

a guide to understanding Hepatitis C

**HCV**



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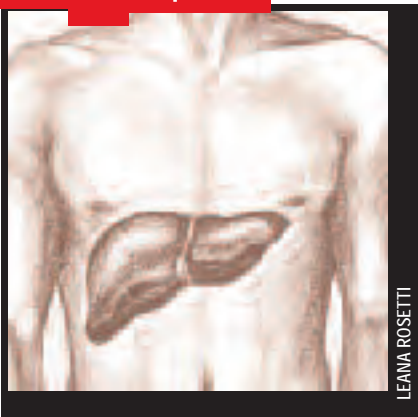
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## HCV

is a blood-borne virus that was previously referred to as non-A/non-B hepatitis. HCV has six major genotypes, numbered 1–6. Genotype 1, which is the most common in the U.S., is the most difficult to treat. HCV enters the body through direct blood exposure. The virus attacks cells in the liver, where it multiplies (replicates). HCV causes liver inflammation and kills liver cells. Up to 80% of people initially infected with HCV may become chronically infected—that is, the infection does not clear up within six months. Most people with chronic HCV do not have symptoms and lead normal lives. However, in 10–25% of people with chronic HCV, the disease progresses over a period of 10–40 years, and may lead to serious liver damage, cirrhosis (scarring), and liver cancer. Today, HCV is the leading reason for liver transplants in the U.S. There is currently no vaccine or cure for HCV, but various treatments can eradicate the virus and/or help slow or stop disease progression for some people.

## Your Liver and Hepatitis



LEANA ROSETTI

The liver is the largest internal organ, located behind the ribcage on the right side of the abdomen. It weighs approximately three pounds and is about the size of a football. The liver is responsible for some 500 vital functions. It processes virtually everything you eat, breathe, or absorb through the skin. The

liver converts substances you eat and drink into energy and the building blocks for muscles, hormones, clotting factors, and immune factors. It stores many vitamins, minerals, and sugars for later use. Liver cells produce bile, which helps the body digest food and absorb nutrients. The liver detoxifies substances that are harmful to the body. It can regenerate its own tissue—as much as 3/4 of the liver can regenerate within a few weeks.

*Hepatitis* simply means inflammation of the liver. It may be caused by viruses, toxic chemicals, drugs, or other factors. The most common forms of viral hepatitis include hepatitis A virus (HAV), hepatitis B virus (HBV), and HCV. These three viruses are related only in that they affect the liver.

## *HCV Transmission*

HCV is transmitted by direct blood-to-blood contact. Transmission routes include sharing drug paraphernalia for both injection and non-injection drugs (needles, cookers, tourniquets, straws, pipes, etc.). Needles used for tattooing, body piercing, and acupuncture may also spread HCV. Sharing personal items such as razors, toothbrushes, or nail files is a less likely, but still possible, transmission route.

**Do not share needles or any other drug paraphernalia, razors, toothbrushes, clippers, nail files, or any items that might contain blood.**

Before 1992, many people contracted HCV through blood or blood product transfusions. In 1992, a reliable blood test to identify HCV antibodies became available. Since then, the blood supply has been screened. Today the likelihood of contracting HCV through infected blood is less than 0.01%. A small percentage of people (estimated at 1–3% for monogamous heterosexuals) may contract HCV through unprotected sexual activity. Among people in so-called “high risk” groups (gay men, prostitutes, people with multiple sex partners, people with STDs), sexual transmission appears to be somewhat more common.

Healthcare workers are at risk for HCV infection because of needlestick accidents and unavoidable situations that may result in direct contact with blood from an infected individual.

Perinatal transmission from mothers with HCV to their infants before or during birth occurs less than 5% of the time. Whether or not transmission occurs may depend on the presence of high levels of

HCV in the mother’s blood; mothers co-infected with HBV or HIV are more likely to transmit HCV to their babies. Some studies have shown that HCV is present in breast milk, but breast-feeding is believed to be safe.

The transmission route for up to 10% of individuals infected with HCV cannot be identified. HCV is not transmitted by casual contact such as sneezing, coughing, hugging, or sharing eating utensils and drinking glasses.

## *HCV Prevention*

Do not share needles or any other drug paraphernalia, razors, toothbrushes, clippers, nail files, or any items that may come in contact with blood. Make sure that instruments used for tattooing, body piercing, and acupuncture are properly sterilized; most practitioners today use disposable needles. All cuts and wounds should be covered.

Although sexual transmission appears to be rare, you can reduce the risk by practicing safer sex, including the use of condoms and barriers. According to the Centers for Disease Control and Prevention (CDC), if you are in a stable, long-term monogamous relationship you do not need to change your current sexual practices, although partners should discuss safer sex options if either partner is concerned about transmission. If a woman has HCV, avoid sex during monthly periods. Proper dental hygiene can prevent bleeding gums, another possible transmission route.

Notify your doctor, dentist, and other healthcare professionals if you have HCV. Healthcare workers should observe standard universal precautions when dealing with blood. If you are a woman with HCV, talk to your doctor if you are thinking about becoming pregnant.

