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Established in 1969, the Canadian Liver Foundation (CLF) was the first organization in the world devoted to providing support for research and education into the causes, diagnosis, prevention and treatment of liver disease. CLF provides information and education programs for patients, families and the general public through more than 30 volunteer chapters across the country.

Because hepatitis C is a liver disease, the Canadian Liver Foundation is committed to providing information and education about this increasingly prevalent infection. This is a rapidly changing field of medicine; information in this pamphlet is current for March 2004.

For more information about hepatitis C or other liver diseases, please call 416.491.3353 or 1.800.563.5483.

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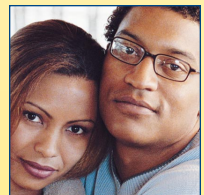
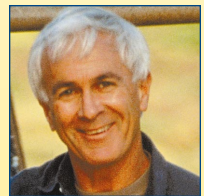
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## A COMPREHENSIVE GUIDE TO LIVING WITH HEPATITIS C

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# Hepatitis C

## **an overview** ————— **2**

Dr. Cameron Ghent  
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## **coping with the disease** ————— **8**

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## **keeping healthy** ————— **12**

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## **treatment update** ————— **15**

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# Hepatitis C: an overview

## What is hepatitis C?

Hepatitis C is a disease that affects the liver, and it is caused by the hepatitis C virus (HCV). The virus causes hepatitis (inflammation in the liver), which can progress to cirrhosis (extensive scarring that prevents the liver from performing its normal functions). Acute hepatitis means the virus has been present in the person's blood for less than six months. Chronic hepatitis means the person has had the virus for more than six months.

Before the discovery of this virus in 1989, many people were diagnosed with "non-A, non-B hepatitis". These patients did not have one of the two known types of hepatitis although they had a similar type of virus. The virus has now been studied scientifically, and many people who were diagnosed with non-A, non-B hepatitis actually had this newly discovered virus. The virus structure is now completely known, and tests have been developed to detect it. We also know there are numerous variations of HCV, and different types of the virus are found in different parts of the world.

## How is hepatitis C transmitted?

HCV is not as easily transmitted as hepatitis A or hepatitis B. The virus requires direct access to blood to infect a person, although a very small quantity of blood-to-blood contact can pass along the disease. The amount



of virus that may be present in the blood from a minor cut or nosebleed is harmless unless there is a way for the virus to enter the bloodstream of another individual,

such as through a minor skin cut, abrasion, sore, or skin puncture. People with hepatitis C should tell anyone who has contact with their blood that they have the virus in order to prevent possibly spreading the disease. This includes dentists, manicurists, tattoo artists, nurses, blood technicians, and possibly co-workers.



The two most common ways of acquiring HCV are from using needles for street drug injection and receiving transfusions of blood or blood products. Widespread use of injected street drugs in the 1960s and '70s led to many people contracting this virus. It's estimated that anyone who uses needles for street drug injection has a 70-80 per cent chance of getting this virus within the first year. This may result from sharing needles and/or sharing a vial or spoon, which has been contaminated with the virus. Sharing instruments for snorting drugs (usually cocaine) is also a risk factor for HCV. In this situation, the blood-to-blood contact may occur through frequent ulcers and injury in the lining of the nose.

Blood transfusion has been a well-known risk factor. However, the risk of infection through blood exposure in Canada has been markedly reduced and is now low (but not eliminated) through the introduction of universal testing of blood donors in May of 1990. Because hepatitis C takes a number of years to develop, some patients are still being diagnosed as a result of blood transfusion many years ago.

Getting a tattoo is another risk factor. If the needles are

new, there may still be a risk if the artist reuses ink from containers used to tattoo others. Body piercing may be a risk factor for acquiring HCV if needles are used for more than one individual (e.g. ear-piercing parties). Acupuncture is a form of body piercing that may transmit viruses if needles are reused without proper sterilization.

