Canadian Hemophilia Society consults qualified health care professionals before distributing any information. The CHS does not, however, in any circumstances recommend particular treatments or treatment choices. The CHS recommends that individuals consult a qualified health care provider before pursuing any course of treatment.



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HEPATITIS C • AN INFORMATION BOOKLET
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ISBN 0-920967-44-2

Legal Deposit: National Library of Canada

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HEPATITIS C

What is hepatitis C?

Hepatitis means inflammation (swelling) of the liver, which can be from a number of causes. The hepatitis C virus (HCV) is a virus that infects the liver, and can cause inflammation and scarring of the liver. The initial phase of HCV infection is called **acute hepatitis C**. If the virus persists in the body for more than six months, the disease enters the **chronic hepatitis C** phase.

In some cases, it may lead to **cirrhosis** (a condition in which healthy liver cells are replaced by scar tissue) that affects the liver's ability to function.

To see what may happen to a person with HCV, let's look at what could happen to a group of 100 people infected with HCV. The virus in the blood becomes undetectable in about 20 of these infected people, even without treatment—this means they have recovered from the hepatitis. Many of the other 80 people go on to the chronic phase of the disease. Of these people, about one-quarter (or as many as 20 people), will have a progressive disease which may lead to cirrhosis after 20 years. The longer a person has the infection increases the chances of developing cirrhosis.

Many people will feel healthy even if they have cirrhosis. A relatively small number of people in the group that develops cirrhosis will experience liver failure or liver cancer (**hepatocellular carcinoma**, or **HCC**). Persons with chronic HCV and cirrhosis should be screened for HCC with an ultrasound and a blood test for **alpha-fetoprotein** (a protein produced by cancer cells) at least once a year.

Six main types of HCV, called **genotypes**, have been identified. Testing for genotype is important for two reasons. First, some genotypes respond better to treatment than others, and so need a shorter course of treatment. Second, it is possible to become infected with more than one genotype after multiple exposures to HCV.



How widespread is HCV?


- HCV occurs throughout the world.
- Overall, the infection rate among men is approximately twice that among women.
- Approximately one quarter of a million Canadians are infected with HCV.
- As many as 5,000 Canadians become newly infected with hepatitis C each year.
- Sharing drug use equipment accounts for about 70% of all HCV infections in Canada. As many as 80% of injection (e.g., needle) drug users will have contracted HCV after one year of using. Overall, 90% will acquire HCV within five years.
- The rate of infection among Canada's Aboriginal people and among prison inmates is relatively high, and a source of great concern.
- Canadians with hemophilia who received blood products prior to 1990 had a 95% rate of infection. This group represents 70% of the entire hemophilia community.

How does HCV infect people?

HCV is spread by blood-to-blood contact. You cannot get HCV through the air or by casual human contact such as kissing, shaking hands or hugging. For this reason, the following situations are considered either higher or lower risk.

Higher risk:

- **People who received a blood transfusion, blood product, organ or tissue transplant prior to June 1990.** After June 1990, screening for HCV in blood and blood products began in Canada. Since 1992, better tests for detection of HCV have been introduced. A small risk (less than 1 infection per million transfused units of red blood cells, platelets or plasma) still exists today. There is no evidence that a case of HCV has occurred through the usage of current plasma derivatives such as immunoglobulins, albumin and factor concentrates.

- 
- **Sharing drug injection equipment (i.e., needles and syringes).** This is true even if you only shared once, though many years ago.
 - **Using cocaine (by snorting) and sharing the straw.**
 - **Accidentally pricking oneself with a used needle from an infected person.** Each accidental needle prick carries a 1-2% risk of infection.
 - **Long-term hemodialysis.** Each person on **hemodialysis** (a procedure that removes extra fluids and wastes from blood, returning the clean blood to the body) runs an estimated 10% risk of HCV infection each year due to exposure to many blood products. The chances of contracting HCV this way will decrease with improved screening of blood and standard precautionary measures for use of single-use medical devices.

Lower risk:

- **Sharing household items (i.e., razors, nail files, and dental floss) that could have blood on them.**
- **Having a skin-piercing procedure using contaminated equipment.**
 - Tattooing:** Getting a tattoo may yet be identified as a significant risk factor as it appears to be the only route of possible infection for a substantial number of people.
 - Body/Ear-piercing**
 - Acupuncture**
 - Electrolysis**
- **Sexual activities.** Unprotected sex with a partner infected with HCV carries a less than 5% lifetime risk of infection. The presence of open sores or a sexually transmitted disease such as herpes or HIV will greatly increase the risk. Infected women should avoid unprotected sex during menstruation.
- **Mother to baby (vertical transmission).** There is approximately a 5% risk, which climbs to 30% if the woman is co-infected with HIV and has a high HCV viral load. There is no evidence to suggest that breast milk can infect a baby, but cracked and bleeding nipples pose a risk.



If I already have HCV, how can I avoid spreading the virus?

If you take the following steps, you will greatly reduce the risk to others of being infected through contact with your blood.

