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## EARLY PAMPHLET SERIES

HepCBC pamphlets or brochures were first mentioned in the March, 1999 *hepc.bull*. Starting with the four topics of Hepatitis C and Sexual Transmission, Drugs, Pregnancy, and the Beauty Industry, later pamphlet topics included Treatment, Seniors, Disability Benefits (in cooperation with **Legal Services Society of BC**), and Helping a Friend/Family Member with HCV (in cooperation with **ANKORS** and **Patricia Johnson**).

These pamphlets were mostly compiled by patient-advocates **Joan Diemcke-King** and **CD Mazoff, PhD**, with kind permission to use content from **Peppermint Patti's FAQs (Patricia Johnson)**. First published in the late

1990s, completely revised in 2006. Printed and distributed with help from Schering CA plus several other generous but anonymous angels. Full text of HepCBC's Early Pamphlets Series (rev. 2006) follows.

### TABLE OF CONTENTS:

|  |           |
|--|-----------|
| Introduction (About Hepatitis C and HepCBC)        | pp. 2-3   |
| HCV and Treatment                                  | pp. 4-5   |
| Drugs and HCV                                      | pp. 6-7   |
| Sexual Transmission of Hepatitis C                 | pp. 8-9   |
| Hepatitis C and Pregnancy                          | pp. 10-11 |
| Hepatitis C and the Beauty Industry                | pp. 12-13 |
| Hepatitis C and Seniors                            | pp. 14-17 |
| Hepatitis C and Disability Benefits                | pp. 18-21 |
| Helping a Friend or Family Member with Hepatitis C | pp. 22-23 |

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*Disclaimer: HepCBC will not be responsible for any damage resulting from the information in this pamphlet. Please consult a physician for medical advice.*

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Last Revised, March 2006*

## What if you have Hep C?

- Do **NOT** consume alcohol
- There are medications available to treat hepatitis C. You need to discuss your options and the side effects associated with treatment with your doctor.
- There is **NO** vaccine against HCV
- To prevent further damage to your liver, get vaccinated for Hep A & Hep B
- Cover open sores or breaks in your skin
- If you have more than one sexual partner, use a condom. Partners should be told that the risk of transmission during sexual activity may increase when there are open sores or if the woman is menstruating. In general, couples who are monogamous need to know that the risk of Hep C being sexually transmitted is minimal but not absent

## Symptoms

### Initial Symptoms

- Flu like symptoms that never seem to completely go away
- Upset stomach
- Intermittent nausea and vomiting
- Low fever
- Fatigue
- Aching muscles and joints
- Headaches
- Slight sore throat
- Loss of appetite

### Chronic symptoms could include

- Light sensitivity
- Stomach swelling
- Personality changes
- Mental confusion
- Fatigue

**Up to 80% of people who have HCV are  
unaware of its presence!**



## Hepatitis C Education & Prevention Society

306-620 View Street  
Victoria, BC  
V8W 1J6

Tel: (250) 595-3892

Website: [www.hepcbc.ca](http://www.hepcbc.ca)

Email: [info@hepcbc.ca](mailto:info@hepcbc.ca)

For information on HCV and treatment, contact  
HepCBC or your local support group or clinic.



## OUR MISSION:

To provide education, prevention & support to those living with or affected by hepatitis C

### *Specifically:*

- To provide education and support to people infected with HCV, their families and physicians.
- To provide education forums about HCV research
- To increase community awareness about resources relevant to people infected with HCV and their families.
- To facilitate fundraising for activities related to hepatitis C education and research.

## WHAT IS HEP CBC?

**HepCBC** is dedicated to educating and advocating for those infected and affected by HCV. It is the agency of record for the BC Hepatitis C Council, an organization which encompasses most of the support groups in BC.

### WHAT DOES HEP CBC DO?

- HepCBC is the home of the hepc.bull, Canada's most up-to-date, informative and pertinent hepatitis C newsletter
- HepCBC provides peer counseling.
- HepCBC updates and distributes PEPPERMINT PATTY FAQ's—Frequently Asked Questions—which includes information on treatment and research.
- HepCBC distributes its own pamphlet series. Topics include HCV & Pregnancy, HCV & the Beauty Industry, HCV & Sexual Transmission, HCV & Treatment, HCV & Seniors, HCV & Disability Benefits, HCV & Drugs, Helping someone who has HCV.
- HepCBC provides professional information sessions to community members and groups, health care professionals, general public and those who are infected.
- HepCBC maintains an extensive, up-to-date library of resources.
- HepCBC provides support for those who are infected with HCV, no matter how the infection occurred.
- HepCBC helps with advocacy and referrals.
- HepCBC gives documented treatment information, options, and advice about how to get treatment.

## WHAT IS HEP C?

Hep C, a blood-borne virus, causes liver disease and attacks all parts of the body. About 400,000 Canadians carry HCV. Only a third is symptomatic. Approximately three quarters of those with HCV develop chronic infection leading to various degrees of liver disease. More than 5000 individuals in Canada are infected with HCV each year.

### WHY IS HCV A HEALTH CONCERN?

Identified in 1989, the Hep C virus has been around for a very long time. Many infected people do not know they have the virus. Some will have no symptoms. For others, the symptoms may appear 20 to 30 years later, but they can spread the virus to others. You may not know you have this disease until your liver has already been damaged, so you need to know if you're at risk!

