

How To GET WHAT YOU NEED WHEN YOU HAVE THE HEPATITIS C Virus (HCV)

FEBRUARY 2003



THE HEPATITIS C VIRUS
(HCV) CAUSES ONE TYPE OF
HEPATITIS. THIS REFERENCE GUIDE IS
FOR PERSONS WHO ARE INFECTED WITH THE
CHRONIC FORM OF HCV

Inside:
What is Hepatitis C Virus
What it Means to Have HCV
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Liver Biopsy
Resources in VT & NH

This pamphlet has been designed as a companion to:
**“HOW TO GET WHAT YOU NEED: A RESOURCE GUIDE FOR THOSE
LIVING WITH A CHRONIC OR LIFE THREATENING CONDITION”**

If you do not have a copy of the “How to Guide,” see the back of this guide for details of
how to get a free copy

WHAT IS HEPATITIS C VIRUS (HCV)?

Hepatitis C Virus (HCV) is a virus that is in the blood. Formerly known as “Non-A, Non-B,” it was discovered in 1988, and the Centers for Disease Control estimates that about 4 million Americans are infected. A person can get HCV when his or her blood comes into contact with other blood that is infected.

WAYS YOU CAN GET HEPATITIS C VIRUS

HCV is transmitted by blood. Any of the following ways could explain how the hepatitis C virus got into your blood:

- Received a blood product before 1992 (blood transfusion, gamma globulin, etc.);
- Drug sharing/reusing equipment (cookers, needles, cotton, straws etc.);
- Body piercing and tattooing;
- Acupuncture with unsterilized needles;
- Coming into in contact with someone else’s blood through work;
- Unprotected sex;
- Mother to child during child birth.

WHAT TO DO IF YOU HAVE HEPATITIS C

1. MAKE AN APPOINTMENT—AND KEEP IT—WITH A HEALTH CARE PROVIDER WHO HAS EXPERIENCE TREATING HCV.

The doctors who generally treat HCV are Gastroenterologists, Hepatologists, and/or Infectious Disease specialists. The Fletcher Allen Health Center in Burlington, VT offers services for people with HCV through Gastroenterology and Infectious Disease. Call 800-358-1144. The Dartmouth Hitchcock Medical Center in Lebanon NH provides HCV services through Gastroenterology (603-650-5261) and Infectious Disease (603-650-6060). If you are looking for a specialist closer to your home, you might consider contacting one of the hepatitis programs for a local referral. There are also hepatitis programs in Boston, MA and in Albany, NY.

2. ASK TO KNOW ALL TEST RESULTS INCLUDING GENOTYPE, VIRAL LOAD, AND LIVER ENZYME LEVELS.

See Page 7 of this guide for a list of frequently used terms.

3. GET TESTED FOR HIV, THE VIRUS THAT CAUSES AIDS.

HCV and HIV are both transmitted in the same way, and so you need to make sure that you do not have HIV. There are many places where you can go for a free anonymous test. There is also a saliva test (Orasure) that is very quick and easy. To learn more about HIV testing, and where you can go, contact 800/882-2437 in Vermont and 800/752-2437 in New Hampshire.

4. HAVE A BLOOD TEST TO SEE IF YOU ARE IMMUNE TO HEPATITIS A AND B. IF NOT IMMUNE, GET VACCINATED.

Getting either of these additional forms of hepatitis could make you very ill and possibly cause death.

5. CONSIDER HAVING A LIVER BIOPSY.

While blood work can give some ideas of what might be going on with your liver, the only way you will know if your liver has been damaged is by a liver biopsy. *See Page 5 for more information.*

**KEEP IN MIND THAT
HCV IS IN THE BLOOD,
SO REDUCE ANY
ACTIVITY THAT COULD
BRING ANYONE IN
CONTACT WITH YOUR
BLOOD.**

While the hepatitis C virus attacks and kills liver cells, most people show *no* signs of being sick when they *first* get infected with the virus. Only one out of five people with hepatitis C have signs of illness when they are first infected. Most people (75%-85%) who get HCV continue to have the virus in their body, and most of these will develop some form of chronic illness later on. So, being identified as having HCV often happens sometime after infection—after getting sick, as part of a routine physical, or when being tested during a blood donation.