**A**fter exposure to HCV, the window period usually lasts 2–26 weeks. The initial phase of hepatitis C is called acute infection. Acute HCV usually resolves after 2–12 weeks. However, up to 80% of people initially infected with HCV do not clear the virus from their bodies, and become chronically infected. Most people with chronic HCV do not have symptoms and lead relatively normal lives. But in 10–25% of people, the disease progresses over the course of 10–40 years. Chronic HCV infection can lead to liver damage, the development of fibrous tissue in the liver (fibrosis), fat deposits in the liver (steatosis), liver scarring (cirrhosis), and liver cancer. In severe cases, a person may require a liver transplant.

**Cirrhosis** is a process in which liver cells are damaged or killed and replaced with scar tissue. Extensive scar tissue formation impairs the flow of blood through the liver, causing more liver cell death and a loss of liver function.

**Compensated Cirrhosis** means that the liver is heavily scarred but can still perform most functions; people with compensated cirrhosis exhibit few or no symptoms.

**Decompensated Cirrhosis** means that the liver is extensively scarred and unable to function. People with decompensated

cirrhosis often develop complications such as high blood pressure in the vein that leads to the liver (portal hypertension), varices (stretched and weakened blood vessels) in the esophagus (swallowing tube) and stomach, internal bleeding, ascites (fluid accumulation), and other potentially life-threatening conditions. They may also experience reversible mental confusion.

**Liver cancer** usually develops at later stages of HCV infection, typically after 25–30 years. The type of liver cancer associated with HCV is called primary hepatocellular carcinoma (HCC).

## Symptoms of HCV

**M**any people report few or no symptoms during the acute phase of HCV infection. Most people with chronic HCV also do not have symptoms and lead relatively normal lives. However, others experience mild flu-like symptoms including nausea, fatigue, fever, headaches, loss of appetite, abdominal pain, and muscle or joint pain. Over time (often years or even decades) people with chronic HCV may develop various symptoms related to liver damage. Chronic HCV is also associated with a wide variety of related conditions.

## Symptoms Reported by People with HCV

### Acute

#### Hepatitis C

- Flu-like illness
- Fatigue (mild to severe)
- Fever
- Night sweats
- Loss of appetite (anorexia)
- Nausea
- Vomiting
- Diarrhea
- Jaundice
- Indigestion
- Headaches

- Muscle or joint pain
- Abdominal pain
- Abdominal bloating

### Chronic Hepatitis C

- Fatigue (mild to severe)
- Fever
- Loss of appetite (anorexia)
- Nausea
- Indigestion
- Headaches
- Muscle or joint pain

- Abdominal pain
- Depression
- Mood swings
- “Brain fog”

### Late-Stage Hepatitis C with Cirrhosis

- Fatigue (mild to severe)
- Fever
- Loss of appetite (anorexia)
- Nausea
- Vomiting
- Fluid retention

- Frequent urination
- Jaundice
- Indigestion
- Headaches
- Muscle or joint pain
- Abdominal pain
- Abdominal bloating
- Depression
- Mood swings
- Cognitive dysfunction
- Lack of concentration
- Mental confusion
- Dizziness
- Peripheral vision problems

## Conditions Linked to HCV

A number of different conditions have been associated with HCV. Some of these are autoimmune conditions, in which the immune system attacks the body’s own tissues. Conditions sometimes seen in people with chronic HCV include Sjögren’s syndrome (characterized by dry eyes and dry mouth), kidney conditions such as glomerulonephritis, and skin conditions such as lichen planus (characterized by white lesions or bumps) and porphyria cutanea tarda (characterized by a sun-sensitive rash). Other related conditions include certain

types of arthritis (joint inflammation), arthralgia (joint pain), thyroid disease, vasculitis (blood vessel damage), and cryoglobulinemia (high levels of a blood protein that settles in the kidneys, skin, and nerve endings). Most serious conditions are associated with late-stage HCV disease, when the liver is damaged and not able to function properly. Many people with HCV never experience any of these conditions. Check with your doctor if you experience any unusual symptoms.

The National Institutes of Health (NIH) estimates that some four million Americans are infected with HCV.

An estimated 8,000–10,000 Americans die annually of complications related to HCV. This figure is expected to triple in the next 10–20 years.

HCV is the leading reason for liver transplants in the U.S.

Individuals with HCV should avoid drinking alcohol and using recreational drugs.

Individuals with HCV should be vaccinated against hepatitis A and hepatitis B.

## HCV FACTS

**T**esting for HCV is not routinely done, so you may have to request a test from your physician. It is recommended that you use the same laboratory for all of your tests, since result ranges and accuracy can vary from lab to lab. Keep copies of your lab and biopsy results for future reference. The tests below can help determine whether you are infected with HCV and the state of disease progression.

### *HCV Antibody Tests*

#### **HCV ELISA**

is a simple blood test that can detect HCV antibodies.

