



# HEPATITIS C:

Managing common symptoms  
and treatment side effects



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SECOND EDITION

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## About CATIE

CATIE is Canada's source for up-to-date, unbiased information about HIV and hepatitis C. We connect people living with HIV or hepatitis C, at-risk communities, health-care providers and community organizations with the knowledge, resources and expertise to reduce transmission and improve quality of life.

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## About the CHS

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## About this booklet

**T**he symptoms associated with **hepatitis C** and side effects from medication used to treat it can make people feel unwell. Some of these symptoms or treatment side effects may even be disabling, in that they are physical or psychological effects that negatively impact daily life. The simple chores of daily living may become hard, and some people may find it difficult to work. This booklet provides information on the common symptoms of hepatitis C and treatment side effects. **The fact that they are described here does not mean, however, that a person will experience some, or even any, of these symptoms or treatment side effects. In fact, hepatitis C has been called “the silent killer” because individuals often have no symptoms until many years after they are infected and the virus has already caused liver damage. So, if you suspect you have been infected, do not hesitate to get tested!**

Practical tips have been included for all the symptoms and treatment side effects mentioned in this booklet. These suggestions come from medical research, health care service providers and, most importantly, from other people living with hepatitis C. You can use the wisdom of others to meet your own challenges and to cope well with the changes forced on you by hepatitis C. You will also learn about websites and phone numbers that will lead to more information on hepatitis C, support and any financial assistance that may be available to you.

Having hepatitis C doesn't mean life can no longer be full and happy. It does mean that you need to *choose* to enjoy life by engaging in fun and enriching activities that hold your interest. Search for people and events that give you something pleasant to look forward to. This will help keep your focus on the present and reduce your worries.



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## Drug companies

### Hoffmann-La Roche Ltd., Canada

Pegasys (peg-interferon) and Copegus (ribavirin)

[www.rochecanada.com](http://www.rochecanada.com)

[mississauga.rochecanada@roche.com](mailto:mississauga.rochecanada@roche.com)

toll-free: 1-800-561-1759

[www.pegasys.com/injecting/hep-c-support.aspx](http://www.pegasys.com/injecting/hep-c-support.aspx) is sponsored by Genentech USA, Inc. (Roche) and is intended for American readers. It provides information on the PEGASSIST Hepatitis C Support Program. It offers up-to-date information about PEGASYS treatment, strategies on how to cope with side effects and how to stay on treatment, as well as a personalized "treatment tracker".

### Merck Frosst Canada Ltd.

Pegatron (combination of peg-interferon and ribavirin)

[www.merckfrosst.ca](http://www.merckfrosst.ca)

toll-free: 1-800-567-2594

phone: 514-428-8600

[www.beincharge.com/bic/index.jsp](http://www.beincharge.com/bic/index.jsp) is sponsored by Schering Corp., the manufacturer of PEGINTRON (the American version of PEGETRON) in the United States. It offers patient support materials such as a patient diary, treatment reminders and a resource library with information about living with hepatitis C and treatment side effects.

**Bristol-Myers Squibb Co.** NS5A inhibitor (in development)

**Johnson & Johnson** Telaprevir (approved for marketing 2011)

**Merck & Co** Boceprevir (approved for marketing 2011)

**Roche & Gilhead Sciences** Polymerase inhibitor (in development)

**Valeant Pharmaceuticals International** Taribavirin (in development) to be marketed globally (except Japan) by **Kadmon Pharmaceuticals**.

**Vertex Pharmaceuticals Inc.** Telaprevir (approved for marketing 2011)

**Episodic Disabilities Employment Network**

[www.edencanada.ca](http://www.edencanada.ca)

The Episodic Disabilities Employment Network is a network of people living with episodic disabilities from across Canada who are seeking supports to find solutions to employment challenges.

**Government of Canada, Access to Travel**

[www.accessstotravel.gc.ca](http://www.accessstotravel.gc.ca)

1-800-665-6478

Information about accessible transportation and travel across Canada.

**Government of Canada, Canada Revenue Agency**

[www.cra-adrc.gc.ca/disability](http://www.cra-adrc.gc.ca/disability)

1-800-267-6999

This website has information on federal tax services available for people with disabilities. Find out more about: GST/HST; Registered Disability Savings Plan; Disability Amount; Gasoline Tax Rebate; or Community Volunteer Income Tax Program (tax preparation clinics).

**Government of Quebec, Office des personnes handicapées du Québec**

[www.ophq.gouv.qc.ca](http://www.ophq.gouv.qc.ca)

Information (in French) about programs and services for disabled people in Quebec.

**Persons with Disabilities Online**

[www.pwd-online.ca](http://www.pwd-online.ca)

Information for people with disabilities and their family members, caregivers, employers and service providers. There is also a link to an online edition of *Services for People with Disabilities: Guide to Government of Canada Services for People with Disabilities and their Families*.

**Service Canada**

[www.servicecanada.gc.ca](http://www.servicecanada.gc.ca)

Click on the link under Health for information on federal government programs and services.

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# Introduction to hepatitis C, symptoms, treatment and treatment side effects

## What is hepatitis?

**Hepatitis is a medical term meaning inflammation (swelling) of the liver.** Hepatitis can be the result of infection by a virus. There are several types of viruses that can cause hepatitis. They are named A, B, C, D and E. Liver damage can also be caused by alcohol, medications and other chemicals and autoimmune disorders leading to other types of hepatitis.

Hepatitis C virus can cause swelling and **fibrosis (scarring)** of the liver. There are several **genotypes (strains)** of HCV. It's important to test for the strain of HCV you have for two reasons. First, some HCV strains are more easily treated than others, meaning effective treatment may take less time. Second, if you have had multiple exposures to HCV, you may be infected with more than one strain. Treatment may change according to which strain is being dealt with.

### SOS Hépatites

[www.soshepatites.org](http://www.soshepatites.org)

French language website from France with information on hepatitis C.

### World Hepatitis Alliance

[www.worldhepatitisalliance.org](http://www.worldhepatitisalliance.org)

The World Hepatitis Alliance is a non-governmental organization that represents hepatitis B and C patient groups from around the world. As a coalition of advocacy groups, the WHA is a global voice for the 500 million people worldwide living with chronic viral hepatitis B or C. In addition to various links and resources, it offers a blog.

### World Hepatitis Day

[www.whdcanada.ca](http://www.whdcanada.ca)

A website devoted to the promotion of World Hepatitis Day in Canada.

## Disability

### Canadian Hemophilia Society

[www.hemophilia.ca](http://www.hemophilia.ca)

View a document called *Federal and Provincial Support Programs*. The opportunities for grants and assistance open to people with disabilities are presented in chart format for each level of government (federal and provincial/territorial). There is also information on scholarship programs and tax benefits.

### Canadian Working Group on HIV and Rehabilitation

[www.hivandrehab.ca](http://www.hivandrehab.ca)

The Canadian Working Group on HIV and Rehabilitation (CWGHR) responds to the rehabilitation needs of people living with HIV/AIDS. CWGHR works with other health groups serving people with "episodic disabilities" to identify common challenges and work together on solutions.

### CATIE

[www.hepCinfo.ca](http://www.hepCinfo.ca)

You can type the word "disability" into the search engine to find information on disability programs in your region.

**Global Hepatitis C Network****[www.globalhepc.net](http://www.globalhepc.net)**

This website is intended to act as an information exchange. You will find a forum, newsletter, news on upcoming conferences/workshops, information on research and useful resources.

**Hépatites Info Service****[www.hepatites-info-service.org](http://www.hepatites-info-service.org)**

French language website located in France with information on hepatitis C.

**Hépatites Ressources****[www.hepatitesressources.com](http://www.hepatitesressources.com)**

This Quebec organisation's website provides information on hepatitis C as well as support and referral services.

**Hepatitis A-Z****[www.hepatitis.org.uk](http://www.hepatitis.org.uk)**

Hepatitis A-Z is a private individual's website. It offers comprehensive information on topics such as nutrition, alternative therapies and vitamins.

**Hepatitis C Support Project****[www.hcvadvocate.org](http://www.hcvadvocate.org)**

The HCSP is a registered non-profit organization in the United States that has a very current and comprehensive list of downloadable fact sheets on hepatitis C. Fact sheets are geared for patients, family members and health care providers.

**Hepatitis Outreach Society of Nova Scotia****[www.hepatitisoutreach.com](http://www.hepatitisoutreach.com)**

A website with hepatitis C-specific information, fact sheets and links to other hepatitis C websites.

**Ontario Ministry of Health and Long-Term Care****[www.health.gov.on.ca/english/public/program/hepc/hepc\\_mn.html](http://www.health.gov.on.ca/english/public/program/hepc/hepc_mn.html)**

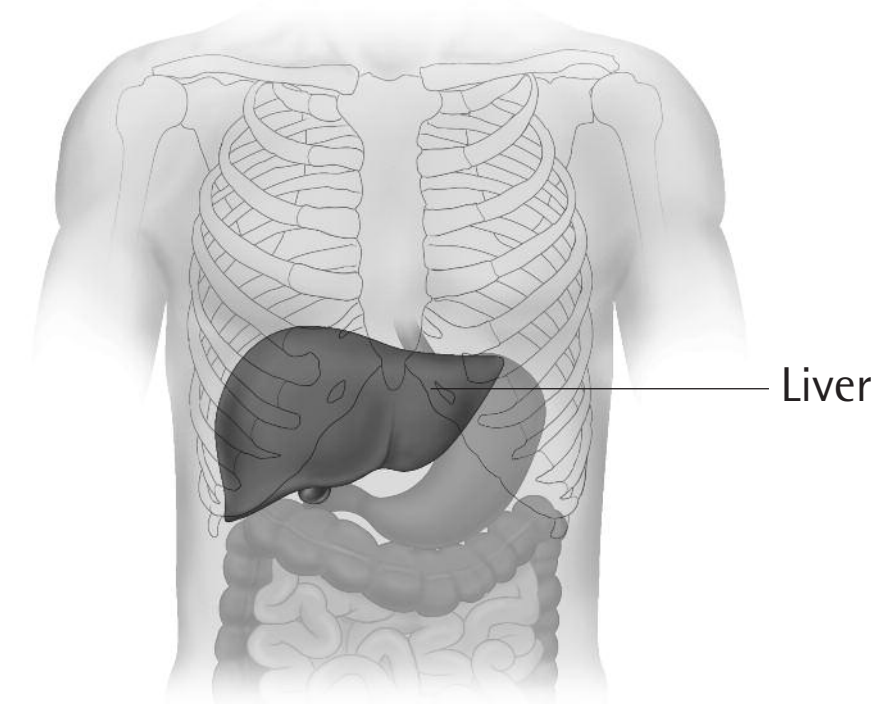
An informational website on hepatitis C, with emphasis on Ontario resources.

**Public Health Agency of Canada****[www.phac-aspc.gc.ca/hepc/rl-cd-eng.php](http://www.phac-aspc.gc.ca/hepc/rl-cd-eng.php)**

View this web page to access HCV resource material available through the Government of Canada. The online resource library has the Canadian Consensus Guidelines for HCV treatment and management. Look for the document entitled *Management of Chronic Hepatitis C: Consensus Guidelines*. The guidelines give detailed information on treatment, including dosage and length of treatment based on HCV genotype (strain).

## About the liver

The liver is the largest organ in the human body. It is on the upper right part of the abdomen, just below the diaphragm and underneath the rib cage.



The liver is your body's filter for breaking down and removing harmful substances in everything you eat, drink, absorb through the skin and even breathe in. The liver neutralizes and then removes these toxins from your body. The liver also has the important job of changing nutrients in the food you eat into energy your body can use.

The liver is also important for these essential body functions:

- Producing bile, which helps with digesting food and absorbing important nutrients;
- Controlling the rate of production and elimination of fat, cholesterol and hormones;
- Storing sugars, vitamins and minerals;
- Metabolizing alcohol, drugs and toxins;
- Clotting blood;
- Fighting infection and removing bacteria from the blood stream.

## What may happen to someone infected with hepatitis C?

The first phase of HCV infection is called **acute hepatitis C**. For most people, this stage lasts only a few weeks to a few months. If the virus stays in the body for more than six months, this second phase of the disease is called **chronic hepatitis C**.

### Acute hepatitis C

If you become infected with HCV, there is a chance that the virus in your blood will become undetectable even without treatment. This is a very good indicator that there will be no lasting effects for you. This happens for approximately 15 to 25 percent of people who experience acute hepatitis C, although some research studies have put the percentage as high as 50 percent. Phrases used to describe this phenomenon include "clearing the virus", "spontaneous clearance" or "spontaneous recovery".

### Chronic hepatitis C

Over the course of 25 to 30 years, healthy liver cells are replaced by scar tissue and there is roughly a one in four chance of getting **cirrhosis (extensive scarring of the liver)**. Cirrhosis may reduce the liver's ability to function and therefore it can lead to serious life-threatening illness. Two factors that increase a person's risk of death when living with HCV are ongoing injection drug use or heavy alcohol consumption. But even with cirrhosis, it is possible that you may still feel healthy. About two to five percent of people with cirrhosis experience **liver failure** each year. For every 100 people who get hepatitis C, roughly two or three will develop **liver cancer (hepatocellular carcinoma)**. Liver cancer only occurs when there is cirrhosis of the liver. Your doctor may ask you once or twice a year to get screened for liver cancer. The screening tests are an ultrasound and a blood test for a protein (alpha-fetoprotein) produced by cancer cells.