Any shared instrument that has been contaminated with blood can transmit HCV. These include razors, toothbrushes and nail clippers. A small unrecognized nick or abrasion can leave a microscopic amount of blood. This blood may then come in contact with another user's blood through a small nick or cut. The risk of transmitting the virus to another family member is so low that no precautions are needed, except to avoid



sharing items such as razors and toothbrushes. As well, cuts and skin sores should be covered to prevent spreading HCV to others.

Sexual transmission of hepatitis C can

occur, although there is less risk of transmission with one sexual partner. With multiple partners, it's recommended to use condoms every time. Menstrual blood can also contain the virus. The risk of a mother passing the virus to her newborn at the time of birth is less than 5 per cent, and breastfeeding is thought to be safe. Caution must be taken if a mother has cracked nipples.

Working in a health-care facility is a risk factor only when workers are exposed to blood or instruments

contaminated with blood. Accidental needlestick injuries (when a worker is poked with a needle after it was used to give an injection) may be a problem for health-care workers. If the needle has been used in a patient with HCV, there is only a 5 per cent chance of getting hepatitis C.

The majority of people who acquire HCV have one or more of these risk factors. Occasionally, someone has the virus without any of these identified risk factors. Experts admit that we have probably not identified all the ways that the virus can be transmitted.

## What symptoms does hepatitis C produce?

This disease often has no symptoms, and many people continue to feel well without realizing they have hepatitis C. The disease, however, may still be progressing and causing damage to the liver. Only a small percentage of people become sick enough shortly after getting hepatitis C to seek medical attention, and they are diagnosed with acute hepatitis. Jaundice (a yellow discoloration of the skin and the white parts of the eyeballs) rarely occurs during the first few months, and may then disappear. Many people feel well during the long "silent" part of the disease when the liver is being slowly damaged. Some experience extreme fatigue and some have persistent itchiness of the skin. A few develop a skin rash, usually around the ankles or over the shins.

The disease progresses at a variable rate. Some patients (less than 20 patients in 100) can get rid of the infection without any treatment. The disease progresses more quickly if the infected person regularly drinks alcohol. About 20 per cent of people with HCV will develop

cirrhosis 20 years after getting the virus.

After cirrhosis develops, complications may develop at any time. These include jaundice, swelling of the feet, ankles and abdomen with fluid, bleeding from large veins in the lower esophagus (swallowing tube), and encephalopathy (mental confusion). Once cirrhosis develops, the person is at higher-than-average risk for developing liver cancer; but only a small percentage of patients with cirrhosis eventually develop this complication.

## How is hepatitis C diagnosed?

There are no symptoms that clearly indicate HCV is present, and many infected individuals have no symptoms at all. HCV, however, should be suspected in anyone who has any of the risk factors described earlier. A blood test for antibodies to hepatitis C suggests that the virus is present. A more sensitive blood test (PCR



for HCV RNA) is then done to detect the actual virus in the blood. This test confirms that the virus is present, but it does not determine the severity of liver damage.

Liver enzymes

(proteins produced by the liver) are released into the bloodstream when the liver is injured. The level of these enzymes in the blood is used to determine current inflammation in the liver. This test does not determine the extent of past damage or scarring. Other blood tests, such as INR (which measures how well the blood

clots) and albumin

(a protein produced in the liver), provide some information about how well the liver is functioning.

A liver biopsy is the best means of determining the severity of liver damage, but this is usually recommended only if there is already evidence that the person has HCV and is likely to require drug treatment for the infection.

## What is the prognosis of hepatitis C?

With early diagnosis, patients can make the necessary lifestyle changes to prevent further liver damage. Care can also be taken to prevent infecting others. Most patients who acquire hepatitis C as adults, and who do not regularly drink alcohol, will never develop any life-threatening complications or die from HCV. There is some evidence that people who acquire this infection in childhood have an even slower progression to serious complications. At most, 20 people in 100 with chronic HCV develop cirrhosis of the liver over a time period of 10-30 years. Even when individuals have progressed to cirrhosis, about 85 per cent remain well for at least 5 years after diagnosis. Because the rate of disease progression varies from person to person, it's important for all individuals with HCV to be evaluated to prevent the disease from progressing quickly.