#### **RIBA HCV**

is a second antibody test that may be performed after an ELISA test to confirm the presence of HCV antibodies. This test is usually only performed in people who test positive by the HCV Elisa but do not have known risk factors for acquiring HCV.

### *Viral Load Tests*

Viral load tests measure the amount of HCV circulating in the blood. HCV viral load is expressed as either copies per milliliter of blood or as a standard unit of measurement called International Units. There are three different types of viral load test: HCV RNA PCR, branched-chain DNA (bDNA), and transcription mediated amplification, or TMA. The bDNA assay is the least expensive, but also the least sensitive. Viral load tests are used to confirm active HCV infection, to predict medical treatment response, and to measure how well the medications are working against the virus during treatment. An association between viral load and disease progression has not been established.

### *Genotype Tests*

Genotype tests are used to determine what type(s) of HCV you have. This information is useful for making treatment decisions, such as how much medication to use, how long treatment should last, and the likelihood of responding to treatment.

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**An association between viral load and disease progression has not been established.**  
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### *Liver Biochemical/Function Tests*

There are various blood tests used to assess how well your liver is working. The liver (hepatic) panel includes measurements that indicate liver function. The most common measurements are alanine aminotransferase (ALT, formerly known as SGPT) and aspartate aminotransferase (AST, formerly known as SGOT). ALT and AST are enzymes that are released into the blood when the liver is damaged. They are often elevated in people with HCV infection. Many people with HCV have mild to moderate elevations of these two enzymes, which are often the first indication that they are infected. Other measurements include alkaline phosphatase (ALK) and gamma-glutamyl transpeptidase (GGT).

Abnormal levels may indicate cirrhosis or bile duct blockage, as well as other abnormalities. In addition, your doctor may measure prothrombin time (an indication of blood clotting speed) and bilirubin levels. Bilirubin is a pigment that is often present in the blood of people with liver inflammation; high bilirubin levels result in jaundice. Many factors such as use of medications and alcohol may cause abnormal lab results. Before drawing your own conclusions, check with a healthcare provider.

### ***Liver Biopsies***

Biopsies are done to measure the severity of inflammation, the amount of scarring, and the general health of the liver. They may also be used to help determine if treatment is needed. The most common procedure is to numb the skin and muscle and then quickly insert a long, thin needle into the liver to draw out a specimen. Many people fear this procedure, but complications are rare. If you are anxious, ask your physician for a mild tranquilizer prior to your biopsy and for pain medication afterwards.

## **HCV Treatment Options**

Until 1998, interferon alone (monotherapy) was the only approved treatment for HCV infection. Today, the standard of care for treating HCV is the combination of pegylated interferon plus ribavirin. Research is ongoing to develop new and better medications, including polymerase inhibitors, protease inhibitors, and antifibrotic medications.

There are also several alternative and complementary treatments that people have used to treat HCV infection, for example, milk thistle (silymarin) and licorice root (glycyrrhizin). Herbal and other alternative therapies are discussed in a fact sheet from the Hepatitis C Support Project.

### ***Approved Pharmaceutical Treatments***

**Standard interferon, pegylated interferon,** and **ribavirin** are the only FDA-approved medications for treating hepatitis C. Interferon, given by injection, is a genetically engineered product based on a set of natural immune system proteins found in the body. Pegylated interferon (PEG) is a long-acting form of interferon that can be injected once a week. PEG maintains a more constant level of inter-

feron in the blood and better reduces the ability of HCV to replicate. Ribavirin is an oral antiviral medication used in combination with interferon to treat HCV infection. Ribavirin alone is not effective against HCV.

### **The Standard of care: Pegylated Interferon plus Ribavirin**

The combination of pegylated interferon plus ribavirin is now considered the standard of care for treating HCV. There

are currently two different pegylated interferon/ribavirin combinations that have been approved by the FDA: Schering's Peg-Intron plus Rebetol brand ribavirin, and Roche's Pegasys plus Copegus brand ribavirin.

### **Schering's Peg-Intron plus Rebetol**

SVR for Peg-Intron plus Rebetol combination therapy is 41% for genotype 1, and 82% for genotypes 2 through 6. Peg-Intron is a reconstituted powder that is dosed according to a person's weight.

### **Roche's Pegasys plus Copegus**

SVR for Pegasys plus Copegus combination therapy is 44-51% for genotype 1, and 70-82% for genotypes 2 through 6. Pegasys is a ready-made solution that is dosed at 180µg regardless of a person's weight. The FDA has also approved Pegasys for treatment of chronic hepatitis B and Pegasys plus Copegus for the treatment of people with HIV and hepatitis C coinfection.