If HCV is not treated, it can result in some pretty serious problems over time, although fortunately the worst problems occur in only a small percent of people:

- ◆ *Inflammation* of the liver (liver swells and may become painful);
- ◆ *Fibrosis* (scar tissue that forms in the liver after it has been inflamed for awhile) occurs in about 10 years;
- ◆ *Cirrhosis* (the liver having a much harder time filtering blood) in 20 years, among 20% of people infected;
- ◆ *Liver cancer*; in 30 years, among 5% of people.

HCV is the main reason that people need liver transplants in the United States. There are also other conditions that are associated with HCV infection. These can include arthritis, fibromyalgia, kidney and skin problems, depression, and maybe diabetes.

WHAT TO DO, CONTINUED

6. AVOID THE FOLLOWING, SINCE THEY CAN HARM YOUR LIVER

- ◆ **Alcohol:** Very toxic to the liver. **Stopping drinking is one of the BEST things you can do for yourself.**
- ◆ **Vitamins A & D supplements:** Since these vitamins go through the liver, do not take these vitamins (especially in large quantities) without checking with your provider.
- ◆ **Smoking**
- ◆ **The following herbs:** plants of Senecio, Crotalaria and Heliotropium families, chaparral, mistletoe, senna, Gordolobo, yerba tea, germander, skullcap, margosa oil, peppermint, valerian, hops, gentian, groundsel, asfetida, mate tea, sassafras, comfrey, Jin Bu Huan, pennyroyal oil, amanita & lepiota helveotia.
- ◆ **Pain relievers**, such as acetaminophen (Tylenol) and ibuprofen (Advil) can be a problem for people with liver disease, so check with your provider before taking them.
- ◆ **Caffeine:** Some people find that when they cut the following out (chocolate, coffee, and some soft drinks), they feel much better.

**STOPPING DRINKING IS
ONE OF THE BEST
THINGS YOU CAN DO FOR
YOURSELF.**

If you have advanced liver disease, you will also want to avoid foods that are high in fat, salt, and sugar, such as processed foods, chips, meats high in fat, cheeses, Chinese food, pickled foods, and some fish.

7. ADOPT A HEALTHY LIFE-STYLE Life-style changes, such as stopping drinking, getting clean and sober, reducing stress, getting moderate exercise, relaxing, and healthy eating can go a long way to reduce damage to your body from HCV.

8. AVOID INFECTING OTHERS BY:

- ◆ Not sharing/reusing drug equipment (needles, cookers, cotton, straws etc.).
- ◆ Practicing safer sex (use of condoms and other barriers so that partner does not come in contact with bodily fluids), particularly if you have multiple partners.
- ◆ Making sure that sterilized equipment is being used for tattooing, body piercing, or acupuncture.
- ◆ Not donating blood, plasma, body organs, other tissue or sperm.
- ◆ Not sharing tooth brushes, razors, or other items that could become contaminated with blood.
- ◆ Covering open sores or other breaks in the skin.

WHAT TO DO, CONTINUED

9. CONSIDER TREATMENT.

This is especially important if your liver enzymes are elevated for longer than 6 months and there is mild to moderate disease. See the next page about treatment.

10. SEE YOUR PROVIDER REGULARLY.

See your provider every 6-12 months for regular blood work and evaluation, if no signs of liver problems are present. If liver problems exist, you may need more frequent visits. Keep all appointments.

11. BE IN CHARGE OF YOUR HEALTHCARE.

Be sure and read Sections 1-3 of the *How To Guide* to learn ways to protect yourself from fraud, how to talk to your provider, where to find sources of information, and most importantly, how to ask for what you need.

12. CHECK WITH YOUR DOCTOR BEFORE TAKING ANY MEDICATIONS OR ALTERNATIVE THERAPIES.

Your health care provider will be able to tell you what could affect your liver.