## Hepatitis C

### American Liver Foundation

[www.liverfoundation.org](http://www.liverfoundation.org)

The ALF has downloadable information sheets on a variety of liver disease topics.

### Canadian Coalition of Organizations Responding to Hepatitis B and C

[www.canadianhepatitiscoalition.ca](http://www.canadianhepatitiscoalition.ca)

The coalition is an advocacy organization focused on uniting organizations and individuals to:

- a) increase public attention on hepatitis B and C; and
- b) pressure government at all levels to commit funding to the prevention, care, treatment, support and research of hepatitis B and C.

### Canadian Hemophilia Society

[www.hemophilia.ca](http://www.hemophilia.ca)

The CHS has information and resources related to HCV, HIV and co-infection on its website. Its members continue to advocate for better care and treatment for people infected by HCV and/or HIV.

### Canadian Liver Foundation

[www.liver.ca](http://www.liver.ca)

The Canadian Liver Foundation is an organization with a mandate to promote liver health and reduce the impact of liver disease through research and education. Volunteer chapters across Canada reach out to liver disease patients and their families. You can download the booklet *Healthy Living with Viral Hepatitis*.

### CATIE

[www.hepCinfo.ca](http://www.hepCinfo.ca)

CATIE's plain-language website on HCV has information for infected people and service providers including a national directory of hepatitis C services.

### Centre Associatif Polyvalent d'Aide Hépatite C

[www.capahc.com](http://www.capahc.com)

This Quebec organisation's website provides information on hepatitis C as well as support and referral services.



Books can help you understand hepatitis C better. Just reading about people who are experiencing similar problems can be reassuring. Authors, however, sometimes try to prove their point of view by giving data that best argues their case. See what evidence is provided to support a specific treatment or service. Is the content detailed or vague? How did the author become an expert on the subject? A health care provider or someone else whose judgment is trustworthy may know of a good book.

Look for the most current information available in other formats because knowledge about hepatitis C and its treatment is changing fast. There are many websites on the Internet (see next pages) that may be useful. The quality of the website's design and links may offer clues to the accuracy of the information. Check to see if the original source of the information is stated. Reputable websites will have a clear cautionary statement saying its advice is informational only and not to be taken as a substitute for visiting a hepatitis C medical professional.



## Symptoms of hepatitis C

Symptoms, if they appear, can range from mild to severe. They may be barely noticed or they may be a big problem for you. Symptoms usually develop gradually and because they can appear and disappear you may experience periods of both good and poor health. Symptoms during the chronic phase may last several weeks or months at a time. However, rather than coming and going, it's possible that symptoms may disappear altogether. **You should also be aware that the symptoms listed in this booklet are not necessarily caused solely or partially by the hepatitis C virus. It is recommended that you consult with a doctor to rule out other sources of the problem(s).**

A symptom (or treatment side effect) may differ from person to person in these ways:

- How often it appears (frequency);
- How much the individual feels it (intensity);
- How long it lasts (duration).

The reason why people with HCV experience symptoms differently may be related to their age, general state of health or the lifestyle they're leading. Also, the liver has a large reserve of cells and so it may function quite normally even when part of it is being destroyed at a slow rate.

All these factors together mean that the degree to which a symptom impacts your ability to work or carry out other daily activities may not match the degree of damage actually done to your liver. For example, you may feel well enough to work even though your liver is quite damaged. Or, you may not be able to work even though tests show little or no damage to your liver. As a result, the people in government and with insurance companies who decide your eligibility for disability benefits may use different definitions for "an HCV-related disability". In other words, the criteria for qualifying for disability benefits may depend on test results showing liver damage or on your ability to work, whether you have symptoms or not.

**The goal of treatment is to get rid of the hepatitis C virus from the body.**

## What is treatment?

**Current treatment for HCV uses a combination of the drugs peg-interferon and ribavirin.** Interferon is given by a once-a-week injection and ribavirin is taken every day in pill form. Your weight may determine the dosages for these drugs. How long you have to take these drugs depends on the genotype (strain) of the virus you have.

**The goal of treatment is to get rid of the hepatitis C virus from the body. A patient is said to have reached a sustained virologic response (SVR) if the virus is undetectable (cannot be measured) in the blood six months after treatment.** For the majority of people who achieve an SVR, the virus does not come back and liver damage is stopped or even reversed. Your chances of obtaining an SVR increase if you are strict in taking all your medication at the appropriate times. Some patients even get a **rapid virologic response (RVR)** at week four or an **early virologic response (EVR)** at week 12 of treatment. If you have either an RVR or an EVR, it means that a blood test was unable to detect HCV in your blood. This is good news because it's an excellent sign that your treatment is working and may take less time than your treatment provider originally thought.

### Will treatment "cure" me of hepatitis C?

For many patients, the hepatitis C virus cannot be found in their bodies after treatment is finished. If you are still free of the virus six months after treatment, **it is very unlikely that the virus will ever return**, and the liver damage due to HCV will have been stopped. It would then be reasonable for you to feel very confident that you have been "cured" of the hepatitis C virus.



## Resources and links

### Tips for finding helpful health information

Following a diagnosis of HCV, people often want to find out what they can do to avoid developing health problems. If health complaints already exist, they may want to learn how to manage them better so they can maintain or improve their health. National organizations with local offices may be able to help.

#### TIPS

Here are some tips when telephoning an organization for more information:

- ✓ Write down your questions ahead of time so you don't forget some of them.
- ✓ Try to be clear when explaining your situation so that you get a specific answer to your question(s).
- ✓ Ask for an explanation if the answer doesn't make sense.
- ✓ If the organization has a service that sounds useful, ask if there is a fee and if a doctor's referral is needed.
- ✓ If the person on the phone can't help you, ask for a referral to someone who can help.

### Special considerations when disclosing to children:

If you have children, it's probable they may sense something is wrong, even if they don't know exactly what it is. If you try to hide symptoms from them, your children may think things are even worse than they really are. A problem may be created in which your children experience more worry from not knowing the reason behind the visible effects of HCV or its treatment on you.

Check Internet sites for help in finding age-appropriate language to use in your explanation of hepatitis C and its effects on you. HCV infection can be a complicated disease and it's hard to describe in simple terms. Children and teens may need many medical words explained to them as their health literacy is not at an adult level.

- ✓ Practice your explanation beforehand so that you can anticipate and then focus on your children's response.
- ✓ Assure your children that it was nothing they did that caused your infection. Be sure to say that your illness has nothing to do with how much you love them.
- ✓ Be as honest as you can. Telling your children that you'll be all better will only make them more upset if it turns out not to be true. On the other hand, being pessimistic can scare them needlessly. Don't be afraid to say "I don't know" if you don't. For children, the amount of information you give them is less important than making them feel comfortable with what you say.
- ✓ Tell your children it's okay to have lots of different feelings and that you do, too.
- ✓ Be careful not to burden your children with too much responsibility. It's okay to give them age-appropriate tasks so they will feel less helpless. This is especially important during the long period of time it will take them to fully understand any type of change that's imposed on the family.



## What is peg-interferon?

Interferon is made by your body in response to a virus in your system. Peg-interferon is an engineered version of this chemical, with a *polyethylene glycol (PEG)* molecule attached to it to keep the levels of interferon higher in your bloodstream for longer periods of time.

There are two forms of peg-interferon used for HCV treatment. Both have been shown to be effective. Peg-interferon alpha-2a is called **Pegasys** and is made by Hoffmann-La Roche Ltd., Canada. Peg-interferon alpha-2b is called **Pegetron** (when sold in combination with ribavirin) and is made by Merck Frosst Canada Ltd.

## What is ribavirin?

Ribavirin is an antiviral drug that has been shown to be effective against HCV when combined with peg-interferon. There are two forms of ribavirin on the market. **Copegus** is made by Hoffmann-La Roche Ltd., Canada, and is sold with its brand of peg-interferon called Pegasys. Merck Frosst Canada Ltd. makes ribavirin in combination with peg-interferon and calls the package **Pegetron**.

## Treatment side effects

**Treatment side effects are common and in some cases the patient may feel worse than he or she did with HCV.** Some people may even stop treatment, although this is the case for only about 10 percent of patients. Not everyone experiences the same side effects from the same drug. Your doctor may be able to change the dosages of your treatment or give you other medications to lessen the side effects.

Since medication may stay in your body for a while after treatment, side effects may not disappear overnight. Side effects from interferon can last up to six months, whereas side effects from ribavirin should stop about 15 days after treatment has ended.

## IMPORTANT

- **About 10 to 15 percent of patients taking peg-interferon/ribavirin treatment experience major depression.** For this reason, you should be assessed for depression before and during treatment so that serious risk to yourself can be prevented. Feeling depressed is a major reason why people stop treatment. On a positive note, scientists are trying to find genetic factors that will predict whether or not you carry a greater risk of experiencing depression if you take peg-interferon. For information on how to manage depression, check under MOOD CHANGES on page 41. Depression usually ends two to four weeks after stopping treatment.
- **There is a potential for birth defects if you are pregnant and being treated with ribavirin.** If you're pregnant or thinking of getting yourself or your partner pregnant, you won't be able to go on treatment because ribavirin can cause deformities in the fetus. Health care providers recommend or even require that two forms of birth control are used, regardless of whether it is a man or a woman receiving HCV treatment. Also, women undergoing treatment are strongly advised to have regular pregnancy checks. Continuing to use contraception, for both men and women, is recommended for six months following treatment.
- **There are also uncommon but serious side effects.** Heart problems such as arrhythmia (irregular heart beat) can be caused by peg-interferon. Ribavirin may worsen an existing heart condition by causing anemia (lowered red blood cell count). Also, an auto-immune disorder (a disorder in which the immune system attacks the body's own tissues) may be set off by these HCV medications.



## TIPS

**In all likelihood, you'll have to rely on your instincts in order to make good decisions about whom to tell, the best time to tell and what to say. Here are some tips for when the time comes for you to disclose you have HCV:**

- ✓ Think about those people who, if they knew, would help you get proper medical care. These could include, for example, your doctors (for appropriate treatment) and dentist (in case of dental surgery).
- ✓ Think about those people who have been exposed to your blood.
- ✓ Think about those people who, if they knew, would be able to minimize the risk of transmission to themselves and to others. These could include, for example, service providers such as acupuncturists, tattoo artists and manicurists.
- ✓ Think about your boss. Since hepatitis C is not spread through ordinary workplace activities, you're under no legal obligation to tell people at work about your infection. However, if your work is poor because of illness, you may choose to tell your boss that you have a health condition that may require some kind of accommodation by your employer to help you out. If you disclose your HCV status to your employer, then the employer is not legally permitted to tell other employees or employers without your consent.

**Here are some additional tips to help you when disclosing to people in your personal life, such as family members and friends:**

- ✓ For your very first disclosure, just choose *one person* you think will not only be understanding, but will respect your wish if you don't want him or her to tell others without your permission.
- ✓ Think about how much personal information you know about the person to whom you are planning to disclose. If you tell a person who hasn't shared much about himself/herself, then that person may feel uncomfortable when you unexpectedly increase the level of intimacy between yourselves.
- ✓ People tend to respond better to those whom they see as really trying hard to cope better. So, when talking about HCV, try and strike a balance between the problems you've been facing and those things that you're doing to deal with the problems.
- ✓ Reassure the person that she or he is not expected to have any answers.

- Breastfeeding is considered safe as long as the mothers' nipples are not cracked and/or bleeding.
- Blood spills should be cleaned up with a mixture of one part bleach to nine parts water.

#### Societal awareness

A Canadian Hemophilia Society Needs Assessment on HCV/HIV Co-infection found that people who were coping well were often more open about the diseases. Respondents did not view HCV and HIV as a social problem and felt that, **over time, it became easier to talk about their positive status as societal awareness of these infections has grown.**

On the topic of disclosure, one interviewee in this research study stated:

*"Most of my friends know I have HIV, HCV and hemophilia. They're quite understanding. For example, last week I ended up in hospital and they were all there to support me. So it's been, if anything, a benefit because I've been able to be closer with my friends. It's created a more intimate relationship and my friends act as an informal support network."*

Another participant said:

*"I don't shy away from disclosure. I'll tell anybody to their face about everything I'm living with. I've never been turned away by anybody ever. But I figure if they did turn away from me, I don't want to know them anyway."*

The most important point in disclosure is this: **Consider your own needs first and foremost and say only what feels comfortable.** Disclosing any medical condition can be risky and some people may not be able to handle what you tell them. On the other hand, you may be pleasantly surprised to find out what someone else is thinking and feeling. The vast majority of people who disclose to a trusted confidante are really glad they did.