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**Ribavirin Warning**  
**Ribavirin has been shown to cause birth defects and miscarriages. Women of childbearing age, their male partners, and female partners of male patients taking ribavirin must use at least two effective forms of contraception during treatment and during the six-month post-treatment follow-up period.**

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### **Treatment Duration and Medications**

The standard duration for treatment of chronic hepatitis C is 48 weeks for genotype 1, and 24 weeks for genotypes 2 and 3. Pegylated interferon is given once a

week as an injection right under the skin. The ribavirin dose is given at 1000/1200 mg/day (depending on a person's weight) for genotype 1 and 800 mg/day for genotypes 2 and 3. Ribavirin is taken orally twice a day with food (breakfast and dinner).

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### **Virological Response**

**how a person's viral load level responds to treatment. When a person's HCV RNA (viral load) becomes undetectable after HCV therapy has been initiated, this is considered a virological response. If the HCV RNA remains undetectable beyond six months, the term sustained virological response (SVR) is used.**

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### **Measuring Treatment Response**

People receiving HCV treatment should be tested on a regular basis to monitor side effects and to make sure that they are responding to therapy. If someone has not responded after three months of treatment, further therapy is unlikely to clear the virus. Many physicians recommend stopping the medications at this time. However, some evidence suggests that interferon can decrease scarring and inflammation and improve liver health even if it does not clear the virus.

### **Investigational Pharmaceutical Therapies**

HCV therapy has seen impressive advances, given that the virus was only identified in 1989. However, current treatment options can have many undesired side effects and treatment success may not always be achieved. There is much research underway to develop new and better HCV treatment options

without some of the serious side effects of current HCV medications. It appears that combination therapy with two or more agents is more effective than monotherapy for treating HCV. For this reason, most new clinical trials will focus on testing the effectiveness of combining the new drugs with pegylated interferon.

HCV protease inhibitors, and HCV polymerase inhibitors, newer forms of interferon, anti-fibrotic and other medications are currently under study and look promising.

***HCV Vaccines***

There is currently no vaccine for HCV, as there are for HAV and HBV. HCV vaccines will be difficult to develop due to the virus' different genotypes and its ability to change, or mutate, during infection. Some progress is being made, but an effective HCV vaccine is not expected for 5–10 years.

***Clinical Trials***

The process of testing a new drug involves establishing its safety and tolerability (Phase I trials), measuring its effectiveness (Phase II

trials), and comparing the new drug to current standard treatments (Phase III trials). After the FDA has granted approval and the new drug is marketed, ongoing studies are done to refine the treatment for maximum safety and effectiveness (Phase IV, or post-marketing trials).

**For the most current information about investigational pharmaceutical therapies visit the HCV Advocate HCV Drug Pipeline web page.**

Clinical trials can be an excellent way to obtain free medication; some trials may also pick up some or all of the costs of physician visits and lab tests. However, if you enroll in a clinical trial you may not be chosen to receive the new drug or the most effective dosage. You should read all clinical trial information and make sure that you fully understand the terms and conditions of the study, such as the withholding of viral load information from the participant.

**Treatment Considerations**

***Predicting Response to Treatment***

Adherence to HCV therapy is an important factor in achieving the highest possible treatment response rates. Treatment with interferon plus ribavirin is more likely to clear HCV if a person has a genotype other than 1, a low HCV viral load, infection with HCV for a shorter time, mild to moderate disease, is female, has a healthy body weight and is of a younger age.

After 12 weeks of antiviral treatment, a 2-log drop in viral load or elimination of HCV predicts a successful response at the end of treatment. These guidelines may be used to help tailor treatment or to stop treatment that is not working. However, some doctors believe that therapy should be continued, because some people still respond to therapy or experience improved liver health even if their viral load does not become undetectable or decrease by the suggested amount.

### **Managing Drug Side Effects**


The most common side effects of interferon and ribavirin include mild flu-like symptoms, muscle and joint pain, nausea, headaches, fatigue, loss of appetite, dry skin, anxiety, depression, and insomnia. Some physical symptoms may be reduced with ibuprofen or acetaminophen in low doses (2 grams per day or less). High doses of acetaminophen can be toxic to the liver. People experiencing anxiety, irritability, or depression may be helped with mild tranquilizers or anti-depressants. Check with your doctor before taking any of these medications.

The key to managing HCV treatment-related side effects is to treat them as soon as they occur. Always report any serious side effects to your medical provider as soon as possible before they become severe.

There are many simple tips to help alleviate some of the less serious side effects of treatment including:

- Take the pegylated interferon before bedtime; this allows most people to sleep through the worst of the side effects since the majority usually occur within 4-6 hours after the injection.
- Drink plenty of fluids (without caffeine or alcohol); this helps to relieve side effects. It is especially important to drink water or clear fruit juices (apple, cranberry, or grape) right before and right after self-injection.
- Some people take an over-the-counter pain reliever one hour before their injection to help relieve side effects. Others may find that taking a pain reliever 2 to 3 hours after the injection works better to relieve the pain.

➤ Exercise is one of the most important components of health maintenance, and this remains true during therapy. Physical activity helps you stay positive and focused and improves well-being. Moderation is the key to physical activity. Some good choices for exercise include stretching, walking, yoga, or any activity that you enjoy.