### TRANSMISSION

HCV is spread through blood to blood contact. It is possible for someone infected with HCV to pass on the virus even if they have no symptoms. The virus enters the bloodstream through broken skin or mucous membrane

### RISK FACTORS

- Using intravenous drugs and sharing equipment (Needles, spoons, water, straws, etc.)
- Receiving contaminated tattoos or body piercing
- Being poked by a needle with infected blood
- Being born to a mother who is HCV positive
- Receiving a transfusion, especially before 1992
- Sharing items such as a razor or toothbrush with someone who is infected.

### HEP C IS NOT SPREAD BY:

HCV is **NOT** transmitted by casual contact, such as hugging, kissing or shaking hands. It is **NOT** spread by being around someone who is sneezing or coughing. HEP C is **NOT** found in food or water.

### IF YOU THINK YOU MAY BE AT RISK

If you have risk factors for Hepatitis C, take a simple blood test for the virus.

## What Else Can I Do?

Some people can continue working, while others are not able to do so. There can be more serious problems. Some people can't be treated because of heart problems, immune system problems, or serious depression. There are more side effects and reasons people can't be treated. Talk to your doctor.



### What else can I do?

- Stop drinking
- Get vaccinated against hepatitis A and B
- Get a pneumonia vaccine
- Get a flu shot each year
- Avoid toxins like paints, gasoline and insecticides
- Check out all medications, even non-prescription medications, with your pharmacists

- Exercise regularly, even if you're tired.
- Eat a balanced diet.
- Join a support group.
- Read all you can about Hep C.
- Be careful with any herbs; some may hurt your liver.
- Ask a registered dietician about vitamins; avoid mega-doses.

For Further Information,  
contact:

# HCV & Treatment



306-620 View St  
Victoria BC V8W 1J6

[www.hepcbc.ca](http://www.hepcbc.ca)  
[info@hepcbc.ca](mailto:info@hepcbc.ca)

Tel: 250-595-3892

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Last Revised, March 2006

# HCV & TREATMENT: SHOULD I BE TREATED?

## HCV & Treatment Should I be treated?

Hepatitis C is generally a slow-moving disease. You have time to think about what you want to do.

You should get these tests:

1. A liver panel (blood test—measures enzymes such as the ALT and AST, clotting time, etc.)
2. An HCV-antibody test.
3. A PCR test (looks for the virus itself)
4. Genotype test
5. Alpha-fetoprotein test or AFP (looks for cancer)
6. Ultrasound (looks for tumors)
7. Biopsy

The first 5 are blood tests. They will give you and your doctor some important information.

The AFP and ultrasound should be done at least yearly, and more

often if you have cirrhosis (scarring). The only way to know how much damage has been done to your liver is from a biopsy. You may have a lot of virus, but no damage to your liver, or the other way around. You may have a high ALT, and no damage to your liver, or a low ALT and quite a bit of damage. If your liver is not damaged, you may wish to wait before being treated. On the other hand, if your liver is damaged, and you have signs of rapid progression, you may wish to be treated as soon as possible.

Remember:

1. The earlier you start treatment, the more likely you are to respond.
2. The younger you are, the more likely you will respond.
3. The disease progresses faster in men than in women.
4. The genotype test will tell you how likely you are to respond to treatment. Genotypes 1 don't respond so well as other genotypes. People with genotype 1 need longer treatment.

## What is treatment like?

The standard treatment is pegylated interferon plus ribavirin. The patient injects the interferon in the stomach or legs once a week, and takes 5 to 6 capsules of ribavirin each day.



There are two brands of treatment approved in Canada: Pegatron and Pegasys.

The side effects of either treatment can be much like having a bad case of the flu. They last about 2 weeks, and then get better. Some side effects can be permanent, like thyroid disease or eye problems. Some people lose weight and have hair loss. Both the weight and the hair return.

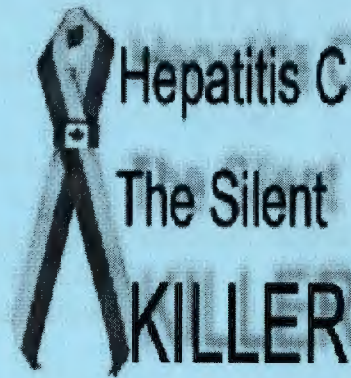
**Using a new disposable needle each & every time is safer than cleaning equipment. Check out your local needle exchange!**

*How can I tell if I have hepatitis C?*

One to two months after the hepatitis C virus infects your body, antibodies appear in your blood. A blood test can detect these antibodies and show that you have been infected with the hepatitis C virus. Not everyone who has antibodies in their blood is still infected with the virus, but most people are. If you have tested positive for the virus, assume you are infected and can infect other people. There is also a blood test that can tell if you are carrying the virus.

*What are the symptoms of hepatitis C?*

Some people feel well, have no symptoms, so they don't know they have hepatitis C. Other people may have a brief illness with symptoms of hepatitis usually appearing six to nine weeks after they have been infected with the virus. Symptoms of acute hepatitis C infection may include: fever, tiredness, jaundice (yellow skin or eyes), abdominal pain, dark urine, loss of appetite, and nausea (feeling sick to your stomach).



**For Further Information,** contact your public health nurse or family doctor. Your nearest needle exchange or support group is:

VARCS: Mobile X  
Mobile Exchange  
Tel. 888-4487

Will pick up used needles.