## Common hepatitis C symptoms and treatment side effects with **TIPS** for coping with them

# Symptoms and side effects chart

	PAGE NO.	SYMPTOMS OF		SIDE EFFECTS OF	
		HEPATITIS C	CIRRHOSIS OR LIVER FAILURE	PEG-INTERFERON TREATMENT	RIBAVIRIN TREATMENT
<b>TIREDFNESS AND WEAKNESS</b>	<b>15</b>				
Extreme tiredness (fatigue)	15	X		X	
Lowered red blood cell count (anemia)	17				X
<b>PAIN AND SORENESS</b>	<b>19</b>				
Flu-like symptoms	19	X		X	
Headache	20			X	
Lowered white blood cell count (neutropenia)	21			X	
Right upper side discomfort	22	X			
Tingling or burning sensation (paresthesia or peripheral neuropathy)	24	X			
<b>EATING PROBLEMS</b>	<b>25</b>				
Dry mouth (xerostomia)	25			X	
Loose or watery bowel movements (diarrhea)	26			X	X
Loss of appetite (anorexia)	27	X	X	X	
Nausea	28	X		X	
Sores (ulcers) in the mouth	29				X
Taste changes	30			X	
Fluid build-up (ascites or edema)	31		X		
<b>SKIN CONDITIONS</b>	<b>32</b>				
Blisters (porphyria cutanea tarda)	32	X			
Blotchy skin (cryoglobulinemia)	33	X			
Hair loss (alopecia)	34			X	
Itchy skin (pruritis)	35		X	X	X
Needle irritation (injection site reactions)	36			X	
Purple or shiny, itchy bumps (lichen planus)	37	X			
Yellowing of the skin (jaundice)	38	X	X		
<b>BLEEDING</b>	<b>39</b>				
Vomiting blood (esophageal varices)	39		X		
Lowered platelet count (thrombocytopenia)	40		X	X	
<b>MOOD CHANGES</b>	<b>41</b>				
Depression	41	X		X	
Low sex drive (loss of libido)	47	X			
Stress (emotional strain or tension)	49	X			
<b>NEUROLOGICAL CHANGES</b>	<b>51</b>				
Extreme confusion (hepatic encephalopathy)	51		X		
Problems with thinking ("brain fog")	52	X			
Sleep problems	53	X	X		

## How is hepatitis C transmitted?

HCV is transmitted by blood-to-blood contact. This means a person can get HCV if blood containing the virus gets into his or her bloodstream. Here is some important information to know about transmission:

- The easiest way to spread HCV is by sharing needles and other drug equipment.
- Tattoos, body piercings and acupuncture may also spread the virus if proper safety measures are not used.
- Receiving a blood transfusion after 1992 is considered safe in Canada due to advances in HCV-detection testing carried out by the blood supply system.

## What is the degree of risk of infection?

People who share your life may want to know the following information:

- People **cannot** catch HCV from you through casual contact, such as shaking hands, sharing kitchen utensils, hugging or kissing.
- Sharing personal items, such as tooth brushes, razors and nail files, carries a minimal, but still possible, risk.
- HCV has rarely been detected in semen and vaginal fluids. Therefore, most experts believe the risk of sexual transmission of HCV is low, but not zero. The risk increases depending on the kind of sex and the likelihood of blood-to-blood contact during sex. The risk is reported to be as low as 0.3 percent in monogamous heterosexual couples who have unprotected intercourse over the long term. However, if you have several partners, it is recommended that you use a condom to prevent many exposures to sexually transmitted diseases, not just HCV. With regard to disclosure of HCV before sex, the best practice is to tell your partner before intercourse; it is unclear whether people infected with the hepatitis C virus have a legal duty to tell their sex partners before sex, but until the courts figure this out, disclosure beforehand may be best.
- A woman who has HCV and gets pregnant has about a one to four percent chance (depending on the research study) of having a baby born with HCV. This mother-to-child route of infection is called **vertical transmission**.

## Sharing information about a hepatitis C diagnosis

Having to deal with the social stigma of hepatitis C is a major concern for many patients. For some, an HCV-positive diagnosis will lead to low self-esteem, social isolation and disclosure problems. There are many examples throughout history where society has not responded with compassion, understanding and support towards a disease. Society is quick to assign meaning and moral judgment, as it does with HCV. People who are sick are often judged as bad and then cast aside as being marginal. This attitude is due to ignorance and fear.

People tend to look to their culture to give meaning to a particular disease. Unfortunately, some people with HCV and those around them may share a belief system – especially beliefs that blame the victim – that creates stigma rather than encourages others to embrace the infected person.

Stigmatization is particularly damaging because it may alter your interpretation of your own personality characteristics. This is a huge problem. If you feel shame or disgrace, then it is not likely you will feel accepted for who you are. That, in turn, could prompt you to interpret things in a more negative way or prevent you from seeing the possibility of positive options.

To counteract the effects of stigma on self-esteem, you can take a couple of steps:

- Ask yourself if you are feeling or behaving differently since you found out you were infected. Go easy on yourself and recognize that you are a person with unique qualities and worth knowing as an individual.
- Do not let hepatitis C define you as an individual.

A Canadian Hemophilia Society Needs Assessment gave clear direction in terms of what kind of strategies are useful for reducing HCV-related stigma. These are:

- knowing how hepatitis C can be transmitted;
- knowing the degree of risk of infection;
- increasing societal awareness.

## Extreme tiredness (fatigue)

### DESCRIPTION

Extreme tiredness is also called fatigue. People often describe it in terms of having “good days and bad days”. Sometimes a string of good days will be followed by days of feeling totally “wiped out”. For other people, fatigue is a daily companion. They feel extremely tired in the morning and completely exhausted before the end of an ordinary workday. They experience a total lack of energy to the point of feeling unable to make any physical or mental effort. This feeling happens even after a full night’s sleep. Experiencing pain and discomfort adds to tiredness by causing loss of sleep and sapping energy during the day. Such a state of chronic weariness may cause a lot of negative changes in life. For example, extreme tiredness can ruin your interest in fun activities and cause you to be impatient with others.

### CAUSE

Extreme tiredness is the most common symptom of HCV. Fatigue is also a side effect of peg-interferon. Severe fatigue may even develop in people whose tests show few or no changes in the liver.

### TREATMENT

- **Start a gentle exercise program:** Being physically inactive will eventually cause your muscles to weaken and you will lose strength and stamina. It would then not be a surprise if you began to avoid even the simplest of chores because it would require a major effort. Start a gentle exercise program, such as walking, that gradually increases in difficulty as you recover your strength and stamina.

### TIPS

- ✓ **Plan peg-interferon injections:** Make sure you can rest the day after your peg-interferon injection.
- ✓ **Plan ahead:** Plan your day so that you have time to rest. Take several breaks or short naps rather than one long rest period.
- ✓ **Save your energy:** It is important to remain physically active if you are able. However, there may be times, particularly if you are on treatment or have advanced liver failure, where you may need to conserve your

energy. Look around your home or workplace and see if you can reorganize the environment so you spend less time in energy-sapping positions like bending, reaching or pulling. For example, lower your shelves, use an assistive device, such as an electric can opener, or keep equipment all in one area. Your kitchen is a good place to start your reorganization. Other tips to try: use a cart with wheels for transporting heavy items like groceries and laundry; use delivery services; double your recipes when you cook so you'll have leftovers to freeze; and have a homemaker service (if you can afford it) deal with heavy household chores.

- ✓ **Ration energy by pacing yourself:** On days that you feel well, you're probably tempted to do all you can to catch up. Try not to overdo it. It is a much better strategy to balance activity with rest or to alternate between a heavy and a light chore. Making to-do lists, in which you write tasks under headings such as must do, heavy chore and light chore, may help to clarify which jobs are high priority. As you go through your day, take a moment to estimate the energy you have left and match it with an activity or chore remaining on your to-do lists.
- ✓ **Be aware of your "windows of energy":** Take notice of any pattern to the changes in your energy level over the course of the day. Do you feel strongest during the morning or mid-afternoon? Take advantage of this pattern by saving the hardest things to do for the time when you are most energetic. Try an easier or shorter version of an activity you enjoy rather than give up because you cannot do it for as long as you would normally like.
- ✓ **Ask for help:** Try not to let feelings of pride or guilt stand in the way of getting help with an exhausting task. Inviting others to share your difficulties often eases the burden of extreme tiredness. A support group is an excellent place to learn coping tips from other people going through a similar experience.

- a) **Boceprevir** may increase the sustained virologic response success rate towards 66 percent. The most common side effect is a low red blood count (anemia).
- b) **Telaprevir** may increase the sustained virologic response success rate towards 75 percent. Side effects may include extreme tiredness, itchy skin or rashes, nausea, headache, low red blood cell count (anemia), sleeplessness, fever and diarrhea.

Other drugs under evaluation include **NS5A inhibitors** and **polymerase inhibitors**. Clinical trials are underway to investigate the safety and effectiveness of drug combinations (for example, **danoprevir**, a protease inhibitor, and **RG7128**, a nucleoside polymerase inhibitor) to treat HCV. This may eventually provide treatment options that are better tolerated that do not include interferon.

#### **Ribavirin replacement**

**Taribavirin** has similar drug properties to ribavirin. However, it is less able to enter red blood cells and is therefore less likely to cause anemia (low red blood cell count). Research has compared the two drugs and found that taribavirin achieved comparable results to ribavirin when combined with peg-interferon. Therefore, taribavirin may be a welcome addition to the treatment of patients who are sensitive to ribavirin-related anemia.

#### **Therapeutic vaccines**

Therapeutic vaccines are being developed that are designed to get rid of liver cells carrying HCV by helping the immune system target the virus. However, research remains in the early stages and vaccines as treatment will not be available to Canadians in the near future.



## Liver transplants

Liver disease due to chronic hepatitis C is the primary reason for liver transplantation in Canada. A liver transplant is not performed until a person experiences liver failure. Transplantation is a surgical procedure that can help a person survive. Achieving a sustained virologic response through HCV therapy appears to increase protection against death in liver transplant patients. Liver transplantation is very successful in Canada, although the hepatitis C virus can return. Having a liver transplant also means that you will likely have to take anti-rejection drugs for the rest of your life to prevent your body from rejecting the transplanted liver.

## Treatments not yet available at time of publication

Although they are not yet approved, the treatments described below have earned optimism within the hepatitis C community based on research results in clinical trials. A pharmaceutical company must successfully go through many stages of pre-clinical and clinical trials (evaluations) of an experimental new drug before it is accepted by government health authorities for use in each country. This is to ensure the drug is safe for humans and the consumer is aware of both the risks and benefits of taking the drug. A drug is said to be "in the pipeline" when it is undergoing this drug evaluation process. Clinical trials are conducted around the world, but each pharmaceutical company must satisfy Canadian health regulations before its drug can be prescribed and sold in Canada.

### Protease inhibitors

The addition of a third medication to the peg-interferon and ribavirin combination therapy may possibly result in a dramatic change to HCV treatment, including the length of time people are required to be on treatment. A protease inhibitor slows down or even stops an HCV cell from making copies of itself by blocking the work of the protease enzyme needed for the HCV replication process to work. The addition of a protease inhibitor may offer hope for those patients for whom the standard peg-interferon/ribavirin treatment did not work. There are two protease inhibitors that will likely be approved for use in 2011.

## Lowered red blood cell count (anemia)

### DESCRIPTION

Red blood cells (erythrocytes) transport oxygen to body tissues. If your body's tissues don't get enough oxygen, your body won't be able to stay healthy. A low red blood cell count is called anemia. This condition may cause extreme tiredness and weakness, shortness of breath, which may cause a person to feel faint or dizzy, dry cough, and rapid heart rate.

### CAUSE

Ribavirin interferes with the production of red blood cells. About 22 percent of patients on this drug will experience anemia.

### TREATMENT

- Your doctor may reduce the dose of ribavirin.
- Your doctor may add epoetin, which is a man-made version of erythropoietin (EPO). EPO occurs naturally in the body and boosts production of red blood cells. The use of epoetin allows for a higher dosage of ribavirin and in studies this has led to a higher rate of patients achieving a sustained virologic response. There are two different products available in Canada for epoetin known by the brand names **Eporex** and **Aranesp**.
- Severe anemia is sometimes treated with a blood transfusion.

### TIPS

- ✓ Regularly see your health care provider to get a blood test called a complete blood count (CBC), which measures red cells, white cells and platelets.
- ✓ Your doctor may send you to a laboratory for a blood test to check if you are deficient in any of the following red cell production factors. If so, taking the appropriate supplement may help with anemia.
  - a) Folic acid.
  - b) Vitamin B12.
  - c) Iron (absorption of iron may be enhanced by taking vitamin C). However, an iron supplement should be avoided if you have cirrhosis.

- ✓ Changes to your diet may help:
  - a) Eating beets will help red blood cells take up oxygen.
  - b) Seeds (for example, sunflower, pumpkin and sesame) are a source of high energy and will help with the tiredness caused by anemia.
  - c) Your doctor may advise you to eat more red meat, especially beef and liver, because it is rich in iron. Eating shellfish and the dark meat of poultry (for example, turkey and chicken) will also raise your iron levels. Other foods that are good sources of iron include dark green leafy vegetables (for example, spinach or kale), peanuts, eggs, beans and dried fruits (for example, raisins).



Ultimately, the decision to treat the two diseases at the same time or one after the other is yours, but to make an informed decision you will probably require your doctor to assess what stage HIV disease you have (as measured by CD4 count). The HCV therapy will still consist of the standard doses of peg-interferon and ribavirin for 48 weeks, but the medication for HIV may need to be changed because of the potential for drug interactions.

### TIPS

- ✓ Have your liver enzymes checked regularly.
- ✓ Get screened for liver cancer because early detection will lead to more effective treatment and an improved chance of survival.
- ✓ Use caution before stopping HIV antiretroviral treatment. There is strong research evidence to conclude that the interruption of antiretroviral therapy for people with HIV who are co-infected with either HCV or HBV is particularly unsafe. For example, stopping your HIV antiretroviral treatment may have the following negative effects:
  - a) It may increase your risk of dying from a non-AIDS condition, including heart, kidney and liver disease. In the case of death from liver disease, treatment interruption speeds up the rate of fibrosis (scarring in the liver) and this may lead to advanced liver disease, including cirrhosis.
  - b) It may increase your risk of getting an opportunistic disease. Co-infected people are advised to be carefully monitored for the development of an AIDS-defining illness (any medical condition from a long list that will automatically result in a diagnosis of AIDS if you are HIV positive).
  - c) It may increase the risk of HBV coming back. Since several antiretroviral drugs for HIV also work against hepatitis B, treatment interruption increases the risk of HBV returning (this is called viral load rebound or virus reactivation).