**Regular exercise may help alleviate some side effects, such as fatigue, associated with interferon therapy.**

For some people, physical side effects are worse when the drug is started and may diminish over time.

The most common reason for stopping HCV therapy is anemia (low red blood cell count), thrombocytopenia (low platelet count), and neutropenia (low white blood cell count). Medications used to control these conditions include erythropoietin (for anemia), and GM-CSF (granulocyte macrophage colony-stimulating factor) for low white blood cells. A low platelet count may indicate cirrhosis, and care should be taken during treatment. Some people may develop thyroid dysfunction while on treatment with interferon. Thyroid function should be closely monitored prior to starting treatment and then every three months during therapy. In most people, thyroid function returns to normal once therapy is discontinued, but some people may develop irreversible thyroid problems that will require continuous medication.

**HCV** can be a difficult disease to manage. Lifestyle plays an integral part in HCV disease management and treatment. Proper diet, exercise, and stress management are all critical to maintaining good health. Many physicians are not fully educated about HCV, and you may have to educate both conventional and alternative practitioners. If you have a family doctor, you may want to quiz him or her about HCV. It is important to find a doctor who is both knowledgeable about and sympathetic to people with HCV. If you are not comfortable with your doctor, look for a new one; ask family or friends for recommendations. Once your HCV diagnosis has been confirmed, your family doctor or general practitioner should send you to a specialist. Generally, you will be referred to a gastroenterologist (a digestive disease specialist) or a hepatologist (a liver disease specialist).

### **Nutrition**

Since the liver processes and detoxifies everything you eat and drink, a healthy, well-balanced diet is essential. A diet that follows the general guidelines for nutritional health based on the new Food Guide Pyramid is generally recommended. Such a diet is low in fat and sodium, high in complex carbohydrates, and has adequate protein.

In the past, diet modification was seen as an important part of HCV management. This is less true today. However, avoiding certain foods may reduce the processing and detoxification work the liver must do, and may improve the overall health of your liver. Processed foods often contain chemical additives, so reduce your consumption of canned, frozen, and other preserved foods. Eating organic fruits and vegetables can help you avoid the pesticides and fertilizers used to grow nonorganic produce. *Read all labels* to acquaint yourself with ingredients.

Protein derived from poultry, fish, and vegetable sources may be most ben-

eficial. It is recommended that people with any type of liver disease should not eat raw or undercooked shellfish (even if they are immune to hepatitis A). It is often recommended that people with HCV should avoid foods high in fat, salt, or sugar. Caffeine is a chemical that must be processed by the liver, and it is recommended that you limit your caffeine intake by reducing your consumption of coffee, tea, and soda. Because chocolate has a high fat (and in some types, caffeine) content, eat it in moderation. Some people with HCV cannot tolerate dairy products. If this is the case for you, you may wish to use nondairy substitutes such as soy milk or rice milk.

A well-balanced diet should contain all the essential vitamins and minerals you need, but some people also take vitamin supplements. Taking megavitamin supplements may be harmful. Avoid taking high doses of vitamins A and D; vitamin A can be very toxic to the liver. If you need extra vitamins and/or minerals, choose a low-dose supplement without iron.

People with HCV should consult a

licensed nutritionist or dietitian for specific dietary recommendations. Do not undertake any unconventional diet without consulting a medical practitioner. In addition, be sure to inform your doctor about any vitamins and minerals you are taking.

### **Alcohol and Drugs**

Many studies have shown that heavy consumption of alcohol can severely accelerate HCV disease progression. In fact, one study showed that 58% of a group of heavy drinkers (more than five drinks per day) with HCV progressed to cirrhosis, compared with only 10% of a nondrinking group with HCV. It is not yet known if light or moderate alcohol consumption is harmful to the liver, but most experts recommend that people with HCV should avoid alcohol. Many drugs (whether prescription, over-the-counter, or recreational) must be processed by the liver. People with HCV should avoid recreational drugs and tobacco. Check with your doctor before taking over-the-counter or prescription medications. Certain herbal remedies have also been shown to damage the liver.

### **General Wellness**

#### ➔ **Stress management**

Controlling stress is a major factor in managing HCV disease. Living with a chronic disease is stressful. Many people report “flare-ups” (periods of increased symptoms) following episodes of stress. Exercise, meditation, and time management can all help reduce stress. Try to maintain a realistic picture of your health and a positive attitude. Understanding the severity of your liver disease is an important part of having a realistic picture of your condition.

#### ➔ **Managing fatigue**

Fatigue and low energy levels are common in people with HCV. Learn your limits and do not overextend yourself. When you plan activities, allow time in between for relaxation or naps. Remember that your health is important—learn to say “no” to friends and family who have unrealistic expectations of your energy level.

#### ➔ **Time management**

Plan activities well in advance and try to make realistic work and play schedules. Use a daily planner to help with organizing and remembering activities. Consult your planner regularly when making appointments and scheduling daily tasks. Don't forget to include restful activities.

