

a guide to understanding Hepatitis C

# HCV

2012



**Alan Franciscus**  
**Liz Highleyman**

## Foreword

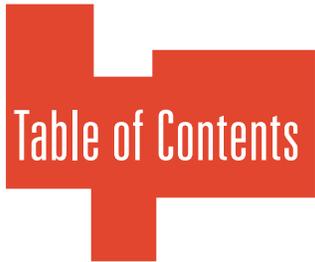
When I was diagnosed in 1996 the information about hepatitis C was scarce and treatment success for people with HCV genotype 1 was only 9%. In 2012 our understanding of hepatitis C has increased by leaps and bounds and now we have a triple combination of three drugs (pegylated interferon, ribavirin and an HCV protease inhibitor) that can cure up to 79% of people with HCV genotype 1. That's a whopping 70% increase in treatment response in 15 years! In the not too distant future it is believed that cure rates will increase even more and there is a real possibility that the majority of people with hepatitis C will have a combination of pills that will cure hepatitis C without the use of interferon and/or ribavirin.

But even weighing the possibility of better medications in the future, it is very importance that if people need to be treated they shouldn't wait for that promised magic bullet. There is no guarantee that the HCV drugs being tested in clinical trials will cure everyone. The key to successfully living with hepatitis C is to learn as much as you can about hepatitis C. This is also true of treatment—work closely with your medical provider to make educated choices about living well with hepatitis C and making the best possible decision about which Food and Drug Administration (FDA) approved HCV medications to use.

I hope that you are as excited as I am about all of the advances in the understanding, care and treatment of hepatitis C. Please stay tuned to HCSP/HCV Advocate for the latest information about hepatitis C.

*Alan Franciscus*

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



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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 is the most common in the U.S. 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



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 ab-

sorb 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 re-generate 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. Now the risk is considered to be less than 1 chance per 2 million units of transfused blood. A small percentage of people (estimated at 0–3% for monogamous heterosexuals) may contract HCV through unprotected sexual activity. Among people in so-called “high risk” groups (gay men, sex workers, 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 in about 4-5% of births. Whether or not transmission occurs may depend on the presence of high levels of HCV in the moth-

er’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 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; practitioners today should only 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.

## HCV Disease Progression

**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, about 75% 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 or result in death.

**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 encephalopathy (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 more than 4 million Americans have been infected with HCV.**

**Up to an estimated 15,000 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***

The HCV ELISA or EIA is a simple blood test that can detect HCV antibodies.

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**A POSITIVE HCV ANTIBODY TEST MEANS THAT A PERSON HAS BEEN INFECTED AT ONE TIME. AN HCV RNA OR VIRAL LOAD TEST MUST BE PERFORMED TO FIND OUT WHETHER A PERSON IS CURRENTLY INFECTED WITH THE HEPATITIS C VIRUS.**  
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#### ***Rapid HCV Antibody Test***

A point-of-care test that collects and processes a sample and gives results after 20 minutes. A fingerprick and whole blood draw has been approved and a CLIA waver issued by the Food and Drug Administration (FDA).

### ***Viral Load Tests***

Viral load tests measure the amount of HCV circulating in the blood. HCV viral load is expressed 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, what type of medicine to use, and the likelihood of responding to treatment.

### ***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 the 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 people with HCV genotype 1 is the combination of an HCV protease inhibitor and pegylated interferon plus ribavirin. People with HCV genotype 2 or 3 are treated with a combination of pegylated interferon and ribavirin. Studies are underway to treat people with HCV genotype 2 or 3 with the combination of an HCV protease inhibitor and pegylated interferon plus ribavirin, but the use of a protease inhibitor has not been approved by the Food and Drug Administration (FDA) for these genotypes. Research is ongoing to develop new and better medications for all genotypes, 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, a HCV protease inhibitor 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 interferon in the blood and better reduces the ability of HCV to replicate. An HCV protease inhibitor is a direct-acting antiviral that inhibits the replication process of the hepatitis C virus. Ribavirin is an oral

medication used in combination with interferon to treat HCV infection. Ribavirin and an HCV protease inhibitor are not effective when used alone. The current standard of care is a combination of pegylated interferon plus ribavirin for genotype 2 and 3, and pegylated interferon, ribavirin and an HCV protease inhibitor for genotype 1.