## Hepatitis C and HIV or hepatitis B co-infection

Co-infection with HCV and **HIV (human immunodeficiency virus causes *acquired immune deficiency syndrome, or AIDS*)** or **HBV (hepatitis B virus)** means that a person has both viruses.

For an HIV-HCV co-infected person, the progression towards liver damage often occurs more quickly. Cirrhosis may occur in 10 to 15 years rather than 20 to 30 years, for example. This may happen because HIV decreases the body's immune response, thereby letting HCV progress more easily. In fact, a leading cause of death for HIV-HCV co-infected patients is from liver failure. Medical scientists are currently investigating the possibility that there is a greater risk for developing problems in the way your brain works if you are HIV-HCV co-infected. When a pregnant woman is co-infected with HCV and HIV, there is a greater risk that her baby will be born with HCV.

In patients infected with both hepatitis B and hepatitis C, only one of the two diseases is usually active. Your doctor will likely recommend you get the standard treatment for whichever of the two viruses is dominant. In most cases, this will be hepatitis C. If you have HCV-HBV co-infection, liver damage can progress more quickly and your liver disease may be more severe. Patients with HCV-HBV co-infection are also at a much higher risk of developing liver cancer.

### The impact of HIV on hepatitis C treatment

The rate of success (about 25 to 50 percent, depending on the strain of HCV) of currently available HCV treatment is lower for those who are HIV-HCV co-infected. If you have never been on HIV or HCV medications before, your doctor will probably suggest treating one disease first. If your liver is doing badly and your immune system is strong, then HCV treatment may be recommended first. If your liver damage is minimal and your immune system is functioning poorly, then HIV treatment may be recommended first.

## Flu-like symptoms

### DESCRIPTION

With flu-like symptoms, your muscles may feel sore and your joints may ache. Fever, swollen glands and chills often follow. There may also be excessive sweating at night during sleep.

### CAUSE

Flu-like symptoms are common with hepatitis C. Peg-interferon may also cause flu-like symptoms, but in most cases these symptoms lessen after two or three weeks of taking the drug.

### TREATMENT

- Ask your doctor about painkillers such as Tylenol (acetaminophen) or Advil (ibuprofen). Carefully follow dosage directions because even over-the-counter medications can damage your liver if you use them too much.

### TIPS

- ✓ Drink plenty of water.
- ✓ Apply heat or ice packs (wrapped in a towel) to areas where you ache.
- ✓ Since flu-like symptoms are linked to peg-interferon, timing your peg-interferon injection close to bedtime may let you sleep through the worst of the discomfort.

# Headache

## DESCRIPTION

About 40 to 60 percent of patients will experience headache ranging from mild to severe, but for most people it is a mild headache that comes and goes.

## CAUSE

Headaches are a side effect of peg-interferon.

## TREATMENT

- Ask your doctor about painkillers such as Tylenol (acetaminophen) and Advil (ibuprofen). Carefully follow dosage directions because even over-the-counter medications can damage your liver if you use them too often.

## TIPS

- ✓ Drink water frequently.
- ✓ Avoid bright lights and loud noises by sitting or lying down in a quiet, darkened room.
- ✓ Avoid dehydrating drinks such as alcohol or liquids with caffeine in them.
- ✓ Put a damp, cool cloth on the back of your neck or forehead. Alternatively, you may find a warm compress works better for you.



when the body's own antibodies attack tissue in the lining of the joints) has been linked to HCV. Arthritis can cause pain, swelling, stiffness and limited range of motion in the affected joints.

Although a direct link between hepatitis C and insulin resistance or **type 2 diabetes** (the inability of the body to get energy from carbohydrates or sugar in the food you eat) has not been clearly established, type 2 diabetes is found more commonly in people with HCV than the general population. However, successful HCV treatment appears to reduce the risk of type 2 diabetes for patients. Type 2 diabetes can be controlled through medication and changes to the diet (healthy eating).

**Thyroid disease** may be triggered by HCV. Additionally, medical research indicates that people with chronic hepatitis C may have as much as double the risk of getting **non-Hodgkin's lymphoma** (a type of cancer that begins in the lymphatic system). However, successful HCV treatment appears to reduce the risk of non-Hodgkin's lymphoma for patients. There is also growing evidence that HCV may increase the risk of **cerebrovascular disease** (stroke).

**For all the non-liver health problems associated with hepatitis C, the number one tip to follow is to seek medical care — there may be medical treatments that can help you.** A health care provider can help confirm the presence of a disease, then offer assistance to manage your symptoms.



## Extra reading for special situations

### Non-liver health problems associated with hepatitis C

Although HCV generally affects the liver, it can, in rarer circumstances, cause disease elsewhere in the body. These diseases are sometimes called **extrahepatic manifestations**.

People with chronic hepatitis C have about double the risk of getting **renal cell carcinoma** (kidney cancer). However, the most common type of kidney disease found in people with HCV is called **membranoproliferative glomerulonephritis**. Symptoms include high blood pressure, joint pain and fatigue due to a low red blood cell count. It can be detected by lab tests and confirmed by kidney biopsy. This condition rarely develops into a significant health problem and treatment with HCV antiviral medications may help correct any complications.

HCV may trigger a response from your immune system leading to an autoimmune disorder (the immune system attacks the body's own tissue). For example, **inflammatory arthritis** (swelling in the joints that occurs

## Lowered white blood cell count (neutropenia)

### DESCRIPTION

White blood cells (neutrophils, lymphocytes, monocytes, eosinophils and basophils) are part of the immune system and protect the body against harmful foreign substances. If the body has a lowered white blood cell count, it will be less able to fight infections. Having a low white blood cell count is called neutropenia.

### CAUSE

Neutropenia is a side effect of peg-interferon. However, it is rare that peg-interferon will cause such a problematic drop in your white blood cell count that you will need treatment.

### TREATMENT

- In the unlikely event you need treatment for peg-interferon-related neutropenia, there is a product called granulocyte colony-stimulating factor (G-CSF) that increases your body's production of neutrophils (a type of white blood cell that fights infection). Although the use of G-CSF has been shown to improve the rate of patients able to achieve a sustained virologic response, treatment-related neutropenia is rarely a problem.

### TIPS

- ✓ Regularly see your health care provider to get a blood test called a complete blood count (CBC), which measures red cells, white cells and platelets.
- ✓ Your health care provider may recommend that you get the flu vaccine.
- ✓ Practice good hygiene, such as taking care of your teeth and gums and frequently washing your hands.

## Right upper side discomfort

### DESCRIPTION

Some people may feel a dull ache on their right side, just below the rib cage. In fewer cases, an ache or pain may travel up to the right shoulder, or be experienced as a sharp stabbing feeling.

### CAUSE

Right upper side discomfort can be a symptom of hepatitis C. It is believed to be due to swelling of the liver, causing the thick membrane surrounding the liver to stretch. However, in most people, right upper side discomfort is from muscle spasm.

### TREATMENT

- Ask your doctor on how best to manage the pain. You may be prescribed pain medication or, if it is available in your community, you may be referred to a pain clinic where pain specialists will teach you a variety of ways to cope with the discomfort.



**Extended health benefit plans:** Your health insurance company (a private plan or the one at your workplace) will likely pay at least a portion of the cost of your medications. Check to see if there are limits or maximums to drug coverage so that your coverage doesn't run out halfway through treatment.

**Compassionate grounds:** The pharmaceutical company that markets the medication you are using may be approached on compassionate grounds. A supportive letter from your health care provider, preferably a physician, will be necessary. For a list of drug companies involved in HCV treatment, go to the section **Resources and links, page 89**.

**Clinical research trials:** Assuming the study is right for you, the cost of the medication(s) being investigated will be covered by the administrators of the clinical research trial. For more information on clinical research trials, go to the section **Extra tips for managing hepatitis C and treatment side effects, page 59**.

### Canadian Red Cross Society Compensation (pre-1986/post-1990)

The courts approved the settlement of the pre-1986/post-1990 hepatitis C claims against the Canadian Red Cross Society in 2001. Call **KPMG's Claim Centre for Hepatitis C** toll-free at 1-888-840-5764 or go to [www.kpmg.ca/hepatitisc](http://www.kpmg.ca/hepatitisc). Deadline for submitting a claim is Sept. 30, 2011.

## How to pay for the cost of treatment

The cost of treatment with peg-interferon and ribavirin is expensive. Those entitled to federal compensation packages are reimbursed for the share of medication costs not covered by a public or private drug insurance plan. Consult with your health care provider so that any issues around expenses are resolved before treatment is started.

**Provincial and territorial governments:** If you have a low annual income (based on the previous year's income tax return) or are receiving social assistance, your provincial/territorial government may either cover the entire cost of treatment or require you to pay a deductible only. However, your doctor will have to apply to the government for special authorization.

For detailed information go to:

[www.hepCinfo.ca](http://www.hepCinfo.ca)

Under **Treatment**, search for *Treatment coverage in your region*.

[www.hemophilia.ca](http://www.hemophilia.ca)

In the document **Provincial Drug Insurance**, you'll find a table outlining the provinces' drug coverage for chronic hepatitis C medication.

**Special government authority:** The provincial/territorial governments do not necessarily fund all medications used to treat a disease. If you are using a drug to manage your symptoms or side effects that isn't covered, there may be a policy provision that allows the government to pay for it anyway. Your doctor will have to complete a form stating that the drug you are using is the only one that will work for you, and that all comparable drugs covered by the government health plan have failed.

### TIPS

- ✓ Try a pain management technique at home. Methods to help you relax, such as guided imagery and visualization, can also give you an immediate, if temporary, pause from pain.
- ✓ Biofeedback is an approach to pain management in which you are given immediate information (feedback) about bodily processes, such as heart rate, that are usually beyond your conscious mind. Over time, you learn to consciously control or regulate conditions like high blood pressure or muscle tension that may be contributing factors to your heightened sensation of pain.
- ✓ Acupuncture is a traditional Chinese system of healing in which pain is relieved by thin metal needles inserted into selected points beneath the skin. Be absolutely sure that the acupuncturist uses sterilized needles and handles them in a safe way.
- ✓ Massage therapy from a registered massage therapist or a shiatsu massage therapist involves the manipulation of the soft tissues of the body (or, in the case of shiatsu, acupressure points on the surface of the skin) with the hands. Massage improves blood circulation and muscle tone and reduces muscle spasm that may be a contributing factor to pain. Other healing traditions that use therapeutic touch include chiropractic, osteopathy, reflexology and reiki.

## Tingling or burning sensation (paresthesia or peripheral neuropathy)

### DESCRIPTION

Sensations of tingling, pins and needles, sharp pain or cramps, burning and numbness may be caused by conditions known as paresthesia and peripheral neuropathy. Usually, the pain is felt in the toes, feet and legs, although sometimes it is in the hands and arms. These sensations are often worse at night.

### CAUSE

The exact cause of HCV-related peripheral neuropathy is not known, although possible explanations include HCV infection of the nerves or a swelling process in the nerves triggered by an HCV-related immune disorder.

### TREATMENT

- Your doctor may try a number of measures to treat the symptoms, including topical creams, pain killers, antidepressants and non-steroidal anti-inflammatory drugs.

### TIPS

You can try the following tips to help soothe the pain and relieve the pressure on your hypersensitive feet or hands.

- ✓ Limit your walking distances and the length of time you spend standing.
- ✓ Wear loose-fitting socks and shoes.
- ✓ Keep heavy bed covers off painful areas and use a small pillow to raise your feet or hands off the mattress while sleeping.
- ✓ Regularly soak your feet or hands in ice water.
- ✓ Exercise regularly to try and improve circulation to the nerves.

### Federal Pre-1986 and Post-1990 Compensation

Call toll-free at 1-866-334-3361, e-mail [preposthepc@crawco.ca](mailto:preposthepc@crawco.ca), or go to [www.pre86post90settlement.ca](http://www.pre86post90settlement.ca).

Like the 1986-1990 claim, the deadline for first application has passed. Now there are only a few specific situations where claims will be accepted. Check out the website for more information.

### Provincial Pre-1986 and Post-1990 Compensation

Several provinces decided to provide compensation to individuals infected in their province with HCV as a result of a blood transfusion prior to 1986 or after 1990.

#### Quebec

Financial Assistance Program for Persons Infected with the Hepatitis C Virus  
Régie de l'assurance maladie du Québec  
toll-free: 1-800-561-9749  
[www.ramq.gouv.qc.ca/en/regie/fin\\_hepatite\\_c.shtml](http://www.ramq.gouv.qc.ca/en/regie/fin_hepatite_c.shtml)  
Deadline for submitting a claim was June 30, 2010.