#### ➔ **Meditation**

Meditation can be a useful tool in managing and living with HCV or any chronic illness. It is simple and easy to learn. Meditation can reduce stress and help you maintain a healthy outlook on life.

### **HAV AND HBV VACCINATION**

**It is strongly recommended that people with HCV get vaccinated against hepatitis A and B if they are not already immune. Severe HAV and HBV infections have been reported in people already infected with HCV. The hepatitis A vaccine consists of two doses within a six-month period, and the hepatitis B vaccine requires three doses within a six-month period. Both vaccines are made from killed viruses and are considered safe and effective. A combination HAV/HBV vaccine was approved by the FDA in May 2001.**

### ➔ **Exercise**

Moderate exercise is highly recommended for all individuals who are not in an acute or end-stage phase of HCV. Exercise can help reduce stress and is important for maintaining good health. However, too much exercise can lead to flare-ups. Select low impact types of exercise such as walking and swimming. Slowly increase your workouts until the desired level is achieved. Always check with your doctor before starting any exercise program.

### **Support Groups**

Many people with HCV feel isolated and find it difficult to cope with the effects of living with a chronic illness. A support group can offer a safe space to discuss the emotional issues surrounding HCV. Furthermore, the information shared by peer members can be helpful in making decisions about a wide variety of issues facing people with HCV. It is highly recommended that you join a support group while undergoing HCV treatment. Support group information can be found

on our website or by contacting the organizations listed at the end of this booklet.

### **The Internet**

The Internet contains a wealth of information, both good and bad. Always check the sources of the information you find. Look for dates and references. Challenge any information you believe is in error. Be skeptical of Web sites that contain the word “cure” or other misleading information. Remember that not all the information you find on the Internet is correct. Talk to your doctor regarding any information you are concerned about. Common sense can take you a long way! Visit our Web site at [www.hcvadvocate.org](http://www.hcvadvocate.org) for recommended sites.

### **ENVIRONMENTAL TOXINS**

**Everything you breathe or absorb through the skin must be filtered by the liver. Fumes from paint thinners, pesticides, and aerosol sprays can damage your liver and should be avoided.**

## Conclusion

Chronic hepatitis C is a liver disease that can have serious consequences. It is important to remember that many people do not experience symptoms or disease progression. Those who do eventually experience disease progression may remain symptom-free for decades. However, some people develop serious liver disease that can result in liver failure or death. New treatments for HCV are currently being tested, and it is believed that better treat-

ment options will be available within five years. Additionally, lifestyle changes such as good nutrition, exercise, and stress management can help alleviate side effects and may slow disease progression.

We hope this information has helped you to understand the hepatitis C virus and how it can affect your physical and emotional health. We welcome any suggestions or ideas for improving this booklet.

..... *For more information about HCV, contact the following organizations* .....

- **Hepatitis Foundation International**  
1-800-891-0707, [www.hepfi.org](http://www.hepfi.org)
- **American Liver Foundation**  
1-800-465-4837, [www.liverfoundation.org](http://www.liverfoundation.org)
- **Hep C Connection**  
1-800-522-4372, [www.hepc-connection.org](http://www.hepc-connection.org)
- **L.O.L.A. (Latino Organization for Liver Awareness)**  
1-888-367-5652, [www.lola-national.org](http://www.lola-national.org)

..... *Suggested reading* .....

**The Hepatitis C Help Book**, by Misha Cohen, OMD, LAc, and Robert Gish, MD.  
St. Martin's Press.

**Living with Hepatitis C: A Survivor's Guide**, by Gregory T. Everson, MD, and Hedy Weinberg. Hatherleigh Press. 800-367-2550.

**The First Year—Hepatitis C: An Essential Guide for the Newly Diagnosed**, by Cara Bruce and Lisa Montanartelli. Marlow and Co.

..... *Pharmaceutical resources* .....

- **Roche Patient Assistance Program—Pegassist**  
1-877-PEGASYS (734-2797)
- **Schering-Plough Commitment to Care**  
1-800-521-7157

..... *HIV and HIV/HCV coinfection resources* .....

- **Project Inform**  
[www.projectinform.org](http://www.projectinform.org)  
hotline: 1-800-822-7422
- **San Francisco AIDS Foundation**  
[www.sfaf.org](http://www.sfaf.org)  
hotline: 1-800-367-2437
- **HIV and Hepatitis.com**  
[www.hivandhepatitis.com](http://www.hivandhepatitis.com)
- **National AIDS Treatment Advocacy Project**  
[www.natap.org](http://www.natap.org)

**ACUTE:** the rapid-onset, short-term initial stage of a disease. Contrast with *chronic*.

**ACUTE HEPATITIS:** the initial stage of viral hepatitis following infection. In HCV, acute hepatitis refers to the first six months of infection.

**ADVERSE EVENT:** an undesired reaction or side effect of treatment.

**ALOPECIA:** hair loss.

**ALT (formerly SGPT):** abbreviation for alanine aminotransferase. ALT is an enzyme produced inside liver cells. It is frequently elevated in people with chronic HCV infection because of a breakdown of the membranes of liver cells due to inflammation. Serum ALT levels are measured using a common blood test.