- Discuss your HCV infection with your donor program if you are planning to give semen, body tissues, or an organ.
- Do not share equipment for drug snorting or injection.
- If you are a person with hemophilia on a home-infusion program, carefully place used needles and syringes into the disposal container provided by the Hemophilia Clinic.
- Do not share personal items that may have tiny amounts of blood on them.
- Avoid skin-piercing procedures.
- Discuss the fact that you have HCV with your sex partner(s).
- Use a latex condom when having sex, particularly if having sex with a woman who is menstruating.
- Talk to your doctor if you are considering pregnancy.
- Clean up blood spills with soap and hot water and then disinfect the area with a 10% solution of bleach (one part bleach, nine parts water). If others are cleaning up, make sure they are wearing gloves. On a dry surface HCV may survive from a few seconds to a few minutes. On a wet surface HCV may survive from a few minutes to an hour or more.
- Blood-stained sheets, towels, linen and clothes should first be washed with bleach using a cold wash, followed by a hot wash.
- Bandage or cover cuts and sores until healed.
- Put all articles stained with your blood (i.e., bandages, paper tissues, tampons, or razors) into a plastic bag before putting them into your household garbage.



DIAGNOSIS

Do I need to be tested?


If you have engaged in any of the higher risk activities identified earlier in this booklet, you need to be tested. Testing is also advised if you have engaged in any of the lower risk activities, or think you may have been exposed to the blood of an HCV infected person. If you regularly use a factor concentrate (recombinant or plasma-derived), it is standard to be tested once a year.

Suspecting you may be infected with HCV but not knowing for sure leaves you at a disadvantage. If the test detects the presence of HCV in your body, it enables you to do the following:

- Understand the extent of liver damage by discussing your test results with your health care provider (HCP).
- Consider early treatment.
- Take precautions not only to prevent the spread of the virus but also to protect yourself from being re-infected with a different genotype of HCV.
- Obtain vaccination against hepatitis A (HAV) and hepatitis B (HBV). These viruses can worsen liver disease if you already have HCV. Obtaining the flu vaccine and the pneumonia vaccine is also wise. (Your local Public Health Clinic may offer one or more of these vaccines for free).
- Monitor the progress of the infection in order to catch liver problems early.
- Learn more about HCV and make appropriate lifestyle changes, such as: choosing to consume less alcohol, improving eating habits, and exercising regularly.

How will I know if I have HCV?

The only way to know if you have been infected by HCV is to get tested. Different blood tests will test for different aspects of HCV. The most important tests are as follows.



Tests to determine whether you have HCV

1. **Anti-HCV (HCV antibody test):** Antibodies are proteins made by a person's immune cells in response to a viral infection or a vaccination. Antibodies circulate in the blood and are usually present lifelong. The anti-HCV test determines the presence of antibodies to HCV and thus indicates previous exposure to the virus. It does not measure the virus itself.


NOTE: Because it may take up to three months after exposure for the body to develop antibodies to HCV, there may be a false negative test result during this time period. A person with a poor or suppressed immune system may have a false negative test result because the body is unable to make antibodies. A person with a poor immune system should therefore be tested for HCV using the nucleic acid PCR test.

2. **HCV RNA (polymerase chain reaction (PCR) test):** This test detects the *actual presence* of the hepatitis C virus in the blood. It is a very sensitive test and can detect the virus within two weeks of exposure. The HCV RNA test is of two types:
 - a) **Qualitative:** This test is the most sensitive and will simply detect the presence or absence of the virus in the blood. The result will be either positive (meaning the virus is present) or negative (meaning the virus cannot be detected).
 - b) **Quantitative:** This test measures the *amount* of virus in the blood (also known as the **viral load**). The result is a number value usually expressed as “copies.”

NOTE: If the results come back anti-HCV positive but HCV-RNA negative, it means that you have been exposed to HCV, but your body eliminated the virus from your body.

Test to determine whether HCV is active

Serum liver enzyme tests: Enzymes supply the energy for cells to perform their normal function. Normally, only small amounts of enzymes leak out of the liver cells and into the




blood stream. However, if the liver cells are inflamed, more enzymes will leak out and their levels in the blood will increase. The common enzymes that are measured are **aspartate aminotransferase (AST)** and **alanine aminotransferase (ALT)**. Having consistently normal returns from liver enzyme tests is an encouraging sign. However, damage to the liver may still be happening, so it is recommended that you also have a liver function test (see below).

NOTE: Raised enzyme levels (including AST and ALT) can be caused by conditions other than HCV, such as metabolic liver disease, fatty liver, or liver disease induced by alcohol, street drugs or certain medications.