#### Ontario

Ontario Hepatitis C Assistance Plan  
toll-free: 1-877-222-4977 or e-mail [infomoh@gov.on.ca](mailto:infomoh@gov.on.ca)  
[www.health.gov.on.ca/english/public/program/hepc/hepc\\_assistplan.html](http://www.health.gov.on.ca/english/public/program/hepc/hepc_assistplan.html)

#### Manitoba

The Manitoba Hepatitis Compassionate Assistance Program (MHCAP)  
toll-free: 1-866-357-0196 or e-mail [mgi@gov.mb.ca](mailto:mgi@gov.mb.ca)  
[www.gov.mb.ca/health/hcv/faq.html](http://www.gov.mb.ca/health/hcv/faq.html)

#### Alberta

Alberta Pre-1986/Post-1990 Hepatitis C Settlement Agreement  
Administrator: 1-866-334-3361  
[www.albertapre86post90.ca](http://www.albertapre86post90.ca)

#### British Columbia

Hepatitis C Tainted Blood Class Action  
Class counsel: Kleins and Lyons  
604-874-7171  
[www.kleinlyons.com/class/settled/hepc](http://www.kleinlyons.com/class/settled/hepc)



- After all the above documents are assembled, take them to your doctor or liver specialist so he or she can complete the relevant sections of the application kit. **The liver specialist's supportive comments are absolutely essential because they will be looked at very closely by the adjudicator.** Your liver specialist should also submit all test results (for example, liver biopsy and blood test results) as medical documentation that supports the position you are no longer able to remain in the workforce.
- Be sure to photocopy all parts of your application kit for your own records before you mail the whole package.
- Don't give up if your application is denied. You will have an opportunity to appeal the decision. Ask for help from a community advocate to help guide you through the process. Act quickly because there will only be a limited number of days (90 days for a CPP disability benefits appeal) for you to respond back and notify the government or insurance company that you intend to appeal its decision.

## Compensation packages

In 1997, the Krever Commission recommended that all people who were harmed by the blood system (acquired HCV via a blood transfusion) be financially compensated. CATIE has a website where you can go for a complete overview of the various HCV compensation plans available in Canada: [www.hepcinfo.ca/en/detail/living-hep-c/compensation](http://www.hepcinfo.ca/en/detail/living-hep-c/compensation).

### 1986 – 1990 Hepatitis C Settlement Agreement

Call the **1986 –1990 Hepatitis C Claim Centre** at 1-877-434-0944 or go to [www.hepc8690.ca](http://www.hepc8690.ca).

The deadline for submitting a claim under this agreement was June 30, 2010. Now claims are limited to people who make a claim within three years of learning of their hepatitis C infection, or within one year of becoming an adult (usually turning 18).

## Dry mouth (xerostomia)

### DESCRIPTION

Dry mouth is when your saliva glands do not produce enough saliva to keep your mouth moist. This can lead to an increased risk for dental problems such as tooth decay, gum problems, mouth sores and other infections in the mouth.

### CAUSE

Peg-interferon decreases the production of natural saliva.

### TREATMENT

- Patients are encouraged to have a complete dental exam before starting HCV therapy. It is also recommended that any potential dental problems (dental fillings and crowns, gum surgery and root canals, for example) are dealt with before beginning treatment.
- Use saliva substitutes and/or saliva stimulants. Gels, moisturizing viscous liquids, moisturizing sprays and oral rinses are examples of saliva substitutes. Saliva stimulants, on the other hand, facilitate salivary flow by either taste or mechanical stimulation, or a combination of both, and include chewing gum, lozenges, pastilles and tablets.

### TIPS

- ✓ Rinse your mouth with water frequently.
- ✓ Suck on sugar-free candies like peppermints to produce more saliva.
- ✓ Maintain dental health by:
  - a) Rinsing out your mouth with water often, especially after meals;
  - b) Brushing regularly with a soft brush before and after meals;
  - c) Flossing regularly, being gentle so that you don't injure the gums;
  - d) Examining your teeth, gums and all areas of the mouth at least weekly.

## Loose or watery bowel movements (diarrhea)

### DESCRIPTION

Loose or watery stools that happen three or more times a day is called diarrhea. The rapid loss of your body's water when you have diarrhea can cause dehydration.

### CAUSE

Diarrhea is a side effect of the combination of peg-interferon and ribavirin used in the treatment of hepatitis C.

### TREATMENT

- Notify your doctor immediately if:
  - a) you have blood in your stools or if they look black;
  - b) you lose more than five pounds in one day; or
  - c) you experience severe diarrhea that lasts more than two days.

### TIPS

- ✓ Drink lots of water and broth or try popsicles to replace lost fluids.
- ✓ Avoid caffeinated drinks such as coffee, tea or soda pop.
- ✓ Eat smaller but more frequent meals throughout the day.
- ✓ Eat foods rich in potassium such as cooked bananas.
- ✓ Eat green leafy vegetables to help you regulate your stools. If your stools are loose, then cut back on your intake.
- ✓ Avoid spicy, fried or greasy foods.
- ✓ Wash the area around your anus with baby wipes or a soft cloth dipped in warm soapy water after each bowel movement to avoid the area getting dry or chafed.

## How to apply for public or private disability benefits

Anyone applying for a disability pension must carefully follow the guidelines included in the application kit. Your application should be easy to read and contain the medical documents, such as reports from consulting specialists and lab test results, needed to support your claim. The following process will help increase the probability that your application will be accepted by the adjudicator who reviews your claim:

**Don't give up if your application is denied. You will have an opportunity to appeal the decision.**

- Be sure to describe fully all your symptoms – particularly any problems with fatigue, depression, anxiety or stress – every time you visit your family doctor or liver specialist. Your physicians' notes for each visit remain on file. They have the potential to become the official medical documents you need to prove that your ability to hold down your job has gradually become more and more impaired.
- When your symptoms are so severe that working is no longer possible, ask your family doctor and/or a health care provider who knows you for a letter stating this.
- Contact a work colleague and ask if he or she is willing to write a personal testimony. It can be short, provided that it describes how your physical health worsened over time, until you reached the point where you were no longer able to carry out your job duties or maintain a regular work schedule.
- If you are comfortable with the idea, have your spouse, partner or a close friend write a letter of support describing any changes observed in your physical health, behaviour and general mental or emotional well-being.
- Disability pension application forms usually require both you and your doctor to complete sections of the application kit. Photocopy the sections you have to fill in and use the copy as a rough draft. Once you are happy with your answers, write your information clearly on the forms to be mailed.

## Private disability benefits/health insurance

Check with your employer's personnel department about the availability of an employee benefits package. You may be eligible for sick leave benefits, short-term disability benefits or a long-term disability pension administered through an insurance company.

If you are thinking about switching from full-time to part-time hours, check with your insurance company first. The reason for this is that the benefits from part-time income may be quite a bit less than they would be if you had submitted a disability claim while on a full-time income.

Remember that when you submit an insurance claim, the paperwork may sometimes pass through your employer's human resources department before being sent to the insurance company. In order to protect your workplace privacy, you may wish to submit the claims directly to the insurance company. However, it's possible that your disability application kit will have a consent clause that allows the employer and the insurance company to share information about your medical condition and your ability to work.

If you are a union member, you may have signed up for a disability plan when you joined your local. Check with the union office to see if you have membership in a benefits plan.

Check your life insurance policy if you have one. Some life insurance policies include a clause stating that if you become disabled and unable to work, life insurance premiums will be paid on your behalf until age 60 or 65, or until you return to work. There is usually a four- to six-month waiting period after notification during which you must continue paying your monthly premium. You will probably require a letter from your doctor confirming your work disability.

Check your mortgage insurance policy if you have one. Mortgage insurance policies sometimes contain a disability clause. If disability prevents you from working for six consecutive months, your mortgage will be paid for the period during which you are unable to work.

## Loss of appetite (anorexia)

### DESCRIPTION

Many people with HCV lose the desire to eat. The result of feeling like not eating is that you may not eat enough to maintain your health. Poor nutrition may cause weight loss, including a reduction in muscle mass. Improper absorption of digested food due to cirrhosis of the liver may result in too little or too much of one or more vitamins, minerals or other substances that are necessary for your body to function normally.

### CAUSE

Loss of appetite can be caused by hepatitis C or peg-interferon. Flu-like symptoms such as nausea and vomiting may also affect your eating habits. Your appetite may worsen if you have cirrhosis or liver failure.

### TREATMENT

- It is very important to give your body the nutrients it needs to function. Ask your doctor about nutritional supplements designed to help you gain and keep a healthy weight.

### TIPS

- ✓ Eat smaller but more frequent meals throughout the day.
- ✓ Drink clear fruit juices for the extra calories.
- ✓ Try ginger root or drinks or candy with ginger in them.
- ✓ Try simple foods (not spicy, acidic, deep-fried or greasy) such as crackers or dry toast.

# Nausea

## DESCRIPTION

Nausea is a word used to describe the very unpleasant feeling of sickness and wanting to vomit.

## CAUSE

Nausea is one of the most common symptoms of HCV infection. It is also a common side effect of peg-interferon.

## TREATMENT

- If nausea leads to frequent vomiting, take many sips of water over short intervals. Your intake of water should add up to about two litres per day in order to avoid dehydration.
- Ask your doctor about anti-nausea medication.
- If your nausea gets better after you eat, ask your doctor to check for an ulcer caused by the bacterium *H. pylori*. The symptoms will go away within a few days if you take the medication as prescribed to get rid of *H. pylori*.

## TIPS

- ✓ Eat soup as it is easier for your body to digest. However, be careful the soup is not high in salt content as high sodium can lead to high blood pressure.
- ✓ Avoid carbonated (fizzy), sugary or alcoholic drinks.

To find out more about federal government pensions for all Canadians, call 1-800-277-9914, or go to

[www.servicecanada.gc.ca/eng/subjects/benefits/index.shtml](http://www.servicecanada.gc.ca/eng/subjects/benefits/index.shtml).

## Tax credits for people with disabilities

The federal taxation system provides tax credits. This means that when you file your income taxes you can apply to have some of your money reimbursed under the following programs.

### Disability Tax Credit

To claim the Disability Amount you must complete Part 'A' of Form T2201 E (Disability Tax Credit Certificate) and have Part 'B' completed by a doctor. Attach this form to your tax return and claim the Disability Amount on Lines 316 and 318 of your tax return. For more help go to [www.cra-arc.gc.ca/E/pbg/tf/t2201/README.html](http://www.cra-arc.gc.ca/E/pbg/tf/t2201/README.html).

### Goods and Services Tax Credit (GST/HST)

For more information on the GST/HST tax credit, call the Canada Revenue Agency Telephone Service at 1-800-959-1953 or go to [www.cra-arc.gc.ca/bnfts/gsthst/menu-eng.html](http://www.cra-arc.gc.ca/bnfts/gsthst/menu-eng.html).

### Quebec Disability Tax Credits

For more information on Quebec tax credits go to [www.revenu.gouv.qc.ca](http://www.revenu.gouv.qc.ca).

The government of Quebec has published a document entitled *Tax Benefits and Persons with Disabilities* that explains the types of tax assistance available to people with disabilities. Go to: [www.revenu.gouv.qc.ca/en/sepf/publications/in/in-132.aspx](http://www.revenu.gouv.qc.ca/en/sepf/publications/in/in-132.aspx).

The amount of your monthly benefit under CPP or QPP disability benefits is calculated on how much and for how long you've contributed to CPP or QPP, provided you've paid into the program in four of the past six years. It doesn't matter how much monthly income you have from other sources or how much money you have in the bank (assets). In order to qualify for disability benefits, your doctor must complete a medical assessment that confirms that your disability is for the long term and that it's preventing you from keeping a regular work schedule. You are required to pay taxes on the benefit.

You will still receive benefits even if you move to another province, territory or country or if your marital status changes. The program allows you to return to work on a trial basis and still receive the disability benefit for one year. If you are unable to manage the job at a later date, a re-application will be fast-tracked.

Service Canada's Telephone Information Service at 1-800-277-9914 is available to answer your questions. You can download the Canada Pension Plan disability benefits application kit at [www.servicecanada.gc.ca/eng/isp/cpp/disabforms.shtml](http://www.servicecanada.gc.ca/eng/isp/cpp/disabforms.shtml).

For more information about the Quebec Pension Plan disability benefits, go to Régie des Rentes (in French and English) at [www.rrq.gouv.qc.ca](http://www.rrq.gouv.qc.ca).

## Other Canadian government income security programs

The federal government offers income security benefits not linked to illness under the following programs:

CANADA PENSION PLAN (CPP)	OLD AGE SECURITY (OAS)
<ul style="list-style-type: none"> <li>• Retirement Pension</li> <li>• Survivor's Pension</li> </ul>	<ul style="list-style-type: none"> <li>• Basic Pension (OAS)</li> <li>• Guaranteed Income Supplement (GIS)</li> <li>• Spouse's Allowance</li> </ul>

## Sores (ulcers) in the mouth

### DESCRIPTION

Sores (ulcers) in the mouth can be extremely painful and will interfere with eating and your quality of life in general.

### CAUSE

Mouth sores are a side effect of ribavirin. They may develop at any time during treatment.

### TREATMENT

- Discuss with your doctor the possibility that you're not getting enough vitamin B12 in your diet.
- If the home remedies below don't work, talk to your doctor about a medication (a mouth rinse) that forms a protective barrier over the mouth sore.

### TIPS

- ✓ Avoid really hot drinks or food.
- ✓ Eat simple food that is not spicy, salty or acidic.
- ✓ Avoid food that is crunchy or hard.
- ✓ Soothe mouth sores with ice or frozen juice bars.
- ✓ Rinse your mouth for one minute with a solution of one teaspoon of salt in a cup of warm water.
- ✓ Use an over-the-counter antimicrobial mouthwash like Listerine. It may provide temporary pain relief by numbing the mouth sore.
- ✓ Put a used black tea bag on the mouth sore (a well-known alternative therapy). Black tea is high in tannin, which may give you some pain relief.