13. BUILD YOURSELF A NETWORK OF SUPPORT.

It is always helpful to surround yourself with people who can give you encouragement, understand your needs, and provide help when you need it. Support can come in the form of friends, neighbors, family, or co-workers. It can also come from others who are also living with hepatitis, such as you might find in a support group. While a support group is not for everyone, it can put you in

contact with people who have dealt with or are now dealing with similar issues. A list of support groups and other networking information in the VT/NH region appear in the resource section of this pamphlet on Page 6.

14. TELL THOSE WHO NEED TO KNOW ABOUT YOUR HCV STATUS. PEOPLE WHO NEED TO KNOW ARE:

- ◆ Medical and dental providers
- ◆ Sex partners
- ◆ Drug using partners

You do not **need** to tell family members, friends, co-workers, or employers. However, do find friends/family that can be supportive of you.

DON'T AVOID NORMAL CONTACT IN YOUR WORK AND SOCIAL LIFE

HUGGING, KISSING, SHAKING HANDS, EATING AND PREPARING FOOD ARE SAFE.

IF YOU ARE STILL USING DRUGS

Whether you have hepatitis C or not, there is a lot you can do to help yourself. If you can, get clean using detox, rehab, 12 step, methadone maintenance, support group or some other type of program.

Getting help is hard work so find someone that you trust and who is willing to help you through the challenges. The *How To Get What You Need Guides for Chronic Health Conditions* (available free to download from the www.cc-info.net website) lists substance abuse treatment programs and mental health resources, which may be something you want to consider.

If you are not able to get clean, don't share your works, since HCV is very easily transmitted by injection, and you could infect someone else. You also could get—or give—other infections, like HIV. You don't want to complicate things by becoming co-infected with HIV or another disease.

Because hepatitis C is a relatively new disease, much is still not known, and new discoveries for treatment are occurring all the time. You should know that Western Medicine has tools to diagnose what's going on with your body, and there is evidence that for some people, some medications are successful in clearing the virus from the body. On the other hand, there are instances where the medical combination therapy is not recommended or advised. In either case, many people also find alternative/complementary therapies to be helpful.

COMPLEMENTARY/ALTERNATIVE THERAPIES

Many people feel that they are helped by using vitamins and supplements. Along with acupuncture, yoga, diet changes, moderate exercise, meditation, and stress reduction, these options can be done *along with* medical treatment (complementary), or *in place of* medicine (alternative therapy).

Some of the most common forms of alternative therapies are milk thistle (Silymarin) which reduces inflammation, astragalus, dandelion, bupleurum, garlic, licorice root, artichoke, alpha-lipoic acid, and vitamin E (warning more than 800 mg./day can be toxic).

*If you decide to use complementary or alternative therapies, it is **very** important to let your provider know so he/she can integrate what you feel may work best for you, and be sure that what you are taking does not harm your liver.*

MEDICAL THERAPIES

While there are many research studies being done and new drugs being tried, the current thinking is that the **combination** of interferon and ribavirin can rid the body of the virus in about half of the people who try it. Interferon can be injected daily, three times a week, or once a week (pegylated form). Ribavirin is taken daily. Depending on the subtype (genotype) of HCV you have, and how well you respond to initial treatment, you may need to take the combination therapy for up to a year.

There are often side effects from treatment, especially flu-like symptoms and depression. Many providers will prescribe an antidepressant as part of the treatment. Other side-effects of the medication include feeling very tired, nausea, and muscle aches. You can also develop anemia (low blood). How you respond to treatment will depend on your body. Some people have no side effects, but others can feel very ill and find they can't do anything while they are on treatment. You need to discuss this with your doctor before you start the combination therapy, and keep in touch throughout the treatment.

The treatment for HCV can cause birth defects in unborn children, so women who could get pregnant, who are on combination therapy, may be prescribed birth control and are advised to wait six months after stopping treatment before trying to get pregnant.

LIVER BIOPSY

IS IT NECESSARY?

You do not *need* a biopsy to be treated for HCV. However, while blood work and physical exam gives some idea of what the HCV may be doing in your body, the only way to know *for sure* what's going on with your liver is by doing a biopsy. The results of this procedure can tell about the stage of disease, the condition of your liver and how you may progress in the future.

HOW IS IT DONE?