Tests to determine whether the liver is being affected by HCV

1. **Liver function tests:** These tests measure liver function by quantifying some of the proteins manufactured by the liver, such as **albumin** and **blood clotting factors (INR)**, **platelets**, or the products excreted by the liver, such as **bilirubin (bile)**.
2. **Liver biopsy:** A **percutaneous biopsy** removes a small sample of your liver (via a needle inserted through the skin) for analysis. It is the most accurate way to assess the amount of inflammation and the degree of scarring (**fibrosis**), including cirrhosis. A biopsy makes it possible to **grade** the inflammation and **stage** the fibrosis.
 - a) **Inflammation** Graded on a scale from 0-4 (higher number = greater inflammation)
 - b) **Fibrosis** Staged on a scale from 1-4 (higher number = greater fibrosis, or stage 4 = cirrhosis).
 - c) **Fat and iron** There are many other features seen on a liver biopsy including the amount of fat and iron in the liver.

NOTE: People with hemophilia or a related bleeding disorder do not normally choose to have a biopsy because of the greater possibility of bleeding, but there are situations in which one might have a biopsy despite this increased risk. A person with mild hemophilia may have a standard biopsy and



take the precaution of coverage with clotting factor. A person with severe hemophilia would almost certainly have a **transfemoral** (accessing the liver across or through the main artery of the thigh) or **transjugular** (accessing the liver across or through the main vein in the neck) biopsy. If bleeding occurs, it backs into the vein. People having an inhibitor to factor concentrate should take the increased risk of bleeding into consideration as it may add an unacceptable level of risk.

NOTE: There are other methods that will indirectly indicate advanced liver disease. Low platelet counts, **splenomegaly** (enlarged spleen), or signs of **portal hypertension** (increased pressure inside the veins that bring blood from the intestines to the liver) are examples. Imaging the liver with **ultrasonic waves** (ultrasound) or by **computed tomography** (CT scan) may also suggest the presence of cirrhosis.



SYMPTOMS

You can have HCV and not know it. During the acute phase the disease is mild and many people do not have symptoms. Only 25% of persons will appear **jaundiced** (the skin and eyes turn yellow) during this phase. In chronic hepatitis, symptoms can come and go, lasting for several weeks or months at a time. HCV may persist for many years without any symptoms although it may be destroying liver cells at a slow rate. The reason for the absence of symptoms is that the liver has a large reserve of cells and so can function normally even when much of it has been destroyed.

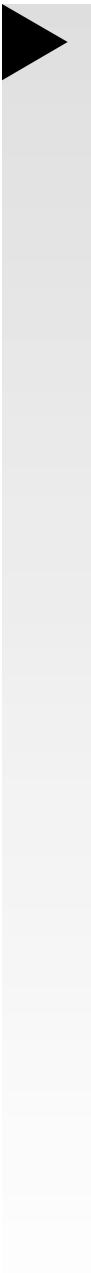
The most common symptom of HCV infection

Lassitude - a lack of energy to the point where you feel you cannot exert yourself. This feeling of extreme tiredness goes beyond fatigue in that it persists even if you have a full night's sleep.

Other symptoms

- discomfort on your right side just below the rib cage (the right upper quadrant)
- fatigue
- nausea and vomiting
- loss of appetite and weight loss
- muscle and joint aches
- itchy skin – usually no rash
- poor sleep
- depression
- “**brain fog**” characterized by problems with short-term memory, concentration, and staying focused on tasks

The above symptoms can occur in the earliest stages of infection but more often tend to develop gradually. They cannot be directly linked to a particular stage of the disease or to any particular abnormal liver test.



Signs relating to liver failure

- jaundice
- dark urine and pale bowel movements
- **ascites** (abdominal swelling due to fluid retention)
- internal bleeding due to enlarged blood vessels in the esophagus or stomach
- “easy bruising”
- **edema** (swelling of the feet)

End stage liver failure:

- **encephalopathy** (a disease of the brain) is caused when the liver is unable to remove certain toxins (e.g., ammonia) from the blood after absorption from the intestine. These toxins reach the brain and cause confusion, drowsiness, extreme agitation, and sometimes coma.



GETTING TREATMENT

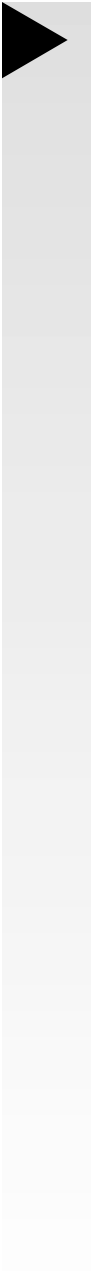
The relationships you have with your **health care providers (HCP's – hepatologist, gastro-enterologist, general practitioner, nurse-practitioner)** are very important. For the relationships to work effectively, all parties need to work at them and respect each other. Honest two-way communication will ensure the best fit between your HCP's recommendations for treatment and your own preferences. You should be seen by a specialist who has a good understanding of HCV, its diagnosis and treatment.

Here are some **Principles of Treatment** to keep in mind.

- All treatment should have your informed consent. This means that you fully understand what the treatment will be, the risks and benefits of treatment, and the cost. Also you have the right to refuse treatment *at any time*.
- Be sure that your HCP knows about *all* treatments (i.e., herbal remedies and dietary supplements) that you are trying.
- Review with your HCP how well each treatment is working. Give treatments a fair trial, but also be prepared to have your HCP make adjustments to the overall treatment strategy.