## Taste changes

### DESCRIPTION

Your sense of taste may change. The change is usually described as having a metallic taste in the mouth.

### CAUSE

A change to your sense of taste is a side effect of peg-interferon.

### TREATMENT

- Your sense of taste will return to normal two to 12 weeks after stopping the HCV medication.
- Take good care of your teeth and gums. Remember to floss, use a soft toothbrush and get regular dental checkups.

### TIPS

- ✓ Use non-metallic cookware such as glass.
- ✓ Eat with wooden, plastic or porcelain cutlery.
- ✓ Eat foods at room temperature. Food should be neither too cold nor too hot.
- ✓ Eat a small piece of dark chocolate as this may help disguise the metallic taste.
- ✓ Find tasty new foods by experimenting with different shapes and textures.
- ✓ Avoid canned food.
- ✓ Rinse your mouth before eating with either club soda, warm salt water or a mouthwash made with a half teaspoon of salt, half teaspoon of baking soda and one cup of warm water.
- ✓ Hide the metallic taste by using herbs, spices, mustard, horseradish, vinegar or lemon and lime juice in your food. Use caution as these may also increase nausea and change bowel habits.

## Employment Insurance Sickness Benefits

Employment Insurance (EI) is a program that provides financial assistance for people who have stopped working because they were laid off, became parents or are too sick to work. In order to qualify for EI benefits, you must have contributed to the plan. Check your last pay stub to see if EI is listed under your deductions. Eligibility for EI varies among provinces/territories. Each province of Canada sets a minimum requirement for the number of insurable work hours you must have worked in the past 52 weeks, or since your last claim. Call Service Canada's Employment Insurance Telephone Information Service at 1-800-206-7218 to get the correct information.

You can apply for EI benefits online at [www.servicecanada.gc.ca/eng/ei/application/employmentinsurance.shtml](http://www.servicecanada.gc.ca/eng/ei/application/employmentinsurance.shtml)

If you plan to take a temporary break from work due to HCV symptoms or treatment side effects, you can apply for Employment Insurance Sickness Benefits, which last for 15 weeks. These benefits are based on the number of hours you worked and your level of earning prior to making a claim. You'll need your Record of Employment (ROE) from your employer (usually sent out within five days of your final payday) and your doctor must complete a medical assessment.

## Canada Pension Plan (CPP) and Quebec Pension Plan (QPP)

Canada Pension Plan (CPP) and Quebec Pension Plan (QPP) are normally for people who have retired from working, but if you have a medical disability, you may be able to receive monthly CPP or QPP payments before retirement. In order to qualify for CPP or QPP benefits, you must have contributed to the plan. Check your last pay stub to see if CPP or QPP is listed under your deductions. CPP or QPP is available to you when you reach the age of 65 (or at age 60 at a reduced rate). However, if you have to stop work due to HCV symptoms or treatment side effects, you may qualify early under the CPP or QPP disability benefits plan.

In your telephone book, look through the listings under your provincial/territorial government to find the office that deals with questions about financial assistance. Here are the websites for each province and territory. Follow the links to take you to the government office that administers income assistance programs:

<b>Yukon</b>	<b><a href="http://www.gov.yk.ca">www.gov.yk.ca</a></b>
<b>Northwest Territories</b>	<b><a href="http://www.gov.nt.ca">www.gov.nt.ca</a></b>
<b>Nunavut</b>	<b><a href="http://www.gov.nu.ca">www.gov.nu.ca</a></b>
<b>British Columbia</b>	<b><a href="http://www.gov.bc.ca">www.gov.bc.ca</a></b>
<b>Alberta</b>	<b><a href="http://www.gov.ab.ca">www.gov.ab.ca</a></b>
<b>Saskatchewan</b>	<b><a href="http://www.gov.sk.ca">www.gov.sk.ca</a></b>
<b>Manitoba</b>	<b><a href="http://www.gov.mb.ca">www.gov.mb.ca</a></b>
<b>Ontario</b>	<b><a href="http://www.ontario.ca">www.ontario.ca</a></b>
<b>Quebec</b>	<b><a href="http://www.gouv.qc.ca">www.gouv.qc.ca</a></b>
<b>New Brunswick</b>	<b><a href="http://www.gnb.ca">www.gnb.ca</a></b>
<b>Nova Scotia</b>	<b><a href="http://www.gov.ns.ca">www.gov.ns.ca</a></b>
<b>Prince Edward Island</b>	<b><a href="http://www.gov.pe.ca">www.gov.pe.ca</a></b>
<b>Newfoundland and Labrador</b>	<b><a href="http://www.gov.nf.ca">www.gov.nf.ca</a></b>

## Fluid build-up (ascites or edema)

### DESCRIPTION

The build-up of fluid in the abdomen is called ascites. You may not feel hungry due to the pressure of the fluid on your stomach. Fluid build-up may also put pressure on your lungs, causing you to be short of breath. The build-up of fluid in the tissues of the feet and legs is called edema.

### CAUSE

Ascites and edema are two of the most common major complications of cirrhosis. If abdominal tenderness and fever are present, the cause may be an infection called spontaneous bacterial peritonitis.

### TREATMENT

- Too much sodium intake can contribute to the fluid retention seen in ascites and edema. You may need a low-salt diet.

### TIPS

- ✓ Avoid canned soups and vegetables, cold cuts, dairy products and condiments such as ketchup and mayonnaise.
- ✓ Check the labels on food packages; many prepared foods contain large amounts of salt.
- ✓ Substitute lemon juice for salt.

## Blisters (porphyria cutanea tarda)

### DESCRIPTION

Fluid-filled blisters on the hands or on any area of the body exposed to sunlight may be caused by a disorder called porphyria cutanea tarda. This condition may also cause darkening or lightening of the skin, hair loss and thickening of the skin.

### CAUSE

Porphyria cutanea tarda is a symptom of hepatitis C. It is caused by an overproduction of the protein uroporphyrinogen when HCV blocks the removal of waste products (porphyrins) from the blood.

### TREATMENT

- Although not curable, symptoms can be managed. Ask your doctor about low dose chloroquine or hydroxychloroquine (anti-malarial drugs).

### TIPS

- ✓ Reduce your intake of foods that contain iron.
- ✓ Reduce your consumption of alcohol.
- ✓ Avoid the sun or use sun block.

Here are the typical steps you must take to apply for provincial/territorial government social assistance:

- Go to or call the local social assistance office and tell them you want to apply for income assistance. They will book you an appointment within a few days or a few weeks.
- Collect the documents you will need to take to the appointment. These could include papers such as a rent receipt, hydro bill with your name on it, bank account statement, photo identification (for example, a driver's license or passport) and birth certificate.
- Give the information to the financial assistance worker when you return for your appointment. He or she will take your information and enrol you in the social assistance program.
- Ask to apply for the disability benefits program once you are accepted for regular social assistance benefits. The financial assistance worker will then give you the application kit.
- Fill out your part of the forms in the disability benefits application kit. Get your doctor to complete the required forms in the kit. A third party, such as your nurse, social worker or physiotherapist, may also have to contribute information to the application.
- Find an advocate who can help you if you are not sure how to fill out your part of the application.
- Return the application kit to the social assistance office. The package will then be mailed to a central office where an adjudicator will review your information. Expect to wait three or four months before you hear a decision.
- Consider appealing the decision if your application for disability benefits is rejected. Obtain the help of an advocate. It is well worth your while because a high percentage of appeals are won if the applicant is well prepared for the appeal hearing. Your advocate will probably accompany you to the appeal hearing.



## Blotchy skin (cryoglobulinemia)

### DESCRIPTION

When a patient develops a blotchy skin rash on his or her legs, it may be caused by a condition called **cryoglobulinemia**.

### CAUSE

Cryoglobulinemia is one of the most common disorders associated with HCV. It is caused by the production of **cryoglobulin (an abnormal blood protein)**. These proteins clump together in blood vessels, restricting the flow of blood. It can lead to **vasculitis (inflammation of blood and lymphatic vessels)** as well as other conditions that affect the kidneys, joints and skin.

### TREATMENT

- Medications may be used to suppress the immune system.
- A medical procedure called plasmapheresis may be used. In this routine, blood is taken, filtered and then returned to the body.

### TIPS

- ✓ If you experience blotchy skin, get it examined by your doctor because it is often the first and possibly only sign of chronic hepatitis C.

## Finances

Treatment for hepatitis C may involve costs, especially if you find you are unable to work. There are various types of financial assistance available to help you make ends meet.

### Provincial/territorial government social assistance

The provincial and territorial governments provide financial assistance for shelter, living expenses and essential medical needs for people who have difficulty paying for them on their own. The governments also have a disability benefit that provides a monthly income to cover housing and living expenses for people who are unable to work at any full-time job because of illness. However, eligibility for these social assistance programs varies among provinces/territories. If you are already receiving some income from elsewhere, it's possible to receive a top-up so that your monthly income will equal the rate of the provincial/territorial disability or social assistance program.



## Hair loss (alopecia)

### DESCRIPTION

Although losing hair is quite common, the loss is severe in only about five percent of people undergoing treatment.

### CAUSE

Hair loss is a side effect of peg-interferon.

### TREATMENT

- Usually hair loss is temporary; hair grows back when treatment is over.

### TIPS

- ✓ Avoid chemicals that perm or dye your hair.
- ✓ Avoid blow dryers, curling irons and rollers.
- ✓ Avoid frequent brushing or combing.
- ✓ Use mild shampoos and conditioners. Occasionally skip these products and just use water. This will help your hair keep some of its natural oils.
- ✓ Change your hairstyle to a shorter one. Some people choose to shave their heads.
- ✓ Consider hats, scarves or wigs if the hair loss negatively affects your self-image.

## Clinical research trials

Participating in a clinical trial may be for you if you cannot afford treatment or if your treatment was unsuccessful. The advantages to taking part in a clinical trial are that you have quick access to a promising drug and you will be closely monitored the whole time. The disadvantages are that the benefits of the drug are not proven, the optimum dosage is unknown and there is a risk of getting an as yet-unknown side effect. Ask your doctor for more information on local opportunities to take part in clinical trials.

## Turn a negative into a positive

Having meaning to your life is a very important aspect to psychological health. Many people achieve meaning in their lives through working on a creative project. Creative projects include music, writing, drawing and painting. Other people achieve meaning through relationships – they try to be the best parent or partner they can possibly be, for example.

You can create a sense of purpose in your life, too. For example, use your experience to help others who live with adversity. You will discover the joy of working to create a less distressing world. Rather than asking "What can the world do for me?", change your question to "What can I offer the world?". You can turn the hepatitis C diagnosis from a negative event into a positive experience if you grasp the opportunity to refocus your priorities in life.



When life isn't going according to your wishes, giving yourself a creative meaning to life and/or a social purpose will help you resist any temptation to give in to apathy. If faith in a supreme being is a source of strength for you, then renew your commitment to a spiritual/religious practice. Seek out the support of others at your place of worship. Feeling good about yourself is essential to your happiness. One way to help this happen is to put your resiliency to work, not only to avoid giving in to hepatitis C, but also to commit yourself to a cause or an idea that embraces and expands the world outside yourself.

For more information go to:

- [www.hc-sc.gc.ca/dhp-mps/prodnatur/index-eng.php](http://www.hc-sc.gc.ca/dhp-mps/prodnatur/index-eng.php)
- CATIE document at [www.hepcinfo.ca/en/simple/treatment/complementary-therapies](http://www.hepcinfo.ca/en/simple/treatment/complementary-therapies)
- *Healthy Living with Viral Hepatitis* at [www.liver.ca](http://www.liver.ca)

## Monitoring your liver's health

Do your best to keep your appointments with your family doctor. This will keep you up to date on your overall health and help you make the best decisions on how to stay healthy. Also try and see a liver doctor (a hepatologist or a gastroenterologist) regularly. Having your liver checked frequently will help you stay informed about your liver's health so you can plan the next step in your treatment.

The health of your liver is usually determined by a liver biopsy. This procedure measures the amount of scar tissue that has replaced healthy tissue in the liver. As with any surgical procedure, liver biopsy comes with some risks. The main risk is hemorrhage (excessive bleeding). However, non-invasive methods are being developed to assess liver health without the need for biopsy. For example, FibroTest and FibroScan are showing good results in identifying HCV-related cirrhosis. FibroScan has been licensed for use by Health Canada since 2009 and is increasingly used across Canada.

A research team in 2009 concluded that although liver biopsy remains the most accurate measure of fibrosis, a significant number of patients will be able to avoid liver biopsy in the future.

## Vaccinations

- **There is no vaccine for hepatitis C.** Talk to your doctor about hepatitis A and hepatitis B vaccines. If you are HIV positive, you may require three doses of hepatitis A virus vaccine instead of the usual two doses in order to get the same protection level.
- Get the flu vaccine. It's a safe and very effective way to prevent flu in you and your family.

**There is no vaccine for hepatitis C.**

## Itchy skin (pruritis)

### DESCRIPTION

An itchy skin rash (pruritis) may appear on the feet and hands. Some people may feel itchy all over their bodies. These rashes are not dangerous unless they become infected.

### CAUSE

Dry, itchy skin is a side effect of ribavirin. Pruritis may also occur with cirrhosis or liver failure.

### TREATMENT

- If you must deal with the itch, rub your skin instead of scratching it.
- Keep your fingernails short so that if you accidentally scratch yourself, you don't risk infection by tearing the skin.
- Talk to your doctor about antihistamines and anti-itch cortisone creams.