AVI Street Outreach Services  
(SOS) Fixed site.  
Needle drop off.  
Tel. 384-2366

**On the Net:**  
[info@hepcbc.ca](mailto:info@hepcbc.ca)  
[www.hepcbc.ca](http://www.hepcbc.ca)

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Last Revised, March 2006



**DRUGS  
&  
HCV**

**hep  bc**

**306-620 View St  
Victoria, BC V8W 1J6**

# HCV and Intravenous Drug Use

## *The Plain Facts*

If you're an IV drug user, there's a good chance you already have hepatitis C. "Hep C," or "HCV," is **over 10 times more contagious than HIV**. It's really easy to get if you shoot or snort, and very difficult, if not impossible, to get rid of. With Hep C it doesn't matter how long you've been shooting or snorting—many people get it after only using once. Up to 85% of IV drug users test positive for Hep C.

The problem is that hepatitis C is sneaky. It can lie there for years without doing anything, and then, when you finally get clean—**WHAM!!**—you get really sick or find out that you're dying because your liver isn't working right.

## **GET TESTED! GET VACCINATED FOR HEP A & B**



If you have ever shared needles, even once, twenty or thirty years ago, you may have Hep C and not even know it. Nine out of ten IV drug users may have it. Get tested. There is a treatment. There is no vaccine for Hep C, but you can protect yourself from getting Hep A & B. It's worse to have more than one hepatitis. Hep A & B vaccines are free for IV drug users and those with Hep C in BC—no questions asked. Check with your local public health unit or needle exchange.

Hep C, like Hep B and HIV, can be transmitted by sharing toothbrushes, razors, nail clippers, or other items that can cause bleeding. Sexual transmission is considered a possible but unlikely mode of transmission. So play it safe.

## *Practice Harm Reduction!*

Sharing any drug injecting equipment or snorting equipment can easily lead to Hep C and other diseases carried in the blood being passed on. Equipment is not just the needle and syringe, but also includes spoons, mixing dishes, filters, water and citric acid.

If you inject drugs, use a new needle and syringe each time. Don't share any injecting equipment. Clean the injection site with alcohol and a new cotton swab. Use sterile water to prepare drugs. Boiling equipment in tap water for several minutes will sterilise it. Don't use old needles, cookers or cotton to prepare drugs. New equipment can be bought from some pharmacies, or is available free from needle exchanges. Most needle exchanges don't require you to bring in old needles to get new ones. You should be able to get a supply of new, sterile needles.

## *Get Rid of Your Used Syringes Carefully*

Taking your old syringes to the needle exchange is the best way to safely get rid of dirty needles. You also get a new supply of clean needles when you bring your old ones in.

Needle exchange programs provide sharps containers for safe disposal. If you do not have one, put the needle and syringe into a tin can, or heavy plastic container with a closing lid (like an empty milk or bleach jug), then dispose of it in a garbage can or take it to your local needle exchange.

If sharing is impossible to avoid, equipment can be cleaned between users as a **last resort**. Bleach should stay in the syringe for at least 30 seconds. Remember not to flush out into the clean bleach solution or water. Do not use hot water: it will make the blood congeal (clot) so traces may be left behind. Boiling equipment may not remove all the blood, and disposable equipment usually buckles if boiled. It is safer to use the needle exchange program!

## **CLEANING EQUIPMENT**

1. Draw 5% regular household bleach solution through the needle into the syringe, fill completely and flush x 3.
2. Soak the bleach-filled syringe in the bottle of bleach solution and leave for 10 minutes.
3. Draw fresh cold water through the needle into the syringe and flush x 3.

Nonoxynol-9 is a chemical used on some condoms and in spermicidal creams. Some people are allergic to it, so it can cause abrasions, and this increases vulnerability to Hep C. If you experience discomfort with nonoxynol-9, stop using it. Lubricants such as KY will not cause irritation.

Condoms are sometimes criticised as being unreliable. In fact, condom failure is usually due to incorrect use or not enough lubricant. It is important to follow the instructions carefully. Neither male nor female condoms should ever be reused.

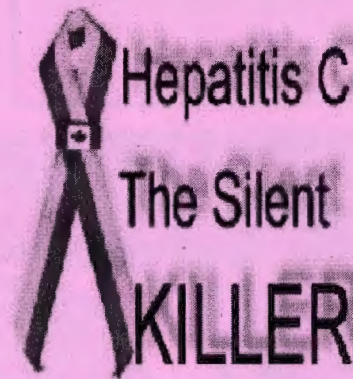
### **ORAL SEX**

It is unknown for Hep C to be passed to someone through oral sex, but it could possibly be passed on if there are cuts or sores in the mouth, bleeding gums, or a throat infection. If menstrual fluid (blood of an hep C infected woman) is also present, there will be more risk of infection. There are no confirmed reports of infection occurring by this route. There is probably not enough Hep C in saliva that is not contaminated with blood to infect another person.

### **OTHER SEXUAL ACTIVITIES**

If sex results in cuts or broken skin, it is good basic hygiene to cover the wound with a water-proof Band-Aid—or better still, to allow it to heal before resuming sexual activity.

Other sexual activities, such as body rubbing, fingering and mutual masturbation will not transmit the virus. French kissing after flossing/brushing or when mouth sores are present is possibly risky, “although deep kissing is not a proven route of transmission and the risk of blood-to-blood contact is extremely low.” (BCCDC)



**For Further Information,**  
contact your public health nurse or  
family doctor. Your nearest  
hepatitis C support group office is:

**On the Net:**  
[info@hepcbc.ca](mailto:info@hepcbc.ca)  
[www.hepcbc.ca](http://www.hepcbc.ca)

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Last Revised, March 2006*



## OF HEPATITIS C



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# Is Hepatitis C a Sexually Transmitted Disease?

The hepatitis C virus could be transmitted during sex if there were blood present, but it is not considered a sexually transmitted disease. Some studies in which it was claimed that HCV was sexually transmitted are known to be flawed because the group tested (mostly prostitutes) also had other risk factors, such as lifestyle risks (sharing of razors, manicure equipment, toothbrushes) and, most notably, intravenous drug use.