Tips to consider when visiting a health care provider

- Just before your visit to the HCP, think about your concerns. What problems have you had with the treatment? What are the advantages, risks and side effects to a particular drug or operation?
- Write down your questions ahead of time with the most important ones first on the list. Maybe only two or three will get answered during the visit. You can even rehearse questions if you feel uneasy about asking them.
- It is so easy to forget or misunderstand instructions, so try repeating back to the HCP the key points you have heard. This allows your HCP to clarify anything that might be confusing and will help you to remember.

- 
- If you are nervous or have trouble understanding the language your HCP speaks, bring someone with you who can help you to relax and to recall what the HCP said.
 - Some HCP's use a lot of medical terms that are difficult to understand. Don't be embarrassed to take notes or to ask for simpler words and written handouts.
 - Take part in decisions about treatment. Share your preferences. If there are obstacles to following your HCP's recommendations (e.g., financial concerns, conflicts with daily routine), let the HCP know.
 - If a second opinion from another HCP would make you feel better, explain this to your HCP so that you can be referred to someone else for a visit. Your HCP should not be upset; it is your right to explore other viewpoints before arriving at a careful, informed decision.



TREATMENT OPTIONS FOR HCV

The goal of treatment

The goal of treatment is to eliminate HCV from the body.

If HCV cannot be measured in the blood six months after the end of treatment, it is called a **sustained viral response (SVR)**. Research has found that the virus remains undetectable for many years in the vast majority of those who reach an SVR. Many doctors believe this is a cure because there is no sign of the presence of HCV, and liver damage has been stopped.


Your chances of obtaining an SVR increase if you strictly adhere to the combination therapy (see below) by taking all the medication at the appropriate times. Other factors include the degree of fibrosis and the amount of inflammation already evident in your liver before you start treatment. Even for those who do not arrive at a SVR, there is evidence to suggest that the treatment can slow the rate of damage to the liver.

The decision to treat

Generally, treatment is considered for patients who have had elevated ALT levels (1.5 times the upper normal limit) for a minimum of three months AND confirmation from a biopsy that there is inflammation or fibrosis present in the liver. There are, however, a number of factors that go into a recommendation to proceed with treatment for HCV.

Ask these questions:

- What are my chances of obtaining a sustained viral response?
- What genotype do I have? Your particular HCV genotype is important to consider for two reasons. The chance of obtaining a sustained viral response varies from genotype



to genotype*. The genotype also determines how long you will be on treatment.

- Do I have a health condition that would react badly to the side effects of treatment?
- Am I pregnant or considering pregnancy? (Ribavirin can cause birth defects).
- Is there a significant chance that HCV will lead to health problems in my case?
- Am I able to closely follow a treatment schedule?
- Do I believe I will be able to tolerate the side effects of treatment?
- Will I be able to take time off work or away from other responsibilities if the side effects are significant?
- How do I weigh the possible impact side effects may have on my enjoyment in life against treatment that may or may not result in HCV being eliminated from my body?
- Can I afford the cost of treatment?

*According to the U.S. National Institutes of Health Consensus Statement on the management of HCV (released in September 2002), the chances of obtaining a sustained viral response in those who have not been previously treated are:

76 – 82% for people with Genotype 2 or 3; and

42 – 46% for people with Genotype 1.

The decision to treat is a matter that requires careful consideration on your part and input not only from your HCP but also from those close to you.



Medications used to treat HCV

Interferon

Interferon is a synthetic form of a protein normally produced by your body to fight viruses. It is given by injection under the skin. Standard interferon is injected three times a week while **pegylated** (sustained release form of interferon) is injected once a week. The pegylated form of interferon is identical to the standard form except that a molecule has been added. This makes the pegylated interferon more effective in fighting HCV because it is slowly absorbed from the injection site and lasts longer in the blood stream.

Interferon may cause the following side effects:

- fever
- temporary nausea and vomiting
- muscle and joint aches
- lowering of white blood cells and platelets which will increase the risk of infection, bleeding, and “easy bruising”
- brain fog
- depression
- hair loss.

Some people will experience the following side effects at intervals:

- fatigue
- loss of appetite
- diarrhea
- sleep problems
- irritability.

Side effects will diminish after two or three weeks of treatment for 70% of people. Approximately 3% of people will be unable to continue treatment because of the severity of the side effects. Stopping treatment is the only way to stop the side effects, but your HCP might be able to suggest ways to help you minimize their impact.



Ribavirin

The drug **ribavirin** interferes with the way the virus reproduces itself while at the same time enhancing the effectiveness of interferon. By itself, ribavirin is not effective against HCV.

Ribavirin may cause the following side effects.

- The most common side effect is a drop in hemoglobin, which transports oxygen through the blood to cells. As a result you may develop shortness of breath, on exertion.
- A non-productive cough is another fairly common side effect.
- A rash and itching may occur.
- Ribavirin can induce fetal deformities.