**ANEMIA:** reduced number of red blood cells or reduced ability of blood to carry oxygen. There are several types of anemia, all with different causes. Symptoms may include fatigue, weakness, pale skin, and difficulty breathing.

**ANTIBODY:** a protein produced by the immune system when a foreign substance enters the body. The presence of antibodies is an indicator of a past or possibly current infection. HCV antibodies are written as "anti-HCV." The test for anti-HCV is often the first step in diagnosing chronic HCV infection. A positive anti-HCV test must be followed by other laboratory tests to confirm the diagnosis. The antibody test alone is not sufficient to make a diagnosis of chronic HCV infection.

**ARTHRALGIA:** joint pain.

**AST (formerly SGOT):** abbreviation for aspartate aminotransferase. AST is an enzyme produced in the liver. When liver cells are damaged, AST is released. Elevated levels may indicate liver disease, but are also seen in people with other conditions.

**AUTOIMMUNE RESPONSE (AUTOIMMUNITY):** a condition in which a person's immune system produces antibodies that attack the body's own tissues. Several conditions associated with hepatitis C appear to have an autoimmune aspect.

**BID:** taken twice a day.

**BILIRUBIN:** a yellowish pigment released when red blood cells are broken down. Normally bilirubin is processed and excreted by the liver. Hyperbilirubinemia (an excess level of bilirubin in the blood) indicates liver damage, and can lead to jaundice (yellowing of the skin and whites of the eyes), pale-colored stools, and dark urine.

**BIOCHEMICAL RESPONSE:** how a person's serum ALT responds to treatment. When a person's elevated serum ALT level becomes normal after HCV therapy has been initiated, this is considered a biochemical response.

**BIOPSY:** a procedure in which a sample of cells or tissue is taken to examine in a laboratory. In HCV, liver biopsies are used to assess the health of the liver.

**BLOOD-BORNE:** transmitted through direct blood-to-blood contact, for example, through sharing needles or through a blood transfusion.

**BRAIN FOG:** mental confusion, memory loss, and/or lack of alertness. Not to be confused with encephalopathy.

**CHRONIC:** long-term or persistent disease. Contrast with *acute*.

**CIRRHOSIS:** liver damage in which normal liver cells are replaced with scar tissue. In **compensated cirrhosis**, the liver is damaged but can still function. In **decompensated cirrhosis**, liver function is severely impaired and scar tissue interferes with normal blood flow through the liver, potentially leading to bleeding varices, ascites, mental confusion, and other symptoms.

**COINFECTION:** concurrent infection with more than one disease-causing organism (e.g., HCV and HIV).

**CYTOPENIA:** low levels of blood cells.

**EDEMA:** swelling caused by the accumulation of fluid in body tissues.

**EFFICACY:** effectiveness; the ability to achieve a desired effect.

**ENCEPHALOPATHY:** disease of the brain. Hepatic encephalopathy, associated with advanced cirrhosis, is characterized by reduced cognitive function, con-

fusion, and memory loss.

**END OF TREATMENT (EOT) RESPONSE:** the disappearance of detectable HCV RNA from the blood at the end of a course of treatment.

**EXTRAHEPATIC:** outside the liver.

**FDA:** abbreviation for the Food and Drug Administration. This U.S. federal government agency has many functions, including the responsibility for granting or denying approval for drugs to be sold to the public.

**FIBROSIS (*adjective* FIBROTIC):** liver damage that involves the development of fibrous scar tissue.

**FULMINANT HEPATITIS:** a severe, life-threatening form of hepatitis.

**GENOTYPE:** genetic variation in the structure of HCV. There are six major genotypes, designated by the numbers 1 through 6. There are also many subtypes, e.g., 1a, 1b, 2a, etc. In the U.S., genotype 1 is predominant (approximately 70–75% of those infected).

**HCV RNA:** the genetic material of the hepatitis C virus. HCV is a single-stranded ribonucleic acid (RNA) virus.

**HEPATIC:** relating to the liver.

**HEPATITIS:** inflammation of the liver. Hepatitis may have various causes, including viruses, toxins, and heavy alcohol consumption.

**HEPATOCELLULAR CARCINOMA (HCC):** a type of primary liver cancer seen in some people with long-term liver damage due to chronic hepatitis C or hepatitis B.

**HEPATOLOGY (*also* HEPATOLOGIST):** the medical specialty that deals with the liver; a hepatologist treats liver disease.

**HEPATOTOXICITY (*adjective* HEPATOTOXIC):** toxic or poisonous to the liver.

**HISTOLOGICAL:** refers to bodily tissue. In HCV, histological improvement means improvement in liver tissue, either reduced inflammation or reduced fibrosis, when comparing pretreatment biopsies with biopsies

obtained typically six months after HCV therapy.