According to Health Canada, however, "The risk of infection through sexual intercourse with a carrier is estimated at 2.5% over 20 years. Transmission from mother to child is uncommon, and the question of risk to breast-fed infants of infected mothers is unresolved."<sup>1</sup>

Hepatitis C is spread mainly by blood-to-blood contact. Thus it is conceivable that sharing a toothbrush or a razor--or even deep-kissing after dental flossing--*might* be more risky than actual sex!

**We conclude that heterosexual transmission of hepatitis C is extremely uncommon, despite frequent and unprotected sexual intercourse.<sup>2</sup>**



Other studies suggest that body fluids of patients with chronic hepatitis C are rarely, if ever, contaminated with the hepatitis C virus. This may help to explain the infrequent transmission<sup>3</sup> of this disease by sexual or close physical contact.

#### Notes

1. Gully & Tepper, "Hepatitis C," *CMAJ* May 15, 1997 (vol 156, no 10): 1427
2. Gordon; Patel, et al. *Am J Gastroenterology* 87: 1849-51 (1992).
3. Fried, Shindo, et al., "Absence of hepatitis C viral RNA from saliva and semen of patients with hep c," *Gastroenterology*. 1992 Apr. 102(4 Pt 1), P 1306-8.
4. [www.phac-aspc.gc.ca/hepc/hepatitis\\_c/drhepc.html#sex](http://www.phac-aspc.gc.ca/hepc/hepatitis_c/drhepc.html#sex)

## How Can I Protect Myself? Some Guidelines for Sex & HCV

If someone has Hep C, it might be passed to another person through sex, but probably only if there is contact with blood and/or lesions. The presence of herpes sores, etc., may make it easier to pass on hepatitis C through sex.

The current recommendations (2003) from the Public Health Agency of Canada:<sup>4</sup>

1. **PEOPLE WITH MULTIPLE PARTNERS SHOULD ALWAYS PRACTICE SAFER SEX.**
2. **LONG-TERM MONOGAMOUS COUPLES SHOULD DECIDE FOR THEMSELVES ABOUT ROUTINE CONDOM USE.**

### USE OF BARRIERS

Safer sex principally means using latex condoms or female condoms and lubricant if you have penetrative sex, or having sex without penetration. This is "safer," not safe sex, because there will always be a tiny risk (for example, condoms can break), but the risk can be made so small that it does not interfere with enjoyment of sex. As well as preventing Hep C transmission, safer sex protects against most other sexually transmitted infections (STDs) and AIDS. Some STDs can do serious long-term damage if they are not treated promptly. Safer sex will also help prevent pregnancy.

Extra lubricant should probably be used to help prevent damage to the membranes or to the condom. Don't use a lot, or the condom could come off. Water-based lubricants, such as KY jelly, are safe to use with latex condoms. Oil-based lubricants, such as Vaseline or massage oils, will damage latex and make the condom unsafe.

## Children and Advanced Liver Disease

Chronic hepatitis C eventually causes cirrhosis or cancer, however, it can take 10 to 20 years or more before cirrhosis may occur. Liver cancer rarely occurs in children.

### Treatment in Children

The AASLD recommends:

1. Diagnosis, testing, and liver biopsy of children thought to have HCV.
2. Because of the high spontaneous clearance rate during the first year of life, children of HCV-infected mothers should be tested at 18 months or later.
3. Healthy children with HCV ages 3-17 may be given interferon alfa-2b and ribavirin by specialists in treating children
4. Children under the age of 3 should not be treated.

There are still many questions about Hepatitis C in children. More studies are necessary to learn more about how the disease progresses and about different treatments.



**For Further Information,**  
contact your public health nurse  
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# HEPATITIS C AND PREGNANCY



hep  cbc

# HEP C AND PREGNANCY



## Reducing the Risk of Transmission During and After Pregnancy

A woman living with Hep C who wishes to become pregnant may be worried about the health of her baby. The chance of the virus being transmitted to the baby is 0-10%, but higher in persons who have HIV or use IV drugs. If a mother also has AIDS, the chances can increase up to 36 in 100. The risk may be even greater in mothers who are infected with both Hep B and Hep C.

Transmission to the baby can happen before or during birth.

Present information shows that transmission may be slightly more likely in infants born to mothers with genotype 1.

Most doctors and midwives will be helpful and supportive to a woman with Hep C who wants a child. Pregnancy with Hep C is not officially discouraged.

A woman may wish to take treatment for hepatitis C before becoming pregnant. She **MUST** wait at least 6 months after stopping treatment before getting pregnant, to avoid birth defects. Infected men on treatment should use birth control during, and for at least 6 months after treatment for the same reason.

Having a Caesarian section does not usually reduce the risk of transmission. However, it is possible that if a woman has an acute case of Hep C or is co-infected with HIV, there is more of a risk of her baby being infected.

## Viral Load and Mother-to-Baby Transmission

Viral load is the amount of Hep C in the blood. If a woman with Hep C has low viral load (less than 1 million copies/mL), it is less likely that the virus will be passed to her baby than if she has high viral load, but there is still a chance that Hep C will be transmitted. If the mother has no virus, the baby will not be infected.

## Breast Feeding

It is not yet known whether the breast milk of a woman with Hep C contains enough virus to infect a baby during breast feeding. Generally, women with Hep C are not advised to avoid breast feeding. No studies have documented transmission of Hep C infection to infants by breast-feeding. One study showed breast-fed infants were slightly less likely to have HCV. Mothers should not breastfeed when their nipples are cracked or bleeding, just in case.