Monotherapy (interferon alone)

Treating HCV with interferon alone (**monotherapy**) used to be the only option available. The discovery of the beneficial effects of ribavirin made combination therapy the international standard of care for HCV. Monotherapy with pegylated is only used for people who cannot tolerate ribavirin or who have cirrhosis and borderline liver function.

Combination therapy (pegylated interferon and ribavirin)

In **combination therapy**, pegylated interferon alpha-2a or 2b (depending on the manufacturer) is given with ribavirin. Pegylated interferon is given by injection, usually once a week. Ribavirin is in capsule form and is taken by mouth, twice daily with food.

The length of treatment depends on the HCV genotype in your body. If you have Genotype 2 or 3, treatment will last up to six months. However it may be discontinued after three months if there has not been a 100-fold decrease in HCV-RNA (as shown by a quantitative PCR test) or a PCR negative test result. This is because there is very little chance of obtaining a sustained viral response if the viral load has not dramatically decreased in the first three months of treatment.



If you have Genotype 1, 4, 5, or 6, treatment will last for up to one year. Again, treatment may be discontinued after three months if there has not been a 100-fold decrease in HCV-RNA or a PCR negative test result. Treatment will probably stop at six months if you continue to test PCR positive because it is very unlikely that you will achieve a SVR. However, since there is evidence that treatment slows the progression of liver damage, research is currently being done to look at long-term maintenance therapy. People involved in research projects do not have to pay for their therapy, but other patients may have to find a way to pay for this extended treatment.

Based on the side effects of interferon and ribavirin, people with certain medical conditions may not be recommended for combination therapy. People are evaluated on a “case by case” basis, but conditions like the ones below are termed “definite contraindications,” meaning that there is a clear risk of a serious problem developing.

- **autoimmune disorders** (inflammation and destruction of tissues by the body’s own antibodies) such as severe arthritis or active uncontrolled thyroid disease
- autoimmune hepatitis
- uncontrolled diabetes
- heart disease
- respiratory disease
- **anemia** (low level of hemoglobin in the blood)

The **cost of treatment** depends on the dosage needed, which depends on your weight (and therefore dosage). In 2004, a person could expect to pay monthly costs ranging from \$1,600 to \$2,300. Guidelines for payment of treatment vary by province and territory. Your provincial or territorial government may either cover the entire cost or expect you to pay a deductible, depending on your financial situation. Your health insurance company (a private plan or the one at your workplace) will likely pay the outstanding balance, if any. Consult your doctor or your Hemophilia Clinic for more detailed information in order to resolve any expense-related issues *before* you start treatment.



Other treatments

Liver transplant

A liver transplant is not considered until the person experiences liver failure. The success rate of transplantation is at least 80%, but infection to the liver with HCV will re-occur. Having a liver transplant also means that you will likely have to take medication for the rest of your life to prevent your body from rejecting the transplanted liver. A liver transplant will cure a person with hemophilia of this bleeding disorder. Liver disease due to chronic HCV infection is the primary reason for liver transplantation in Canada. The Canadian Liver Foundation or a doctor who specializes in liver diseases (hepatologist) can provide you with more information.




HCV AND HIV CO-INFECTION

Co-infection with hepatitis C and HIV means that a person has both the hepatitis C virus and the **human immunodeficiency virus (HIV)** – the virus responsible for **acquired immune deficiency syndrome (AIDS)**. People with HIV often have HCV. Nearly all persons with hemophilia and HIV are co-infected because blood products transmitted both viruses. Having HIV increases the risk of getting symptoms and serious liver disease sooner. This might happen because HIV decreases the immune response thereby letting HCV progress more easily.

Is HCV treatment different if I am co-infected?

- Treatment for HCV is only effective if the HIV is under good control. Generally, good control of HIV is considered to be when blood tests show a **CD4** (a surface antigen on helper T-cells very important for resisting viruses) count over 250 and a low or undetectable HIV viral load.
- People who are co-infected have a delayed response to interferon. Your doctor will likely try to measure the effectiveness of treatment by seeing if you have achieved a response (negative HCV RNA) to the HCV treatment after twelve weeks of therapy.
- Persons with AIDS are more susceptible to infections. Since interferon lowers the count of white blood cells, unusual bacterial infections may occur when on treatment for HCV.
- Some anti-HIV drugs may cause liver damage. The negative effects on the liver will usually go away if the drug is stopped or the dose is lowered. The least liver-friendly anti-HIV drugs may be ritonavir, d4t/stavudine, and nevirapine.
- For people with hemophilia who are co-infected, the dosage for certain HIV drug combinations requires careful individualized assessment to avoid drug toxicity.



What about liver transplantation?

In the past, people with HIV and HCV were not considered for liver transplants. However, this has changed.

- Seek the opinion of your local transplant centre.
- Clinical Trials: The Canadian Hemophilia Society (CHS) can provide co-infected persons (who have their HIV under control) with information on Trial Protocols involving liver transplantation and how to contact the doctors involved.
- Transplantation in the United States: The cost of a liver transplant in the United States is significant, at approximately \$200,000 U.S. at time of publication.

What should I do if I am co-infected?