### TIPS

- ✓ Drink lots of water.
- ✓ Wrap a cold pack in a towel and apply it to the rash.
- ✓ Take an oatmeal bath.
- ✓ Use unscented skin moisturizers or body lotions.
- ✓ Use soap that contains a moisturizer or has high oil content.
- ✓ Use laundry detergents that are formulated to be mild on the skin.
- ✓ Wear loose-fitting clothing.
- ✓ Avoid taking long hot showers or baths.

## Needle irritation (injection site reactions)

### DESCRIPTION

Some people experience pain, swelling or irritation on the skin surface when peg-interferon injection is given. This is called an injection site reaction.

### CAUSE

Improper handling of the needle you use for injecting peg-interferon poses a serious risk for infection at the injection site.

### TREATMENT

- Review the correct injection techniques found in the peg-interferon instruction insert.
- Check with your doctor or pharmacist to be certain you are using the recommended size needle.

### TIPS

- ✓ Wash your hands with soap and water.
- ✓ Apply alcohol and let it dry for about 15 seconds before injecting.
- ✓ Make sure the peg-interferon is at room temperature.
- ✓ Inject the drug at a 90-degree angle.
- ✓ Don't massage the injection site. Cover it with a bandage instead.
- ✓ Use a different place each time you inject. It may be easiest and least painful to rotate the sites between your stomach and your thighs.
- ✓ Never reuse the needle and syringe. Put both of them in a sharps container (a puncture-proof disposable container that can be picked up at your pharmacy).

doctor. Discuss the pros and cons with your health care provider before deciding to use marijuana to relieve pain and nausea. For more information go to [www.hepcinfo.ca/en/faq-s](http://www.hepcinfo.ca/en/faq-s).

## Diet

Good nutrition contributes to overall health and keeps the liver in good condition because the liver refines and detoxifies everything you eat. A balanced diet even helps a damaged liver regenerate new cells.

- Drink plenty of clear fluids, especially water.
- Drink some coffee. Coffee has been linked to lower rates of liver disease progression in HCV-infected individuals. Caffeine intake from about two cups of coffee a day has been associated with less scarring in the liver. It is coffee – not caffeine obtained from other sources, such as tea or caffeine pills – that has been linked to liver benefits.
- Learn how to eat healthy meals by going to Health Canada's website and getting *Eating Well with Canada's Food Guide*. Following the guidelines will give your body the proper balance of carbohydrates, fat and protein. The guide is available for download at [www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php](http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php)
- Locate a dietitian in your area by going to [www.dietitians.ca](http://www.dietitians.ca) and looking under *Find a Nutrition Professional*. This website also has two booklets (in French and English) that you may find informative: *Helping You Feel Your Best!* and *Dealing with Discomforts. Hepatitis C: Nutrition Care – Canadian Guidelines for Healthcare Providers* can be consulted at [www.hemophilia.ca](http://www.hemophilia.ca).

**Discuss with your doctor the pros and cons of a natural health product before you spend a lot of money on it.**

## Natural health products

Natural health products are vitamins and minerals, herbal remedies, homeopathic medicines, traditional Chinese medicines, probiotics and supplements such as amino acids and essential fatty acids. Natural health products do not require a doctor's prescription because they are considered safe enough to sell over the counter. However, from both health and financial standpoints, it may be worthwhile to discuss with your doctor the pros and cons of a natural health product before you spend a lot of money on it. Natural health products can have benefits and side effects, just like any other drugs.

## Substances to avoid

- Alcohol use will increase the rate of disease progression.
- Tobacco may accelerate the progression of liver disease in people with chronic hepatitis C. Smoking harms the liver, especially in people who both smoke and drink alcohol. Smoking also increases the risk of developing liver cancer and **non-Hodgkin's lymphoma (cancer that begins in the lymphatic system)**. Another reason to quit smoking is that it will hurt the chances of a successful liver transplant in people with smoke-damaged lungs.
- Supplements such as iron and vitamins B2, A and D may cause additional harm to the liver.
- Some medications, including over-the-counter medicines, herbal remedies and nutritional products, may cause problems. Check all medications with your doctor or pharmacist.
- Certain foods, such as grapefruit, may interact with medications prescribed by your doctor. Ask your doctor about what foods may cause problems.
- Excess calories from carbohydrates in the diet can cause fat deposits in the liver.
- Many chemicals (for example, cleaning solvents, pesticides and aerosols) in the workplace and at home have the *potential* to harm the liver. Although exposure to these chemicals has not been proven to be toxic to the liver in low concentrations, it makes sense to avoid them if possible.

## Medicinal marijuana

Marijuana (pot, cannabis, hash) is a controversial topic for people with hepatitis C because sometimes it is helpful and sometimes it is harmful. Using marijuana even moderately or for any length of time may increase scarring of the liver. However, marijuana has helped people to manage difficult side effects from hepatitis C treatment, like nausea, low appetite, aches and pains, and helped them to stay on treatment for the relatively short period required to clear the virus. Although marijuana is illegal to possess or sell, some people can get permits to possess and use small amounts for personal medical use, which requires the sign-off of a

## Purple or shiny itchy bumps (lichen planus)

### DESCRIPTION

Extremely itchy purple pimples or white patches on the skin may appear on the inside of the wrists and ankles, the lower legs, back, nails and genitals. This rash may be caused by a condition called lichen planus. This condition may also cause painful sores on mucous membranes, including the mouth.

### CAUSE

The exact cause of lichen planus is unknown. It seems to be triggered by stress or viral infections such as hepatitis C. Studies show that anywhere from 3.5 percent to 60 percent of people with lichen planus have hepatitis C.

### TREATMENT

- Your health care provider may suggest medicines such as topical steroids and antihistamines to help stop the itching.
- Photochemotherapy light treatment may be recommended.

### TIPS

- ✓ Avoid alcohol, tobacco, spicy foods, peppermint, cinnamon and citrus foods as these appear to trigger lichen planus in the mouth.
- ✓ Drink lots of water.
- ✓ Wrap a cold pack in a towel and apply it to the rash.
- ✓ Take an oatmeal bath.
- ✓ Use unscented skin moisturizers or body lotions.
- ✓ Use soap that contains a moisturizer or has high oil content.
- ✓ Use laundry detergents that are formulated to be mild on the skin.
- ✓ Wear loose-fitting clothing.
- ✓ Avoid taking long hot showers or baths.

## Yellowing of the skin (jaundice)

### DESCRIPTION

The yellowing of the skin and whites of the eyes is called jaundice. This condition may also cause itchy skin. The itch may occur on a particular part of the body or it may occur all over the body. Constant scratching (even when asleep) can damage skin, particularly if the fingernails are long.

### CAUSE

Jaundice is caused by the build-up of bile (bilirubin) in the blood. A small percentage of people will appear jaundiced during the acute phase of HCV infection. Jaundice is also a condition associated with cirrhosis and liver failure. Jaundice may appear with hepatitis A or hepatitis B infection. In rare situations, jaundice can be caused by a harmful build-up of certain drugs (drug toxicity) in your system.

### TIPS

- ✓ Drink lots of water.
- ✓ Wrap a cold pack in a towel and apply it to the rash.
- ✓ Take an oatmeal bath.
- ✓ Use unscented skin moisturizers or body lotions.
- ✓ Use soap that contains a moisturizer or has high oil content.
- ✓ Use laundry detergents that are formulated to be mild on the skin.
- ✓ Wear loose-fitting clothing.
- ✓ Avoid taking long hot showers or baths.



## Extra tips for managing hepatitis C and treatment side effects

A major contributing factor to living well with HCV is adopting a healthy lifestyle. It is not a cure but part of your overall management of HCV. Keep informed about HCV by asking questions of the right people, reading and finding out what community resources are available to help, including support groups. It is important to learn those attitudes and behaviours that help you achieve the highest possible physical, mental and spiritual well-being. **Self-help is essentially all those decisions you make and actions you do to keep HCV under control.** Whether or not you are having treatment, there are a number of self-care strategies that can assist you in living well with HCV.

- ✓ Try to get into the habit of getting seven to eight hours of sleep each night. It is not a good strategy to sleep less during the week, then try to catch up on the weekend.
- ✓ If your bedroom is near a lot of noise, consider a technological aid such as a sleep machine (a small box that creates white noise or soothing sounds, such as ocean waves) to block out noise that interferes with falling asleep.



## Vomiting blood (esophageal varices)

### DESCRIPTION

Bleeding from the **esophagus (food tube)** may cause one to vomit blood and/or to have bloody, runny, black bowel movements.

### CAUSE

Blood going through a damaged liver may back up into the **veins (varices)** in the stomach and esophagus, causing these veins to enlarge. Sometimes this swelling will cause the veins to **bleed (hemorrhage)**. Bleeding of the esophageal varices is linked to cirrhosis and liver failure.

### TREATMENT

- You may be prescribed antibiotics or a medication that constricts the varices.
- Endoscopic surgery may be used to tie up the bleeding varices.
- In an emergency situation, doctors will use a device called TIPS (transjugular intrahepatic portosystemic shunt) to control bleeding. Recent research recommends TIPS be considered early if a patient is at risk for not responding to the above-mentioned standard treatments.

### TIPS

- ✓ See your health care provider if you experience any of the above symptoms.

## Lowered platelet count (thrombocytopenia)

### DESCRIPTION

Platelets are cells containing proteins that help clot blood. They have a role in stopping bleeding. Having a low platelet count is called thrombocytopenia. When severe, this condition increases the risk for bruising and bleeding. This condition may be very serious in those with bleeding disorders.

### CAUSE

A lowered platelet count is a side effect of peg-interferon. Also, research studies have found a link between the stage of fibrosis (scarring in the liver) and thrombocytopenia.

### TREATMENT

- If you vomit blood or have runny, black bowel movements, see your doctor immediately for treatment.

### TIPS

- ✓ See your health care provider regularly to get a blood test called a complete blood count (CBC), which measures red cells, white cells and platelets.

## Sleep problems

### DESCRIPTION

Even with daytime naps, many people with HCV find it difficult to stay awake when they want to. Sleep is also less refreshing. The most common sleep problem is known as **day-night reversal**. **This occurs when a person lies awake all night, then sleeps through much of the day.**

### CAUSE

Having a problem sleeping may be caused by the stress of living with hepatitis C, but it is also more common in people who have cirrhosis or liver failure.

### TREATMENT

- If you choose to use over-the-counter sleep aids, check with your doctor first.
- Regular cardiovascular exercise (for example, aerobic exercise like running or cycling) helps with sleeping.

### TIPS

- ✓ Keep the awake world out of your bedroom. Remove the television, laptop or work papers you may have brought home from the office.
- ✓ Place your clock somewhere away from your head so the light from the clock dial doesn't shine on you.
- ✓ Keep your bedroom dark and cool.
- ✓ Steer clear of caffeine and alcohol shortly before bedtime.
- ✓ Don't go to bed hungry, but don't eat a big meal close to bedtime either.
- ✓ Before going to bed, try a relaxation technique such as a breathing exercises, meditation, keeping a journal, light reading or warm bath.
- ✓ Go to bed at the same time every night.
- ✓ Get out of bed if you are unable to get to sleep in about half an hour. Do something fairly boring for a while, then try again to fall asleep.



## Problems with thinking (“brain fog”)

### DESCRIPTION

Some people experience what is often called “brain fog”. Brain fog is how people describe being forgetful or unable to concentrate. The medical terms for a problem in the process of thinking are **cognitive deficit** or **cognitive impairment**. About one-third of HCV-infected people have cognitive deficits, most commonly difficulty concentrating and slowed thinking. This can interfere with your ability to learn, focus on a task for a long time or do more than one task at the same time. It can easily chip away at your confidence in being able to finish tasks on time, as they take longer and are more likely to have errors.

### CAUSE

Brain fog may have a direct link to HCV, although its possible causes remain unknown.

### TREATMENT

- When your head is clearer, try and keep your mind active by doing activities that require you to concentrate, such as doing crossword puzzles or reading.
- Along with exercising your brain, exercise your body. Physical exercise increases blood flow to the brain. Extra blood will nourish your brain cells and help reduce the build-up of plaque (fatty deposits) in the blood vessels including those in the brain.

### TIPS

- ✓ Try and keep track of the time of day when you feel most confused. Plan to rest during this time period.
- ✓ Buy a daily or weekly pill container to hold medications such as ribavirin. Keep a record to track when you have to take your medication. Make a check mark at the time you take your medication.
- ✓ Use Post-It notes to remind you of important appointments.
- ✓ Find a permanent place to put your keys and other important items.
- ✓ Start to-do lists with titles like *Must Be Done* and *Nice to Get Done*. Focus on one task at a time and cross it off when you finish. Make your lists in the evening for the following day.

## Depression

### DESCRIPTION

Depression is a word used to describe an emotional state in which you feel terribly sad for a couple of weeks or even months at a time. It's far worse than a case of general sadness because you also get a feeling of hopelessness and you take hardly any pleasure in things that previously made you happy. Your energy level may go way down to the point where even simple tasks like getting dressed in the morning seem like too much effort. Sometimes depression is hard to recognize because it can sneak up over weeks or months. You may not even realize your mood has changed until someone close to you says something like, “You don't seem like yourself these days”, or asks, “How come you're so quiet?”.