A liver biopsy is done by inserting a needle through the skin on the side of the abdomen and into the liver for a fraction of a second, and taking out a small piece of liver tissue. Risks are low, with bleeding from the site of needle entry being the main complication. This occurs in less than 1% of patients. While it is a safe procedure, it is important to discuss the risks and benefits in detail with your provider. Fear of the biopsy is generally much worse than anything that happens during or after the procedure.

IS THERE PAIN?

Liver biopsy is generally done under local anesthesia, as an outpatient. It should not be painful. It is important to note that **a history of substance abuse may require you to have more anesthetic**. Only you know your pain threshold. If you require more anesthetic for dental work than most people, you'll likely need it for the biopsy. Talk to the doctor before the procedure so that both of you are clear about what type of anesthesia you may require.

WHAT ABOUT AFTERWARDS?

In about half of people, there is no pain afterwards. You may experience a brief pain in the area where the needle was inserted that may spread to the right shoulder, or possibly in the pit of your stomach. If you need it, the doctor can provide a light painkiller immediately after the biopsy. You will be monitored for several hours after the biopsy, to make sure there is no serious bleeding or drop in blood pressure.

DEVELOPING YOUR SUPPORT NETWORK

Whether you choose to do treatment or not, you will benefit from the support of others to help you. Think about what specific things you need so that when others want to help, you can give them ideas. Only you know how you feel and what would be most helpful. Be clear and ask for what you need. There are a number of ways to develop your support network:

- Family, friends, and neighbors are often more than willing to be called on to be there for you.
- If you are part of a 12 step program, talk with some of the members. You can arrange to have them meet at your home for a meeting from time to time.
- If you are part of a faith community, social group, or a community organization, talk to those you trust about your situation.
- On-line support groups or message boards can often give you opportunities to connect with others who are facing similar challenges. The national web-based resources are a good start to finding an on-line resource.
- Support groups can help you connect with others who are facing similar issues, and you can often learn important skills, strategies, and information. Support groups in Vermont and New Hampshire are listed below. Because meeting times and places can change, be sure to call ahead to confirm.

REGIONAL HEPATITIS SUPPORT GROUPS

NEW HAMPSHIRE

Portsmouth

Portsmouth Regional Hospital
3rd Tuesday of the month.
Contact: Lynee Borges (603) 433-2488

Derry

Derry Public Library
Main Street, Derry
4th Tuesday of the month, 6:30-8:30pm
Contact: Phyllis Hurrell, (603) 432-8802

Laconia

Lakes Regional Healthcare/Wellness Center
80 Highland St. Laconia
2nd Wednesday of the month, at 6:30pm
Contact: Mary Hartman: (603) 524-3211, ext.3835

Manchester

Nursing Home Care Unit Solarium
Veterans Administration Hospital
Smyth Road Manchester
2nd Tuesday of every month, 7:00 PM
Contact: Maria Gavin 1-800-892-8384, ext. 6193

Upper Valley

VA Hospital in White River Junction
Hepatitis Education/Support Group
3rd Thursday of every month from 6:30-8PM
Contact: Mary Crance (802) 296-5191 or
hepcmary@hotmail.com

VERMONT

Vermont Hepatitis Support Network: Offers support group referrals and information.
Contact Cris Zern, (802) 223-5986 or
criszern@aol.com

Upper Valley

VA Hospital in White River Junction
Hepatitis Education/Support Group
Open to the Public.
3rd Thursday of every month from 6:30-8PM
Contact: Mary Crance (802) 296-5191 or
hepcmary@hotmail.com

DEPRESSION

Depression can be common in people with HCV. Severe depression can be one of the side effects of treatment with interferon. Be sure to let your support network know this and seek mental health support to help you with depression or anxiety if it does occur.

Pharmaceutical Company Support

Roche, Schering Plough, and Amgen are the pharmaceutical companies that make the medications used for hepatitis C. Each of these companies have information and/or support programs for people who are taking their brand of combination therapy.