- Discuss the potential risk of combinations of drugs with your health care provider and pharmacist.
- Have your enzyme levels checked regularly.



STANDARDS OF CARE

The Canadian Hemophilia Society, in collaboration with other organizations, is trying to establish standards of comprehensive care for HCV in the hemophilia and hepatitis clinics across Canada. Currently, the clinics follow their own guidelines because they are managed and operated independently. This means that care may vary depending on where you live. Until one set of standards of care for all patients are established, you can do the following.

- If you are a person with hemophilia or a related bleeding disorder, make sure that you are in the care of a doctor in a hemophilia treatment centre.
- If you live in a rural community, ask your doctor to contact the nearest hepatitis experts to get information for you.
- Make sure that your doctor is communicating with your liver expert. Ask for copies of correspondence such as consultation letters or reports, etc.
- Don't be afraid to ask for counselling to help you and your family deal with the issues surrounding your HCV infection.




HEALTHY LIFESTYLE

How can I take charge of my health?

Living well with HCV means adopting a healthy lifestyle. It is not a cure but part of your overall management of HCV. A healthy lifestyle means that you keep informed about HCV by asking questions, reading, and finding out what community resources are available to help. It is important to learn those attitudes and behaviours that help you to achieve the highest possible physical, mental, and spiritual well-being. Your decisions and actions are ultimately the most important ones for keeping HCV under control. Key aspects of a healthy lifestyle include the following.

Nourish your body

- **Avoid alcohol.** Research is clear that zero intake of alcohol is best. Alcohol “excites” or activates HCV and may therefore speed up the progression of the liver disease.
- **Avoid using illegal drugs and smoking.**
- **Avoid taking medication when it is not necessary.** Check all your medications, including “over the counter” medicines bought in the drug store or health store, with your health care provider. A person with hemophilia or related bleeding disorder should monitor liver functions if on anti-inflammatory medications for chronic joint disease.
- **Avoid chemicals (e.g., cleaning solutions, solvents, pesticides, and anything in aerosol containers) at work and at home; these are toxic to the liver.**
- **Exercise regularly.** Exercise will help you to stay physically and emotionally healthy. Consider the following when starting an exercise program.
- Consult your health care provider first.
- Don’t overdo it on “good days”, and do nothing on “bad days.”

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- People with hemophilia or a related bleeding disorder should stop exercising if a bleed occurs. A physiotherapist at the Hemophilia Clinic may give you appropriate exercises.
 - **Eat a balanced diet.** Good nutrition can keep the liver healthy because the liver refines and detoxifies everything you eat. A balanced diet can actually help a damaged liver to regenerate new cells.
 - Megavitamin therapies, iron supplements and certain specialized nutritional products could possibly contribute to liver damage. Talk to your health care provider or pharmacist if you are taking, or plan to take, any of these products.
 - **Get enough sleep.** Listen to your body: take a break or nap if you feel tired during the day.
 - **Try meditation, relaxation techniques, and massage.**

Nourish your mind

- **Reduce stress**
- Adjust your work or daily schedule.
- Get emotional support from others. Share your problems and tell others about your needs.
- Set and work toward goals.
- **Keep your sense of humour.**
- **Keep a positive attitude (and never lose hope).**

Nourish your spirit

- **Keep a positive self-concept and sense of purpose.** People who believe in their own worth and in the meaning of their lives experience more happiness, satisfaction and serenity. Avoid blaming or criticizing yourself.
- **Take part in uplifting activities.** Having HCV doesn't mean life can no longer be full and happy. It does mean that you need to choose to enjoy life and to take the time to have fun and enriched experiences.
- **Seek strength from your beliefs and take part in**

spiritual activities.

ALTERNATIVE THERAPIES

Alternative therapies are systems of healing that are not regarded as part of standard treatment by the medical profession. Many of these therapies take a holistic approach, meaning that they take into account not only the diagnosed disease, but also the physical, social and mental factors of the patient's condition. Although well established, the following therapies probably are not covered by provincial/territorial medical plans. It is possible for an alternative therapy to have side effects, or to cause a reaction to anti-HCV medication. To avoid the possibility of harm it is best to first talk to your health care provider, former patients, and qualified practitioners of the alternative therapy.

Therapies that do not use pharmaceuticals

- **Acupuncture:** A traditional Chinese system of healing in which symptoms such as pain are relieved by very tiny metal needles inserted into selected points beneath the skin. *Be absolutely sure that the practitioner uses sterilized needles and handles them in a safe way.*
- **Homeopathy:** A system of medicine based on the theory that "like cures like." The patient is treated with extremely small quantities of substances that are themselves capable of producing the symptoms of the disease in question.
- **Naturopathy:** A system of medicine that relies upon the use of strictly "natural" substances for the treatment of disease. Herbs, food grown and prepared without artificial fertilizers and preservatives, clean air and pure water may all be used to rid the body of "unnatural substances" which are seen to be the underlying cause of most illnesses. Traditional Chinese Medicine, which incorporates an herbal approach, is the preferred treatment in the Far East for most medical conditions.