## Children with Hep C

In children, viral infection is usually silent, although children as young as 8 years old can become quite ill from HCV.

Children are less likely than adults to have symptoms of infection with Hepatitis C, and thus may be able to transmit the virus unknowingly.

Having hepatitis C does not seem to affect a child's growth.

All children, with or without hepatitis C, should be taught proper hygiene.

razors. If you do use straight-edged razors, choose single use disposable blades, and clean and disinfect the blade handle, as described above, between each client.

6. Refuse to cut cuticles.

7. Utilise single-use, disposable needles, ink pots and autoclave tools between each client in tattooing and piercing salons (*"Doctors warn tattoos, piercing can be dangerous to your health," New York Amsterdam News, 11-18-95, pp PG.*)

8. Don't dip clean tattooing needles into previously used ink.

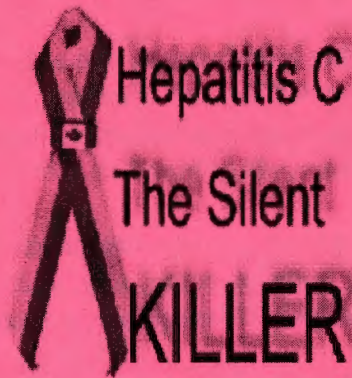
9. Use latex gloves. Wash hands and put on a fresh pair of gloves between each client.

10. Clean and disinfect surfaces and non-disposable items between clients.



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HEPATITIS C  
&  
THE



BEAUTY INDUSTRY



## What is Hepatitis C ?

**H**epatitis C is a disease of the liver caused by the hepatitis C virus (HCV). Hepatitis C was identified in 1989. Before 1989, this type of hepatitis was called non-A, non-B hepatitis, meaning that it was not caused by the viruses that produce hepatitis A or hepatitis B (two other viruses that can cause liver inflammation).

The hepatitis C virus is now recognised as a world-wide epidemic, infecting 1 in 70 people world-wide. That means there are 10 times as many people infected with Hep C as with the AIDS virus. Probably 85% or more of those infected remain so for the remainder of their lives. The disease produced by the virus can lead to liver failure, cirrhosis, liver cancer & death.

### How is Hepatitis C spread?

The virus is usually spread by direct contact with the blood of an infected person. This happens most often by:

Sharing drug snorting or injection equipment such as straws and syringes.

Having received a transfusion of blood or blood product in a country where the blood supply was not tested for hepatitis C. In Canada, this applies to transfusions before 1990. As of March 1990 all blood and blood products have been screened for HCV—but a very small risk still remains.

Needlestick injuries.

Sharing toothbrushes, dental floss, razors, nail files, hair trimmers, brushes, combs, or other items which could have tiny amounts of blood on them.

Skin piercing procedures, such as tattoos, body-piercing, acupuncture or electrolysis, if the equipment is not sterile.

Sexual intercourse (rarely).

An infected mother passing it to her new-born infant. Whether breast milk can transmit the virus is not yet known.

Although a significant number (10-40%) of Hep C carriers don't know how they contracted the disease, avoiding these situations can help to prevent the spread of hepatitis C.

**There Is No Vaccine  
Against  
Hepatitis C**

Experts speculate that the virus may be spread through invasive procedures such as those performed in the field of medicine and the beauty industry.

Given these facts, it is important that professionals involved in these fields take all available precautions so as to stop the spread of this as well as other emerging epidemics. Normal cleaning and sterilisation recommendations (described below) are effective, provided they are carefully and consistently followed.

### *We recommend that you:*

1. Consult with your local public health unit/department about the precautions to use in your profession.
2. Before disinfection, preclean/wash items in fresh soap & water to remove visible contamination.
3. Use heat to disinfect blood-contaminated items, such as an autoclave, and follow manufacturer's recommendations. Alternatively, use a 1:10 to 1:100 dilution of 5% household bleach and immerse items for at least 10 minutes. Rinse items well with water. Make up a fresh bottle of bleach solution each day, and shield it from any light. (*"Hepatitis C: Risk of a Haircut,"* by Gitlin, Nolte, and Weiss, Emory University School of Medicine, and *"Dental instrument and device sterilization and disinfection practices," JHosp Infect 1996 Apr Issue: 4 Volume: 32 pp 295-304*)
4. Have your client bring his/her own manicure or pedicure tools.
5. Eliminate the use of straight-edged

Tobacco makes liver cancer more likely in Hep C sufferers. There is nothing doctors will recommend in the way of special diet unless you have cirrhosis, but most people find they feel better on low fat diets.

### **Alternative Treatments**

Check with your doctor before taking any alternative medicine. Some herbs are safe, and may help. Others can be toxic. It's best to consult with a reputable naturopath or health food store, and have your blood monitored for possible liver damage any time you try a new treatment.



# HEPATITIS C & SENIORS



306-620 View St  
Victoria, BC V8W 1J6

*The information in this brochure is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV*

*This pamphlet series printed thanks to Schering Canada  
Last Revised, March 2006*

[www.hepcbc.ca](http://www.hepcbc.ca)  
[info@hepcbc.ca](mailto:info@hepcbc.ca)

Tel: 250-595-3892

## HEPATITIS C & SENIORS

**S**ometimes elderly people are not diagnosed with hepatitis C because the symptoms are similar to what we tend to expect from the aging process: tiredness, achy joints, sleep problems, stomach and digestive problems, strange rashes, memory loss, and so on. The elderly should expect to feel good, and to investigate matters when they don't. It may be that the problems can be remedied.