Roche (Copegus®, Pegasis®, Roferon®):
24-hr phone line: 1-877-PEGASYS (1-877-734-2797)
www.pegasis.com/resources/pegassist.asp

Schering Plough: (Rebetron®, Intron A® plus Rebetol®), PEG-Intron/Rebetol®):
24-hr phone line: 1-788-437-2608 www.beincharge.com

Amgen: (Infergen®) www.infergen.com

REGIONAL WEBSITES:

CCIN (Chronic Conditions Information Network of Vermont & New Hampshire): This website offers information about chronic conditions in both NH and VT, and hosts the HepatitisWebsite: <http://www.cc-info.net/hepatitis/hep.html>

CDIS (Chronic Disease Information Service): A program of the NH Area Health Education Center, this provides information about New Hampshire services available to support people with chronic and/or life threatening conditions.
www.chronic-disease.net

NATIONAL WEB-BASED RESOURCES

- **American Association for the Study of Liver Diseases (AASLD):** www.aasld.org
- **American Liver Foundation** www.liverfoundation.org
- **Canadian Liver Foundation:** www.liver.ca
- **Centers for Disease Control Hepatitis:** www.cdc.gov/ncidod/diseases/hepatitis
- **HCV Advocate:** www.hcvadvocate.org
- **HIV and Hepatitis.com:** www.hivandhepatitis.com
- **National AIDS Treatment Advocacy Project:** www.natap.org
- **National Institute of Diabetes, Digestive and Kidney Disorders** www.niddk.nih.gov

Ask the Experts/Question & Answer Forum

- **Johns Hopkins Viral Hepatitis Page:** www.hopkins-id.edu/diseases/hepatitis/index_hep.html
- **The Body/Forum on Hepatitis and HIV:** www.thebody.com/Forums/AIDS/Hepatitis/index.html

HELPFUL TERMS

Genotype is the type of virus you have. There are six types of HCV, with a number of subtypes. The most frequent form in the United States is 1A or 1B. It is important that you know what type of HCV you have, since it will affect the choices for treatment.

Viral load indicates how much HCV virus you have in your blood.

Alanine Aminotransferase (ALT) is one of several liver enzymes. If the ALT in your blood stays high, it indicates that your liver may be inflamed. However, the only way you can be sure what is happening to your liver is through a liver biopsy.

CCIN

The **Chronic Conditions Information Network** assists those who live or care for those with chronic conditions so that they are able to obtain accurate and relevant information in a timely manner. The CCIN offers the following services:

WEBSITE

A free, electronic network of information and resources on chronic life threatening conditions (including asthma, diabetes, hepatitis, and HIV) affecting people and their providers in Vermont and New Hampshire. In addition to disease-specific information, the site directs users to resources in the region that can address related issues such as work, disability, legal matters, social services, and other support services. This website can be reached at www.cc-info.net.

PAMPHLETS AND INFORMATIONAL MATERIAL:

CCIN develops and publishes a variety of printed materials relating to living with chronic conditions in Vermont & New Hampshire, including "How To Get What You Need: A Resource Guide for Persons Living with Chronic/Life Threatening Conditions."

Condition-specific companion pamphlets, such as this Hepatitis C Guide, are also in production. All published materials are available in PDF format, and can be downloaded for free from the CCIN Website (www.cc-info.net).

CCIN CONTACT INFORMATION

PO Box 3, Cavendish
VT 05142
Phone: (802) 226-7807
Website www.cc-info.net
email ccin@cc-info.net

NEWS DIGESTS

CCIN has three email digests available free of charge to providers.

SHH (STDs, HIV AND HEPATITIS)

Postings are twice a week, and contain the latest research findings on prevention and treatment relating to sexually transmitted diseases, HIV, and hepatitis. To subscribe write "Subscribe SHH" in the subject heading and e-mail margoc@ludl.tds.net

CDIS

(CHRONIC DISEASE INFORMATION SERVICES)

Posted on the 15th of each month, this digest contains the latest research on asthma and diabetes, as well as regional and on-line continuing education opportunities. This is a service of the NH Area Health Education Center. To subscribe write "Subscribe CDIS" in the subject heading and e-mail margoc@ludl.tds.net

PREVENTION DIGEST

Posted each week, this digest is for providers who work in the field of HIV prevention. For more information on this digest contact margoc@ludl.tds.net

CCIN is a 501 (c) 3 nonprofit organization serving Vermont and New Hampshire

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