Therapies that use touch

- **Chiropractic:** The treatment of diseases by manipulation, mainly of the vertebrae of the backbone. Chiropractors believe that nearly all disorders are caused by incorrect alignment of bones, with consequent malfunctioning of nerves and muscle throughout the body.
- **Massage:** Manipulation of the soft tissues of the body with the hands. It is used to improve circulation and muscle tone, and to reduce muscular spasm.
- **Osteopathy:** A system of healing based on the assumption that many diseases are associated with disorders of the musculoskeletal system. Diagnosis and treatment includes palpation, manipulation and massage.
- **Shiatsu:** A system of healing that may be described as acupressure massage. Pressure is applied by the hands to selected points on the surface of the skin, which correspond to the acupuncture points beneath the skin.
- **The Three Rs:** Reflexology, Reiki, and Rolfing are from Eastern and Western traditions that involve therapeutic touch.

Therapies that use the mind

- **Altered States of Consciousness:** Clearing the mind of stressful thoughts and daily worries is seen to have healthy benefits. Meditation, primarily a spiritual practice, is also basic to lifestyle choices such as yoga. Techniques such as Guided Imagery and Visualization help patients create a vision of a future without symptoms, or at least an immediate, if temporary, pause from discomfort.
- **Biofeedback:** The patient is immediately given information about what are usually unconscious bodily processes (such as heart rate). Over time the patient learns to control disturbances in bodily regulation (such as hypertension).



PSYCHOSOCIAL ASPECTS


How can I deal with financial difficulties?

Severe symptoms of HCV or the side effects of treatment may affect your ability to work. You may find you could use some form of income assistance. Depending on your circumstances, you may be able to collect benefits from the following places:

- **Human Resources Development Canada Employment Insurance (EI):** Benefits are calculated based on the number of hours worked. Applicants for EI Sickness Benefits must have a minimum of 600 hours of insurable work in the past 52 weeks. If you provide medical proof of illness, Sickness Benefits will last for 15 weeks. EI also offers retraining programs if illness prevents you from keeping your current position.
- **Canada Pension Plan (CPP) and Quebec Pension Plan (QPP):** If you have paid CPP/QPP premiums, you may qualify for a disability pension. Eligibility is based on the number of years you have contributed and a detailed medical assessment you must submit to indicate your condition is both “severe and prolonged.”
- **Social Assistance:** Your local welfare office may provide you with financial assistance for shelter, living expenses and essential medical needs. Eligibility for a disability pension varies among provinces/territories.
- **Employee Benefits Package:** A disability pension paid out by a private insurance company may be available through your employer. Check with your personnel department or union representative for specific plan details.

What is the impact of HCV on family relations?

Family relationships may be affected by HCV even if you do not have symptoms. At first there may be tension or friction between family members because it takes time for some



people to adjust to even small changes in lifestyle. Be sure to keep communication open and try to maintain usual family activities. A counsellor may be able to help.

How do I tell my children that I have HCV?

There may be visible effects of HCV or the treatment, and changes in your life that children will pick up on. Your children may actually experience more worry from not knowing what is wrong than from knowing the truth. If you decide to tell your children about HCV, do so honestly and directly.

- Carefully choose a time to tell your children.
- Tailor explanations to suit the ages of your children. Be prepared to reassure them if they ask about death.
- If children avoid the subject, provide information in a non-threatening way such as leaving a booklet on the table.
- Just like you, children of all ages need reassurance and information. It takes time to adjust, so be patient with them and yourself.

As a parent, how can I help my teenager with HCV?

Teenagers tend to think of the present and believe that nothing bad can happen to them. They also tend to have a strong desire to show independence. A lack of symptoms and the desire to fit in with friends may result in risky behaviour. These are all obstacles to getting your teenager to understand the possible long-term effects of HCV.

- Promote healthy options for personal exploration, e.g., sports, arts, hobbies.
- Encourage your teenager to talk to you or someone supportive about his/her feelings.
- Avoid overprotecting your teenager.



How can I support a family member or friend with HCV?


Having a network of people who are socially supportive is important because it helps to buffer or moderate the effects of stress on physical and mental health. Your friend or family member will cope better if information, emotional support and practical assistance are available when needed.

- Learn about HCV.
- Avoid judging the person.
- Listen to the person before trying to take over. It allows the person to express what he/she needs, wants and expects from you. You'll see where you fit in.
- Expect the person's mood and outlook to vary.
- Reinforce hope and optimism.
- Try not to neglect other relationships.
- Take care of yourself and talk to your own supportive people.

As a young man with hemophilia, how will HCV affect me?

It is difficult to feel different and usually very hard to say no to your friends if they are experimenting with alcohol, drugs and sex. Having HCV, with or without HIV, can have an impact on your lifestyle and self-esteem. To protect your health:

- Do your best to follow the treatment plans for each diagnosis (e.g. hemophilia, HCV, and possibly HIV and arthritis).
- Avoid risky behaviour such as drinking at parties.
- Practice safer sex. Although HCV is rarely transmitted sexually, you may wish to consider telling anyone with whom you had unsafe sex. Your present partner(s) may also want to get tested.
- Learn how to correctly interpret symptoms. The muscle pain associated with interferon may feel like a bleed, or a bleed may be mistaken as a side effect of treatment.