**INCUBATION PERIOD:** the period of time between initial exposure to an infectious microorganism and the development of disease symptoms.

**INTERFERON (IFN):** a naturally occurring protein in the human body produced by the immune system. Interferon interferes with viral replication. Genetically engineered products based on the natural protein have been developed by several pharmaceutical companies, and are approved for the treatment of chronic HCV infection.

**JAUNDICE:** yellowing of the skin and whites of the eyes due to high bilirubin levels in the blood. Jaundice is often a sign of liver damage or gallbladder disease.

**LIVER:** a large organ on the upper right side of the abdomen that plays an important role in the metabolism of sugars and fats, synthesizes several proteins, and filters toxins from the blood.

**MALaise:** a generalized feeling of illness and discomfort; a flu-like feeling.

**MONOTHERAPY:** use of a single drug for treatment. Traditionally, monotherapy for chronic HCV infection is interferon alone.

**MYALGIA:** muscle pain.

**NEUTROPENIA:** an abnormally low number of neutrophils, resulting in increased susceptibility to infection.

**NEUTROPHIL:** the most common type of immune system white blood cell. Neutrophils are phagocytes that engulf and destroy invading organisms such as bacteria and fungi.

**NONRESPONDER:** a person who does not show sufficient improvement while undergoing treatment. In HCV, a nonresponder is a person who does not experience a normalization of ALT levels or disappearance of HCV RNA.

**PEGYLATED INTERFERON (PEG-INTRON, PEGASYS):** a form of interferon that has a long half-life in the body and can be injected less often (typically once per week). Pegylated interferon is approved for the treatment of HCV.

**PERCUTANEOUS:** through the skin.

**PERINATAL TRANSMISSION (VERTICAL TRANSMISSION):** transmission from a mother to a fetus or newborn. Vertical transmission may occur *in utero* (in the womb), *intrapartum* (during birth), or *postpartum* (e.g., via breast-feeding).

**PLATELET:** see *thrombocyte*.

**PRURITUS (adjective PRURITIC):** itchiness.

**QUALITATIVE:** relating to, or expressed in terms of, quality. A qualitative viral load test measures the presence of a virus.

**QUANTITATIVE:** relating to, or expressed in terms of, quantity. A quantitative viral load test measures the amount of viral genetic material.

**QUASISPECIES:** individual genetic variants of HCV. Within a single genotype there may be multiple quasispecies.

**RELAPSE:** recurrence of disease symptoms following a period of improvement. In HCV, relapse can refer to an increase in viral load after it has been suppressed by antiviral treatment.

**RESPONSE TO TREATMENT:** how a disease responds to drug therapy. The term can refer to a biological, histological, or virological response.

**RIBAVIRIN (COPEGUS, REBETOL):** an antiviral medication that is used in combination with interferon for treatment of chronic HCV infection.

**STEATOSIS:** buildup of fat in the liver.

**SUBCUTANEOUS (SQ):** underneath the skin; usually refers to a drug injected under the skin.

**SUSTAINED RESPONDER:** a person who maintains a long-term response to treatment. In HCV, a sustained responder has a long-term beneficial result from HCV treatment (usual endpoints are normal ALT and undetectable HCV RNA) that persists after treatment has been stopped (six months is the generally accepted time interval).

**SUSTAINED VIROLOGICAL RESPONSE (SVR):** see *virological response*.

**THROMBOCYTE (PLATELET):** a type of blood cell responsible for normal blood clotting.

**THROMBOCYTOPENIA:** an abnormally low number of platelets, which may result in abnormal bleeding and bruising.

**THYROID GLAND:** an organ at the base of the neck that produces thyroxin and other hormones involved in regulating metabolism.

**TREATMENT-NAIVE:** a person who has not had prior treatment for a particular condition.

**VACCINE:** a preparation administered to stimulate an immune response to protect a person from illness. A vaccine typically includes a small amount of a killed or inactivated microorganism, or genetically engineered pieces. A therapeutic (treatment) vaccine is given after infection and is intended to reduce or stop disease progression. A preventive (prophylactic) vaccine is intended to prevent initial infection.

**VARICES (adjective VARICEAL):** an abnormally dilated or swollen vein, artery, or lymph vessel resulting from portal hypertension.

**VIRAL LOAD:** the amount of virus (e.g., the HCV RNA level) that can be measured, usually in the blood.

**VIRAL REPLICATION:** the ability of a virus to reproduce copies of itself.

**VIROLOGICAL RESPONSE:** how a person's viral load level responds to treatment. In HCV, when a person's HCV RNA becomes undetectable after HCV therapy has been initiated, this is considered a virological response. If the HCV RNA remains undetectable beyond six months, the term sustained virological response (SVR) is used.

**VIRUS:** a microscopic, infectious organism that invades a living host and makes copies of itself (viral replication).

**WINDOW PERIOD:** the time between exposure to a microorganism and the production of sufficient antibodies to be detected in a test.

Notes



A series of horizontal lines for writing notes, consisting of 20 evenly spaced lines.





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