## Coping with hepatitis C

It is estimated that this virus now infects up to 300,000 Canadians and has a significant influence on their social and emotional health. Receiving news that you have the hepatitis C virus (HCV) can be a confusing and alarming experience. Typically it takes many years, even decades, before this virus begins to damage the liver and cause cirrhosis. Indeed, many patients are unaware that they have HCV until they begin to experience symptoms of liver failure.

Sickness is never welcomed nor invited into our lives, but it is a reality of being human. Receiving news of illness naturally leads to anxiety and worry. Illness is seen as an intrusion into our usual patterns of stability, comfort and sense of control over our lives. From the time of diagnosis, the presence and reality of HCV cannot be changed. You can make choices, however, as to how you accept, tolerate and adapt to the disease.

The medical course, progression and symptoms of hepatitis C can vary with different patients. Some develop few symptoms and experience the virus as a minor inconvenience. Other patients develop a progressive infection leading to cirrhosis and possibly a liver transplant. The typical symptoms of advanced hepatitis C include chronic fatigue, jaundice, fluid retention and confusion. Unfortunately, when a patient is diagnosed with HCV, there is no way to predict how advanced the disease will become.

If you have been recently diagnosed with HCV, try to live as normal a life as possible. Avoid predicting or anticipating symptoms, which may take years to develop. If symptoms do develop, deal with them one at a time in a gradual, adaptive way. Try to select and develop a style

of stress management that suits your personality. Some people are task or action oriented; others prefer to be distracted by activities such as work or a hobby. This helps them focus away from their illness.

Everyone needs and benefits from practical and emotional support. As you adapt to hepatitis C in your life, periodically evaluate your progress in coping. Are your actions, thinking and beliefs helping or harming you? Maintain strategies that are positive and effective, and avoid self-defeating behaviours and expectations. If you have persistent fatigue, conserve your energy for planned tasks. Try not to schedule too many activities in the same day. Rest if you are tired. Also, it may be helpful to adjust your expectations of yourself and consider what you realistically can and cannot control. It is normal for patients with advanced hepatitis C to be limited as to what they can accomplish. Try to set achievable goals for yourself given the reality that you are living with the virus.

When ill, some patients withdraw from other people and social situations. Work at maintaining your personal friendships. If you sense discomfort in others who know about your illness, you may want to ask them directly about their concerns. Most people are frightened by what they don't understand, and discussion can help deal with their confusion or mistaken beliefs. For example, the virus is not spread by hugging, casual contact, coughing, food or water, or from sharing cooking utensils or drinking glasses. Hepatitis C might interfere with your quality of life, but it does not prevent you from enjoying social and family relationships.

It is also important to maintain good nutrition. Patients with liver disease should follow a healthy, balanced diet and exercise moderately as their health permits. You can

read more about healthy living in the following article by Dr. Adams. Physical activities are beneficial as they help develop and maintain muscle strength. Exercise is also a stress reducer and helps to re-energize people. Don't neglect your spiritual side, however you define it. This does not necessarily mean formal religion, however, traditional faith is a comfort for many.

Hepatitis C not only affects the patient but also has an impact on the entire family. Part of adapting to illness can mean changes to the roles and responsibilities of those living with you. They may have to assume new household tasks or even leave the workplace to take care of you. Such changes can take their emotional toll on everyone. It is therefore important for both caregivers and receivers to balance their own personal and health needs. Frequently, caregivers risk "burnout" by attempting to over-extend themselves. Clear, frequent and open communication can help reduce the build up of tension that so often leads to arguments and angry words.

It is also recommended that patients and family members, including children, openly and frequently discuss their needs, concerns and expectations. These can change during the course of the illness. While young children may not fully understand a parent's liver disease, they will be aware of any new tension or change in the family atmosphere. If anxious, they may quietly worry or act out their feelings. Continue to provide them with comfort and affection as well as giving them explanations about your illness in language they can understand. Teenagers may brood or withdraw from their feelings. If they are reluctant to talk about their concerns with you, they may find talking to another relative or your doctor helpful. Every family needs to develop its own solutions to cope with its particular challenges. Although most families enjoy the support,

care and comfort that other family members provide, personal time or time alone for the patient and adult caregivers is also important. This should be included in families' discussions of their needs.