➔ **PEGYLATED INTERFERON IS A MEDICATION THAT IS GIVEN BY INJECTION (RIGHT UNDERNEATH THE SKIN) ONCE-A-WEEK**

➔ **RIBAVIRIN IS A PILL TAKEN ORALLY TWICE A DAY WITH FOOD.**

➔ **AN HCV PROTEASE INHIBITOR IS A PILL (TAKEN EVERY 7-9 HOURS WITH FOOD).**

➔ **DO NOT USE RIBAVIRIN WITHOUT INTERFERON.**

➔ **DO NOT USE AN HCV PROTEASE INHIBITOR WITHOUT INTERFERON AND RIBAVIRIN.**

## **Genotype 1**

People with HCV genotype 1 who have never been treated (treatment-naïve) or who have had a previous course of interferon/ribavirin (treatment-experienced) are treated with a triple combination of an HCV protease inhibitor (pills), pegylated interferon (injection) and ribavirin (pills). People who take the triple combination have up to a 79% chance of curing hepatitis C.

Treatment duration is usually based on the type of response at 4 weeks (rapid virological response (RVR)) and 12 weeks (early virological response (EVR)), and other time points during therapy. Based on these factors, treatment can be tailored to 24, 36 or 48 weeks total treatment duration.

## **Genotypes 2 and 3**

People with HCV genotype 2 or 3 are typically treated with a combination of pegylated interferon plus ribavirin (without an HCV protease inhibitor). The chances of being cured of hepatitis C with pegylated interferon plus ribavirin is up to 82% in people with genotype 2 or 3. Total treatment duration is usually 24 weeks.

## **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.**

## **Virological Response**

Virological response is defined as 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.

**Rapid Virological Response (RVR)** means that the HCV RNA (viral load) is undetectable after 4 weeks of treatment.

**Complete Rapid Virological Response (cRVR)** means that HCV RNA (viral load) is undetectable at treatment week 4 and 12.

**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. Increasingly, treatment duration is being guided by type of response (response guided therapy) at certain time points during therapy.

The treatment duration for people with HCV genotype 1 is guided by treatment response at certain time points during therapy for a total treatment duration of 24 to 48 weeks. HCV treatment duration for people with HCV genotypes 2 or 3 is typically 24 weeks and guided by early virological response. If someone has not responded after certain times during treatment, further therapy is unlikely to clear the virus and treatment should be stopped.

**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. A combination therapy with two or more agents is more effective than monotherapy for treating HCV. For this reason, new clinical trials will focus on testing the effectiveness of combining the new drugs with pegylated interferon and ribavirin. There are studies of a combination of direct-acting antivirals (DAAs) without

interferon that are in development and look very promising.

HCV protease, NS5A, and 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 many 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 postmarketing trials).

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**FOR THE MOST CURRENT INFORMATION ABOUT INVESTIGATIONAL PHARMACEUTICAL THERAPIES VISIT THE HCV ADVOCATE HCV DRUG PIPELINE WEB PAGE.**  
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## HCV Treatment Options

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. For more information about clinical trials go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

## Treatment Considerations

### Managing Drug Side Effects

The most common side effects of interferon, ribavirin and an HCV protease inhibitor 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 stopped, 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 [www.myplate.gov](http://www.myplate.gov) 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 beneficial. It is recommended that people with any type of liver disease should not eat raw or under-

cooked 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 non-dairy 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 unless otherwise directed by a medical provider.