### **I've Been Diagnosed. Now What?**

If you're diagnosed with hepatitis C, get informed. Check with your local support group.

*Make sure that you:*

- Get re-rested to confirm the diagnosis.
- Get vaccinated against hepatitis A and B, and get tested to see if the vaccinations took.
- Ask about the pneumonia and flu vaccines.
- Get sent to a specialist.
- Get copies of all tests.

*The specialist should:*

- Order an ultrasound yearly, if your family doctor didn't.
- Order an alphafetoprotein test yearly to check for cancer.
- Order a liver biopsy. (This is usually done by needle aspiration, but there are other options, for example, if there is a bleeding problem).
- Discuss treatment options with you (Get a second or even a third opinion if you don't agree).

### **Am I Contagious?**

Transmission of hepatitis C is rare, but can occur with blood-to-blood contact, such as when your blood comes into contact someone's open cut, or by sharing of razor blades, toothbrushes and sharp personal grooming aids, like nail clippers. Yes, you may hug and kiss your grandchildren. Sexual transmission occurs



rarely, and long-time couples are not advised to change their normal habits. All family members should be tested, just in case.

### **How can I avoid spreading Hep C?**

- Keep your toothbrush, toothpaste, razors and nail clippers where no one can use them by mistake.
- Clean the sink personally every time you brush your teeth. Use a plastic spray bottle containing a bleach / water mixture along with paper towels, or wipes.
- Wipe up any blood spills carefully, using vinyl or rubber gloves, first with water and paper towels, and then with a 10% household bleach solution. If any glass is involved in the cleanup, pick up the pieces first and wrap them in newspaper before placing them in a plastic bag. Wrap the soiled towels in a plastic bag and put it in the trash. Do not use bleach on skin (or pets' claws). Use 70% Alcohol (rubbing alcohol) on skin. (This can also be used on colour-sensitive fabrics.) Remove and discard gloves. Wash your hands when you're done.

### **Will I die from Hep C?**

Hepatitis C can remain "dormant" for decades, but can also result in liver cancer, cirrhosis, liver failure, and serious bleeds. About 80-85% of people infected with HCV will develop chronic hepatitis; of those, 20-30% will progress to cirrhosis. Another 20-30% may develop chronic HCV infection without abnormal elevations of liver enzymes in the blood. —Source: *Prevention, Diagnosis, and Management of Viral Hepatitis*, AMA.

Liver cancer is thought to be produced by constant inflammation and regeneration of liver tissue over about 30 years. Most, if not all, cases of liver cancer occur in people with cirrhosis. In other words, if you don't have cirrhosis, you probably don't have to worry about liver cancer. Once cirrhosis begins, the chance of liver cancer is 1 to 4% a year. Source: *National Institutes of Health Consensus Statement on Hepatitis C 1997*

Some doctors think that most people who are infected during middle age will probably die of their underlying disease or of old age, rather than hepatitis C.



Source: *Natural History and Clinical Aspects of HCV Infection*, H.J. Alter, MD.



Other doctors think that progression of the disease is faster in older patients.

### Should I be treated?

The only proven treatment is interferon and its various combinations.

Treatment results are not as good for older people. Recent studies are being done on people with cirrhosis, with good results, however. Several things affect treatment



results: age, sex (women respond better than men), mode of transmission

(transfused patients are harder to treat), enzyme levels, genotype, viral load, and the amount of interferon

taken. *Source: Kim SR, et al, Prediction of efficacy of interferon treatment of chronic hepatitis C by Pathol Int 1998 Mar;48(3): 215-220*

**Remember:** Not all interferons are created equal. Some are more effective than others.

**Fact:** Those over age 60 are often not treated. Doctors probably wish to protect their patients from the uncomfortable side-effects of interferon, but in many cases, the disease itself causes more discomfort than the treatment, and often older people do respond to treatment.

Most patients have had to fight to be treated in Canada. This is especially true for seniors.

### Can I be transplanted?

Those over 65 are usually not transplanted. Exceptions are made.

### Can diet help?

There is a more rapid development of cirrhosis and liver cancer alcoholics with chronic HCV infection. To be safe, don't drink.

## SUBSCRIPTION/ MEMBERSHIP FORM

Please fill out & include a cheque made out to HepCBC - Send to:

HepCBC  
306-620 View St  
Victoria BC  
V8W 1J6

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Prov. \_\_\_\_

PC \_\_\_\_\_

Home( ) \_\_\_\_\_

Work( ) \_\_\_\_\_

Email: \_\_\_\_\_

Membership + Subscription to the  
*hepc.bull* (1 year): \$20.00

I enclose a donation of \$ \_\_\_\_\_

If you've ever asked yourself any of these questions, we can help you find the answers:

- I have hepatitis C? What do I do now?
- I feel very weak, tired, confused, and nauseous. Will I die?
- I had a biopsy, and they said I was fine. But I'm always tired and my stomach hurts. Why?
- The doctor said I need to go on treatment for my disease, what does this mean?
- I am scared, feel very alone, isolated and depressed. What can I do?
- Are there any support groups for hepatitis C?
- Someone told me I need help filling out the disability form. Do I? I'm too sick to work.
- I'm in the "Window" from 1986-1990 for those with blood transfusions. I get a pay out, don't I?
- I have worked all my life and have been paying into CPP. Now I can't work, but I have been turned down for my CPP disability twice. Where can I find help?
- I'm too tired to shop and cook, or clean my house. I need help?
- I can't work anymore, and I've been turned down for my Provincial disability. I can't pay my rent, and I'm scared. Can anyone help me?