Some patients worry that their disease is a threat to other family members' health. All family members should become familiar with how the virus is transmitted to others. With the use of safe practices around the home, the risk of transmitting HCV to others is extremely low, as mentioned in Dr. Ghent's overview article.

Many patients are unable to work when they have advanced stages of hepatitis C. The resulting loss of income can place families under considerable financial hardship. Canada has numerous income maintenance programs that can help. These programs are available at the federal, provincial and municipal levels, and application forms can be obtained from the various government offices.

Despite their best efforts to cope, some patients develop poor self-esteem, anger, sadness and depression as a result of their illness. These feelings may also occur in family members. Become familiar with local resources that are available, including Canadian Liver Foundation chapters, which have support groups where members meet regularly to discuss their concerns. If you prefer to speak with a professionally trained counsellor, you can ask your doctor for a referral.



## Keeping healthy with hepatitis C

The most important aspect of keeping healthy is preventing any further damage to the liver. Alcohol (including spirits, wine, beer, light beer) is potentially



harmful to the liver and should be avoided. Regular use of alcohol allows the virus to grow more readily in the liver and in the blood so it's essential to avoid the use of alcohol if you have hepatitis C.

It is also important to avoid drugs that can damage the liver. There has been a lot of publicity about the potential danger of acetaminophen (Tylenol) in patients with liver disease. In general, acetaminophen is one of the safest and well-tested medications that physicians use. It is well known, however, that an overdose of acetaminophen (swallowing a whole bottle) can result in death from liver failure. A few cases of liver damage have been reported when alcoholic patients have taken eight extra-strength tablets on a daily basis for a long time. If patients require high doses of painkillers, alternative drugs should be discussed with their physician.

Although most medications rarely damage the liver further, it is still useful to have your liver blood tests checked after starting any new, prescribed medication. For example, sleeping pills are particularly hazardous because the liver usually filters these drugs out of the blood. When a patient has liver disease, the damaged liver cannot filter the blood properly so the patient

becomes drowsy and confused. You should check with your physician before starting any new medications.

Herbal remedies may contain unknown substances that can damage the liver.<sup>1</sup> Because herbal therapies do not require government approval, there is far less information about their effectiveness and safety. Many prescribed drugs have similarities to natural products, yet they have been rigorously tested to determine any possible interactions with other drugs. You should ask herbal product practitioners for scientific evidence that their product is effective and safe.

To prevent the possibility of getting another form of hepatitis, and risking greater liver damage, some patients obtain a vaccine for hepatitis A and B. Various hepatitis vaccines are available to make immunization fit the needs of the individual patient. The safety of these vaccines is well established.

Many patients ask if there is a special diet once they are diagnosed with hepatitis C. The most important dietary recommendation is to stop using alcohol because the virus progresses more rapidly in people who drink alcohol. Many patients take vitamins. A daily vitamin is harmless, but a high dose of vitamins is never recommended. Patients on a healthy diet should not require supplemental vitamins.

If your disease has not progressed to cirrhosis, the dietary recommendations are similar to any other person. Your diet should include lots of fresh fruits and vegetables with reduced fat, cholesterol, sugar and processed foods. If you have cirrhosis, it is important to reduce the amount of salt and protein in your diet. To reduce salt intake, patients cannot use salt shakers (including artificial salt replacements) and they must

reduce their use of processed foods, including fast food, canned foods and smoked meats, which contain large amounts of salt. Salt reduction allows fluid pills to be more effective while reducing fluid accumulation in the abdomen and ankles. To reduce the amount of protein, patients usually eat less meat and add more vegetables to their diet. Protein restriction decreases the confusion that sometimes occurs when patients have cirrhosis.