### CAUSE

Peg-interferon is known to cause depression in some people. In addition, the following changes associated with HCV and its treatment may cause or add to a depressed mood in some people:

- More difficulty getting around or following through with normal daily activities;
- Less ability to participate in leisure activities such as exercise or social events;
- More difficulty keeping up at work;
- Job loss resulting in less income and the end of a daily routine;
- A shift in roles at home causing feelings of having lost your place in the family;
- Less ability to make future plans.



**This chart is meant as a guide only to help you figure out if depression is going unnoticed by you. The changes are ones that commonly occur when people sink into depression.**

CHANGES RELATED TO DEPRESSION	
Changes to your <b>physical</b> self	<ul style="list-style-type: none"> <li>▪ More or less appetite, or a gain/loss in weight.</li> <li>▪ More or less sleep.</li> <li>▪ More or less activity.</li> <li>▪ More alcohol, cigarettes or drugs.</li> <li>▪ Less energy.</li> </ul>
Changes to your <b>social</b> self	<ul style="list-style-type: none"> <li>▪ More time spent alone or feeling lonely.</li> <li>▪ More thoughts that nobody understands you or even cares how you're doing.</li> <li>▪ More time spent arguing with people.</li> <li>▪ Less time spent with friends or family members.</li> <li>▪ Less interest in sex.</li> </ul>
Changes to your <b>thinking</b> self	<ul style="list-style-type: none"> <li>▪ More difficulty concentrating on tasks.</li> <li>▪ More difficulty remembering things.</li> <li>▪ More difficulty making decisions.</li> <li>▪ Less confidence at your place of work.</li> <li>▪ Thoughts of death or suicide.</li> </ul>
Changes to your <b>emotional</b> self	<ul style="list-style-type: none"> <li>▪ More crying spells.</li> <li>▪ More frustration.</li> <li>▪ More angry outbursts or irritability.</li> <li>▪ Feeling like a failure or feeling guilty.</li> <li>▪ Feeling helpless or overwhelmed.</li> <li>▪ Less motivation.</li> <li>▪ Less enthusiasm.</li> </ul>
Changes to your <b>spiritual</b> self	<ul style="list-style-type: none"> <li>▪ Feeling empty.</li> <li>▪ Loss of hope that things will get better, or expecting the worst in situations.</li> <li>▪ Loss of meaning or purpose in your life.</li> <li>▪ Less spiritual practice.</li> <li>▪ Less trust in people in general.</li> </ul>

## Extreme confusion (hepatic encephalopathy)

### DESCRIPTION

Extreme confusion, along with sleepiness and/or an agitated mood, are symptoms of a condition called hepatic encephalopathy. Early signs include changes in sleeping pattern or the development of tremors. In the worst cases, it can lead to coma.

### CAUSE

Hepatic encephalopathy may occur when the liver is unable to remove harmful waste products from the blood. It is a condition associated with cirrhosis and liver failure.

### TREATMENT

- **Rifaximin** is an antibiotic that lowers the level of ammonia in the blood by getting rid of ammonia-producing bacteria in the colon. Research has shown this drug helps to stop hepatic encephalopathy from reoccurring, thus improving the quality of life of patients.
- **Lactulose and lactitol** are commonly used to treat hepatic encephalopathy. They are thought to reduce ammonia absorption into the blood and improve elimination of waste through bowel movements. However, there is minimal to no documented evidence that lactulose is an effective therapy, especially when compared to the antibiotics rifaximin, neomycin, ribostamycin and vancomycin.

### TIPS

- ✓ If your dietary protein intake is greater than what your liver is able to process, it can lead to a build-up of toxins that interfere with brain function. However, your body needs proteins, so restricting your daily protein intake should only be carried out under the direction of your doctor.

## TREATMENT

- **Exercise:** Many people find that exercise allows them time to think things through because there are fewer distractions or interruptions. Exercise reduces stress hormones and so will help your body relax.
- **Learn a new calming technique:** Breathing exercises combined with flexibility exercises like yoga can have a calming effect. Research on an approach called mindfulness-based stress reduction is showing very good outcomes. For more information go to:  
[www.mindfullivingprograms.com/relatedresearch.php](http://www.mindfullivingprograms.com/relatedresearch.php)

## TIPS

- ✓ **Plan ahead:** Make a short list of tasks for the next day, then tick them off as you complete them. Try not to get sidetracked by less important obligations that don't have deadlines attached to them. You can plan ahead for both the short term, such as allowing enough time for you to travel from A to B, and the long term, such as completing a disability pension application.
- ✓ **Be aware of interactions with people in your life:** Sometimes your stress will be linked to specific people, so you will need to figure out how to communicate better with them. For example, do you have to be clearer in stating your point of view? More willing to compromise? On the other hand, talking with a trusted friend, even if you don't come up with a solution, will likely make you feel better.
- ✓ **Make time for yourself:** Try spending an hour a day simply relaxing alone without distractions. Also, schedule at least one event during the week so that you can look forward to something. Enjoyable activities will help take your mind off the stressful things troubling you.

## TREATMENT

- **Choosing the type of treatment for depression that is best for you**  
Most people will choose one of the following three ways to treat their depression: antidepressant drugs, talk therapy or a combination of both. Antidepressant drug treatment combined with psychological (talk) therapy has a higher success rate than when medication is used by itself.

The use of antidepressant drugs continues to grow and family doctors are becoming increasingly comfortable in prescribing these medications, rather than referring their patient to a psychiatrist. The advantages of taking antidepressant medication are twofold. First, drugs can make the difference in getting a person through a particularly severe spell of depression. Second, provincial/territorial health care plans and insurance companies will probably cover a portion or the entire cost of most antidepressants. The major disadvantage to antidepressants is their side effects. The most common side effects associated with antidepressant use are dry mouth, weight gain, sleep problems and loss of sexual interest or ability.

The advantages of talk therapy are also twofold. First, people in therapy learn coping skills that can be used throughout life during tough times. Second, talk therapy has no side effects. Talk therapy requires a time commitment (probably at least six sessions) and is emotionally hard work. Also, it may be more difficult to get your insurance company to reimburse the cost of therapy or there might be a limit on the number of sessions your insurance will cover.

- **Choosing the mental health professional right for you**  
Therapists in private practice charge by the session, so costs can mount quickly. But lack of money should not stop you from finding help. Many therapists charge according to a sliding scale, which means you can get a discount off the regular fee if you have a small income. Similarly, counselling at a local community mental health agency will take into account your ability to pay. Psychiatrists' fees are covered by provincial/territorial health care insurance. Medical social workers and psychologists attached to hospital programs are paid by the health care system. Check with your extended benefits plan to see if counselling services are covered such as through an Employee Assistance Program (EAP).

The most frequently studied talk therapy is called cognitive behavioural therapy (CBT), in which you learn to recognize and change negative thinking patterns causing your distressed mood. Essentially, you can change how you feel by changing what you think and do. CBT is considered to be a first-line treatment of choice for people with depressive disorders. Many therapists use CBT along with other strategies to help you feel more like yourself again.

Psychiatrists use talk therapy along with prescribing antidepressants. Registered clinical (mental health) professionals who offer therapy but not drugs include psychologists, social workers and counsellors. Research shows that a therapist's professional degree and the type of therapy he or she uses are not as important as the quality of your relationship (that is, your trust and the positive feelings you have towards your therapist) in ensuring a successful outcome. It's important to take the time to carefully choose the right therapist for you.



## Stress (emotional strain or tension)

### DESCRIPTION

For some people, stress (emotional strain or tension) can be more disabling than the physical effects of an illness. Stress can also make the symptoms of hepatitis C worse and may even affect the progression of the disease.

A person's life situation, even without HCV infection, may be terribly stressful. Taking care of the basics will likely take priority over symptom management or the threat of poor health in the future. Worry about where to sleep at night or when the next meal will come is more real for some people than concerns about liver damage, whether they have symptoms or not.

Physical symptoms of stress include lower back and neck pain, headaches, nervous tics, irregular heartbeat or racing pulse, having the feeling of a lump in the throat, sweating, dry throat and mouth, stomach pain and sleeplessness.

### CAUSE

You can create stress for yourself when you worry about the future. Having HCV can certainly change your outlook on life. Quite often stress is caused by worry over events that may or may not happen in the future, but that you believe to be outside your control. For some people, stress comes from having to deal with the losses caused by a chronic illness. People living with HCV may have several stressors in common:

- Fear of physical and mental deterioration;
- Fear of tests, such as a liver biopsy (obtaining a sample of liver tissue by putting a needle through the skin into the liver), and then the worry while waiting for test results;
- Concern that important health care services may not be available when needed;
- Uncertainty about the future and feeling unable to make plans;
- Worry about transmitting the virus to others;
- Tension that has developed in important relationships;
- Fear that others will pass judgment and treat you differently because of their attitude about hepatitis C.

- ✓ **Depression:** Depressed people tend not to see themselves as sexy, and this can reduce the desire for physical intimacy. Complicating matters is the fact that antidepressant medication may reduce interest and/or the ability of a man to get and keep an erection. If this is a side effect for you, talk to your doctor about changing the dosage of your medication. Your doctor may also consider adding an erectile dysfunction drug that increases blood flow to the penis, resulting in an erection when sexually stimulated. Women may find the application of a water-soluble lubricant will take care of vaginal dryness, which may also be a side effect caused by the HCV drug peg-interferon.
- ✓ **Reluctance to discuss sex with your partner:** Your relationship will likely be strained if a decrease in sexual activity is accompanied by a reluctance to discuss the changes. Your partner may take it as a personal rejection. Talking with your partner about your desires, pleasures and fears around sex can really help to reduce tension. Your partner may see this as an invitation to talk about his or her own feelings and concerns about sex. For example, your partner may have stopped initiating sex, fearing that physical contact will be too painful for you.
- ✓ **Here are some questions you can ask yourself before talking with your partner about sex:**
  1. Has HCV caused any changes in my attitude or emotions towards sex?
  2. Where on my body do I enjoy being touched and what areas should be avoided because they're just too sore?
  3. Are there sexual activities that are less or more pleasurable since I was diagnosed?
  4. Are there new things, such as sexual positions, that I want to try?
  5. Does my partner worry about having sex with me?

- **Finding a mental health professional**
  - Your family physician may prescribe an antidepressant drug or make a direct referral to a psychiatrist, community counselling agency or hospital psychiatry/psychology/social work department.
  - You may find a good fit with a therapist through a recommendation from a family member or close friend.
  - Your local HCV support group may know of a mental health professional who has experience in working with people living with HCV.
  - Your community may have a mental health/family services agency that offers counselling services.
  - Your workplace may have an employee assistance program as part of your employee benefits package. Your employer will not be told you accessed counselling services or why, and the therapist's report will not be sent to your employee record.
  - Online search engines are available at the professional association websites for psychologists or social workers registered in your province/territory.
  - Your local telephone directory won't offer much detail, but will likely provide listings under the headings of counsellors, psychologists and social workers.

#### TIPS

- ✓ Add a daily exercise routine.
- ✓ Try to be around other people, even if only for a little while each day.
- ✓ Let people close to you help out with their company, encouragement, affection or ability just to listen.
- ✓ Take part in activities, even if you don't especially want to. You may find you underestimate the amount of enjoyment you actually get from the experience. Low expectations are a product of negative thinking, so it's important to give yourself the opportunity to counter these thoughts and give yourself something to look forward to.

- ✓ Set some priorities, then focus on them one at a time. Usually breaking a priority or task down into smaller parts helps give you more confidence as you take each small step closer to your goal.
- ✓ Expect your mood to improve gradually. Feeling better does not occur overnight. Feeling a little better each day is how depression normally lifts.
- ✓ Discuss with your doctor whether or not a prescription for antidepressant medication and/or a referral to a therapist is right for you. Treatment for depression may be the answer if your usual coping skills aren't working or if your depressed mood significantly interferes with your life for a couple of weeks or more.
- ✓ Recognize that you may need a professional diagnosis if you apply for disability benefits. There are licensed/registered therapists who are qualified to use a manual called the DSM-IV-TR in order to assess and diagnose depression. The DSM-IV-TR recognizes that a person may have a mental disorder due to a general medical condition. Some people fear being labelled with a mental health disorder and dealing with that stigma. However, a diagnosis based on the DSM-IV-TR may be required by insurance companies.

## Low sex drive (loss of libido)

### DESCRIPTION

The lowering of one's sex drive is sometimes called loss of libido. Sexuality is not only about physical activity, but it also includes your feelings of attractiveness, your desire for emotional closeness and your openness to sensory experiences. There's a general acceptance that there's no one way to sexual fulfillment.

### CAUSE

Living with HCV may cause changes to your sexual activity, but it does not mean you have to give up intimacy or a satisfying sexual relationship. The tips below may help you manage the changes to intimacy and sexuality imposed on you by HCV.

### TREATMENT

**If concerned about a change in your sex life, try the following process to resolve the situation:**

- Identify the change. Is it, for example, your level of desire, your sense of being attractive, tension within the relationship, your mood or the onset of physical pain?
- Ask yourself whether or not these changes are something you need to worry about.
- If yes, ask yourself whether or not you're willing to talk to someone about it.
- If yes, ask yourself who would be the most appropriate person. That could be your partner, a trusted friend, your family doctor, a nurse or doctor working in your local hospital's sexual health program (if available) or a therapist.

### TIPS

- ✓ **Pain:** Before sex, try to reduce your pain by taking a warm bath or doing a few light stretching exercises.
- ✓ **Fatigue:** Plan for sex by pacing your day's activities so that you're well rested.