## Hepatitis C & Disability Benefits



306-620 View St  
Victoria, BC V8W 1J6

Tel: 250-595-3892

[www.hepcbca.ca](http://www.hepcbca.ca)  
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## HEPATITIS C & DISABILITY: WHAT YOU NEED TO

### *Your Doctor(s):*

If you have been diagnosed with hepatitis C you should be under the care of a specialist. If you are not, ask your family doctor to recommend one. Your doctors should be your closest allies, both in your battle with hepatitis C and also in obtaining your disability benefits, should you qualify.

### *Disability Benefits:*

There are several types of Disability Benefits available to residents of BC: Canada Pension Disability Benefits; Disability Benefits from the BC Government; Worker's Compensation; and various private plans. All have very different qualifications, and procedures, which your local advocate can explain to you.

### *Advocates:*

Advocates are community workers who have a great amount of experience fighting for citizens' rights in many areas: housing, income assistance, disability benefits, and so forth. Often advocates can

be found at community organisations, such as AIDS organisations, or organisations for the disabled, such as the BC Coalition of People with Disabilities, TAPS or the ACPD. They can also be found at various Legal Services Society offices throughout the province. For help in locating an advocate nearest you, you can call the Advocacy Access Project at 1-800-663-1278, or HepCBC at (250) 595-3892.

Often people feel their case is so clear cut that they can take care of it themselves. Big Mistake! Unfortunately, the decision to award disability is not based on how you feel, or even on how you look, but on very special criteria that each disability plan has established. Unless you meet these criteria, you will not get your disability—no matter how deserving you may feel that you are.

Arguing your own case is exhausting. If you are ill, this is the last thing you need. Advocates know the ropes and they are there to help you.



## *Qualifying for Disability Benefits:*

If you are applying for Canada Pension Plan Disability benefits, the most important aspect, aside from your condition, is whether or not you have made enough contributions to the Canada Pension Plan, and when you have made them. If you have not paid into this plan because you have not been working, or have not worked recently, you may not be eligible. Your advocate, or a lawyer from Legal Services, can help you understand whether or not you should apply for CPP Disability.

If you are applying for BC Disability Benefits, it can help if you have applied for and received your CPP, but not having CPP Disability will not disqualify you from getting BC Disability Benefits.

## *Some of the Issues:*

### **The Runaround:**

Getting disability even if you are really sick is not easy. Often you will need to have lots of papers and doctors' appointments and interviews. When you are feeling really sick and tired, it is very frustrating to have to go to one appointment after another, all the while not knowing how you are

going to eat, let alone pay the rent.

### **Hep C and Doctors:**

Perhaps the single most important document you will need when making your disability claim is your doctor's letter. Unfortunately, many doctors, no matter how sympathetic they may be to your plight, do not know how to fill in the form properly. Your advocate will be able to provide you with guidelines that you can give to your doctor, to help him or her fill out the form more effectively.

Sadly, there are still many doctors out there who do not understand the nature of hepatitis C.

Many continue to think that it is only a liver disease, and that, unless you are suffering from end-stage liver disease (cirrhosis, ascites, bleeding), you cannot be disabled.

Other doctors and specialists are beginning to understand that hepatitis C, while it does cause liver disease, also causes a host of other problems related to autoimmunity. In fact an article in the *American Journal of Gastroenterology* states that "up to 70% of patients with chronic hepatitis C" may suffer from autoimmune related disorders.<sup>1</sup>



It is the presence of autoimmune activity (your body fighting the hepatitis C virus) that causes the fatigue, muscle aches, confusion, bone aches, feverishness, nausea, itching and mood swings from which people with hepatitis C suffer. Often, none of this can be established by a specific blood test, although some autoimmune disorders do have special "markers" in the blood.

When the Federal Government decided to compensate certain individuals who received tainted blood between 1986 and 1990, they concluded that those under the plan with Grade 2 Liver Fibrosis (a stage of scarring in the liver) would be eligible for "loss of income" payments. In making this decision, the government may have set a precedent which could make it easier for anyone with Grade 2 Fibrosis (non-bridging Fibrosis) to qualify for long term disability benefits, which is what "loss of income" payments are.<sup>2</sup>

Those under the compensation scheme with Grade 3 Fibrosis (bridging fibrosis) or cirrhosis have been awarded even more because the government recognizes that the more heavily scarred the liver is, the more disabled the person will be.

However, in order for anyone to know to what extent your liver is scarred, you must undergo a liver

biopsy, which is not the most pleasant of experiences, but should be standard procedure for everyone with hepatitis C.

*Notes:*

1. *American Journal of Gastroenterology*, Vol 96 number 2, 2001: 910-911.
2. *Hepatitis C: January 1, 1986-July 1, 1990 Class Actions Settlement*, p. 18.

### Locating an Advocate

*On the Net:*

Povnet has a publication, *Your Welfare Rights*, which lists advocates in communities throughout BC. <http://povnet.web.net/weldisability.html>

*Vancouver*

The **BC Coalition of People with Disabilities** has an Advocacy Access Program. They will direct you to an advocate nearest you: 1-800-663-1278.