Many patients with HCV experience fatigue and insomnia. If you have this problem, you can improve your sleeping without any medications by beginning a regular exercise program. Gradually increasing your exercise (walking, fast walking, swimming, aerobics, or running) and quitting smoking are two important steps towards improved health.

#### Reference :

1. Schuppan D, Jia JD, Brinkhaus B, Hahn EG. Herbal products for liver diseases: a therapeutic challenge for the new millennium. *Hepatology* 1999; 30(4): 1099-1104

## Hepatitis C: treatment update

Treatment of hepatitis C can be challenging. Ideally, with successful treatment, patients not only feel less fatigued but they will enjoy a better quality of life. The goal is to eliminate the hepatitis C virus (HCV) from the body. When this happens, the likelihood of transmitting the virus to others is eliminated, and the risk of liver disease progressing to cirrhosis and liver cancer is reduced significantly. Achieving this goal, however, is difficult. Although HCV may initially respond to treatment, it can reappear after treatment is completed, thus continuing its slow progression towards cirrhosis.

In the past, treatment was limited to a drug called interferon. Because interferon does not have a direct anti-viral effect, it is no surprise that most patients had a very poor response. Only 6 per cent of patients were able to eliminate HCV after six months of continuous treatment with interferon. Another drug, ribavirin, has been used in combination with interferon. This has improved the success rate of treatment. Approximately 40 per cent of individuals using this combination therapy completely eliminate HCV from their body. Success ranges from 20-80 per cent, and depends on several factors: the amount of scarring in the liver; the amount of virus in the body, as well as the specific genotype of hepatitis C. These factors, along with the patient's ability to complete treatment, have significant impact on its success.

The interferon protein has been improved to a longer action formulation. This now allows for a once a week injection. Patients inject the drug just under the skin, not intravenously. Possible side effects include fatigue, low-grade fever, poor appetite, weight loss, muscle cramps,

mild hair loss, and mood changes such as irritability, anxiety, or depression. Ribavirin, which is taken orally, has adverse effects on the developing fetus so it cannot be used when pregnancy is a possibility. It also may result in nausea, rash, or significant itching.

When patients are treated with this drug combination, close monitoring is required throughout the treatment period. This will be for a minimum of three months and possibly as long as twelve months. Because of their side effects, the risk for some patients is greater than the potential benefit. All these factors are considered before using these drugs to treat patients with hepatitis C.

As mentioned earlier, the treatment goal is to eliminate the hepatitis C virus completely, which will prevent the progression of liver disease. Currently, the most effective treatment is a combination of pegylated interferon and ribavirin. After this treatment, tests are done to determine if the virus is still present. If the virus is not detected 6 months after therapy, then the progression of liver disease has been stopped. Approximately 40-80 per cent of patients are now able to eliminate this virus from their body using this combination of drugs. Other treatment options are being developed, and these drugs should have fewer side effects with a higher success rate. In the meantime, treatment and long-term follow-up care for hepatitis C patients should be managed by a physician specialist.

Sometimes, HCV progresses until the patient needs a liver transplant. Many people with HCV believe that they will eventually require a liver transplant. This is clearly not the case. Of approximately up to 300,000 Canadians who are infected with HCV, only 100 of them annually need a liver transplant. The vast majority never progress to this state of advanced liver disease.



Liver transplantation, when required, provides excellent results. Hepatitis C is the most common indication for liver transplant in Canada. It is well known that all patients will eventually re-infect the transplanted liver with the virus. Within three to five years, 15-20 per cent of these patients will have cirrhosis again. To treat recurrent HCV after transplant, most transplant physicians try to reduce the amount of the patient's anti-rejection drugs. This is an attempt to reduce the amount of active virus that can flourish when the immune system is suppressed. The combination of pegylated interferon and ribavirin is also being studied in transplant patients with HCV.

For individuals with HCV that require life-saving liver transplantation, it is comforting to know that the five-year survival rate is 80 per cent. This success rate is similar to what other liver recipients experience, and indicates that the short and long-term survival for transplant patients with liver disease is quite high.



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