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- Get vaccinated for both hepatitis A and hepatitis B. **There is evidence that hepatitis A can cause worsening of liver disease if you already have HCV.** If you were born after 1983 you probably have been immunized against hepatitis B.

What emotions can people with HCV experience?

If you are living with HCV you may feel as if you have lost something in life due to changes in health, routine and perhaps your vision of the future. The emotions you and your family experience may mirror those felt by people going through a grieving process. Grieving is usually associated with death but people diagnosed with HCV (and other illnesses) can feel grief too, due to the sense of loss.

The following steps may not occur in this order, but they will likely touch your life at some point.

- **Shock and denial.** You may feel so numb that you act as if nothing has happened. This may help you cope initially as a sort of anaesthesia, but can become a problem if you don't take care of yourself (e.g., drinking instead of avoiding alcohol, and not seeing a health care provider).
- **Emotions erupt.** Your emotions may break out in heavy sighs or crying spells as you become more aware of your painful loss.
- **Loneliness.** You may withdraw from others that you feel "don't understand."
- **Illness.** Your body may temporarily break down due to this new stress in your life.
- **Panic.** You may not feel like your old self, or you might wonder "How will I manage?" This panic should pass.
- **Guilt.** With no ready answer on who or what was responsible for the HCV infection, you blame yourself. This will naturally lead to feelings of guilt or even anger at yourself.
- **Depression.** Commonly precipitated by feelings of isolation, hurt and sadness.
- **Anger.** Precipitated by the unfairness of your loss, your anger may be directed at your health care team, those close to you, God.

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- **Difficulty adjusting to a new situation.** You may resist letting go of your attachment to the past. You may consequently withdraw further into yourself in an attempt to analyze your own thoughts and emotions.
 - **Hope.** Eventually breaks through and begins to grow again.
 - **Affirming reality.** Involves reconstructing your life using the resiliency and strengths you have learned you possess when experiencing the grieving process. You adjust to any limitations, set new goals, and learn to appreciate your new life.

How can I deal with my feelings?

- **Go ahead, feel what you feel.** Don't tell yourself that a particular feeling is bad or try to pretend it's not there. Your feelings are natural and you have a right to them. They can even help you move on to a more comfortable state of mind.
- **Recognize your feelings.** What are you actually feeling? Sometimes one emotion is covering up a different emotion. For example, sadness might cover up feelings of anger; anxiety might indicate excitement. Admitting to yourself "I'm angry" or "I'm scared" is a big step toward coming to terms with your feelings.
- **Get to know what triggers your feelings.** What led up to the feeling? Do some people, situations or anniversary dates create a certain feeling in you?
- **Express your feeling and then let it go.** You might fear alienating friends and family, but repressed feelings can fester and grow. "Bottling" up anger, for example, can result in excessive bitterness. Expressing your feelings can be done in constructive ways that cause no damage to yourself or others. Examples include crying, talking with others, or writing in a journal.
- **Try to be as active as you can.** Activities that hold your interest will help keep your mind off fears, depression and worry. Look for people and situations in which you can invest your love and energy.
- **Reward yourself.** Give yourself something pleasant to anticipate. Set aside at least 15 minutes daily to do something you really enjoy.



How can I get emotional support?

Living with HCV can cause emotional responses that you may need help dealing with. It's not unusual to feel stressed or depressed. At those times some people may only feel comfortable talking to a family member or friend. Others may prefer to consult with a qualified therapist. There may be a local support group or organization that can arrange to have you meet others with HCV.

FINAL THOUGHTS

Current research


- Gene therapy and drug development are promising research areas.
- Techniques for screening for viruses and removing them from blood products continue to advance.
- Blood products (e.g., factor concentrates VIII and IX) will eventually become wholly synthetic (no human or animal components).

What else can I do?

- Act to encourage change. Those in authority need to hear the views and special needs of people with HCV. Encouraging governments to fund more research on treatments or to help pay for treatment are typical areas for advocacy.
- Join or set up your own support group.

Where can I get more information or assistance?

- Your health care provider
- Canadian Hemophilia Society at 1-800-668-2686 or www.hemophilia.ca
- Hemophilia Comprehensive Care Clinics (Contact the CHS for the clinic nearest you)
- Canadian Liver Foundation at 1-800-563-5483 or www.liver.ca

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- Your local Chapter of the Hepatitis C Society of Canada (Check your phone book for contact information)
 - Health Canada (www.hc-sc.gc.ca/english/)
 - Hepatitis C 1986-1990 Class Actions Settlement (www.hepc8690.ca)
 - US web site on HIV/HCV co-infection (www.hivandhepatitis.com)
 - Canadian Hemophilia Society. 2004. *Hepatitis C: Common Disabling Symptoms and Treatment Side Effects*. ISBN 0-920967-45-0
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