**Enquiry BC** will help you find the Legal Aid office nearest you: 1-800-663-7867

*In Victoria*

Together Against Poverty (TAPS)  
(250) 361-3521

Action Committee of People with Disabilities (ACPD)  
(250) 383-4105

## WHAT SHOULD I SAY?

Do you really want to help? Here are a few of the "Best" things you can say to your HCV-positive friend:

- ◆ "I love you!"
- ◆ "I care."
- ◆ "You're not alone in this."
- ◆ "I'm not going to abandon you."
- ◆ "Do you want a hug?"
- ◆ "I am going to take care of myself so you don't need to worry that your pain might hurt me."
- ◆ "I listen to you talk about it, and I can't imagine what it's like for you. I just can't imagine how hard it must be."
- ◆ "If you need a friend..." (and mean it.)
- ◆ "Is there anything I can do to help?" (and mean it.)
- ◆ "I am going food shopping tomorrow. Give me your list and I will pick it up, bring it home to you and help put it away."
- ◆ "I don't care if you get tired and cranky. I love you and spending time with you is still fun."
- ◆ "I will be over in half an hour with dinner and a video, and then I will leave so you don't have to entertain me."
- ◆ "It's okay, you don't have to be brave for me. Let me be the strong one for a while."
- ◆ "It is a gift to me that you permit me to help and support you. I know how hard it is for you to ask for help."

## West Kootenay/Boundary Support Groups

### Castlegar/Grand Forks

Contact: Robin – 365-6137

### Kootenay/ Boundary

Meetings: Second and fourth Tuesday of each month, 7pm, 1159 Pine Ave, Trail

Contact: Brian 368-1141, k-9@direct.ca

### Nelson Hepatitis C Support Group

Meetings at ANKORS, 101 Baker St.

For information on the next meeting call Ken Thomson at ANKORS

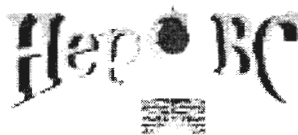
1-800-421-2437, (250) 505-5506 or

Ken Forsythe (250) 355-2732, keen@netidea.com

### Nakusp Support Group

Meetings: Contact Ken

1-800-421-2437, (250) 505-5506



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Patricia Johnson & C.D. Mazoff  
cdm@hepcbc.org

# HELPING A FRIEND OR FAMILY MEMBER WITH HEPATITIS C



# ANKORS

Hepatitis C Support and Education  
Project

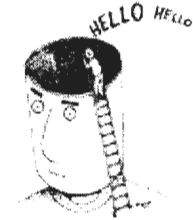
1-800-421-2437  
505-5506

## TIPS FOR COPING WITH HAVING A FAMILY MEMBER WITH HEPATITIS C

### Remember:

- ◆ You cannot cure your family member. Despite your efforts, symptoms may get worse or may improve. Enjoy the good times.
- ◆ If you feel much resentment, you are giving too much.
- ◆ It can be as hard for you to accept the illness, as it is for the ill family member.
- ◆ You may learn something about yourself as you learn about a family member's journey through illness.
- ◆ Separate the person from the virus. Love the person, even if you hate the virus or side effects of the medication.
- ◆ It is not OK for you to be neglected. You have needs & wants too.
- ◆ Your chances of catching hepatitis C from casual or sexual contact with a family member is extremely low, providing proper precautions are taken to avoid blood contact.
- ◆ Everyone's blood has the potential to make someone else sick. Never share razors, toothbrushes or drug injection/snorting equipment. Make sure that tattoo, manicure, electrolysis and acupuncture establishments use sterile equipment.
- ◆ The illness of a family member is nothing to be ashamed of.
- ◆ You may encounter discrimination from an apprehensive public.
- ◆ You and your family member may have different comfort levels around disclosure of information to others. It is important to discuss this and be respectful of each other's needs.
- ◆ No one is to blame.
- ◆ Don't forget your sense of humour.
- ◆ Acknowledge the courage your family member may show in dealing with the illness.
- ◆ Your family member is entitled to his or her own life journey, as are you.
- ◆ Resist the survival-oriented response of shutting down emotionally. Find someone to talk to. You are not alone.
- ◆ Sharing your thoughts and feelings with others in a support group is helpful and enlightening for many.
- ◆ It may be necessary to renegotiate the way things have been done in your relationship, both emotionally and physically.
- ◆ Recognizing that a person has limited capabilities should not mean that you expect nothing of them.
- ◆ You may experience grief issues about what you had and lost, or about what you never had.
- ◆ After denial, sadness, and anger comes acceptance. The addition of understanding yields compassion.
- ◆ Diseases are a part of the varied fabric of life.
- ◆ Don't shoulder the whole responsibility for your ill family member.
- ◆ Forgive yourself and others for mistakes made.
- ◆ Physicians have varying degrees of competence, knowledge and experience.
- ◆ If you can't care for yourself, you can't care for another.
- ◆ The needs of the ill person do not necessarily always come first.
- ◆ Chronic illness affects the entire family, not just the person who actually has the disease.

- ◆ It is natural to experience a range of emotions such as grief, guilt, fear, anger, sadness, hurt and confusion.
- ◆ Support your local Hepatitis C group and the search for a cure!



## WHAT SHOULDN'T I SAY?

**Most people really do want to be helpful, but sometimes they just don't seem to think before they speak.**

**Here are a few of the "Least Helpful" things you can say to your HCV-positive friend:**

- ◆ "It's all in your head."
- ◆ "You just need to get out and exercise more."
- ◆ "No one ever said life was fair."
- ◆ "You think you've got problems..."
- ◆ "Maybe you should eat better/take vitamins."
- ◆ "You don't look sick!"
- ◆ "Everybody knows HCV doesn't have any symptoms. You're just looking for attention."
- ◆ "That which does not kill us makes us stronger."
- ◆ "Believe me, I know how you feel. I was sick once."
- ◆ "So, you feel sick. Don't you always?"
- ◆ "Oh, cheer up!"