Most people would benefit from a consultation with a dietitian. 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. 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 lim-

its 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 AS WELL AS AN ACCELERATED DOSING SCHEDULE IS FDA APPROVED.**

➔ **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 unfounded claims 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 and death. New treatments for HCV are currently being tested, and it is believed that better treatment options will

be available within five years, but talk with a medical provider to find out if it is safe to wait. 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.



## Resources

### *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)
- National HCV Helpline  
877-HELP-4-HEP (877-435-7443)

### *Suggested Reading*

- **Healing Hepatitis C**, by Christopher-Kennedy-Lawford and Diana Sylvestre. HarperCollins.
- **Living with Hepatitis C: A Survivor's Guide**, by Gregory T. Everson, MD, and Hedy Weinberg. Hatherleigh Press. 800-367-2550.
- **Free from Hepatitis C: Your Complete Guide to Healing Hepatitis C**, by Lucinda K. Porter, RN. Square One Publishers.

### *Pharmaceutical resources*

- **Genentech (Member of the Roche Group):**  
1-877-PEGASYS (1-877-734-2797)  
[www.genentechaccesssolutions.com/portal/site/AS/](http://www.genentechaccesssolutions.com/portal/site/AS/)
- **Merck (includes Schering-Plough subsidiary):**  
1-866-939-HEPC (4372)  
[www.merck-cares.com](http://www.merck-cares.com)
- **Kadmon Pharmaceuticals:**  
1-800-405-8506  
[www.3riverspharma.com](http://www.3riverspharma.com)
- **Vertex:**  
1-888-552-2494  
Patient Assistance: [www.vrtx.com/patients.html](http://www.vrtx.com/patients.html)

### *For more information about clinical trials*

- [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

### *Tattoo resources*

If you are thinking about getting a tattoo it is important to realize that there is a very real chance that you could get hepatitis B, hepatitis C or another infection while having a tattoo if safety practices are not followed very carefully. Find out more at: [www.hepatitistattoos.org](http://www.hepatitistattoos.org)

**ACUTE:** 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 REACTION (SIDE EFFECT):** an undesired action or effect of a drug or other treatment.

**ALOPECIA:** hair loss.

**ALT:** see alanine aminotransferase.

**ANEMIA (adjective ANEMIC):** 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 (IMMUNOGLOBULIN):** a protein produced by plasma cells (a type of immune system white blood cell) when they encounter foreign invaders. Specific antibodies bind to specific invaders, or antigens, and target them for destruction. The presence of antibodies indicates current infection with or past exposure to a pathogen.

**ARTHRALGIA:** joint pain.

**AST (formerly SGOT):** an enzyme (also called aspartate transaminase) 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 muscle damage. A normal level is below 42 IU/L.

**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 (e.g., lichen planus, Sjögren's syndrome) appear to have an autoimmune aspect.

**BID:** taken twice daily.

**BILIRUBIN:** a yellowish pigment released when red blood cells are broken down. Normally bilirubin is processed and excreted by the liver. An excess level of bilirubin in the blood (hyperbilirubinemia) may indicate liver damage, and can lead to jaundice (yellowing of the skin and whites of the eyes), pale-colored stools, and dark urine. A normal bilirubin level is below 1.3mg.

**BIOPSY (BX):** a procedure in which a sample of cells or tissue is taken for laboratory examination. Liver biopsies are used to monitor liver disease progression in people with HCV.

**BOCEPREVIR (VICTRELIS):** an HCV protease inhibitor developed by Merck to treat hepatitis C.

**BRAIN FOG:** mild mental confusion, memory loss, and/or lack of concentration and alertness. May be a symptom of toxic chemical build-up due to impaired liver function. See hepatic encephalopathy.

**cEVR:** see complete early virological response.

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

**CIRRHOSIS:** a type of liver damage in which normal liver cells are replaced with fibrous scar tissue.

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

**COMPLETE EARLY VIROLOGICAL RESPONSE (cEVR):** HCV RNA negative at treatment week 12.

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

**DAA'S:** see direct-acting antivirals.

**DIRECT-ACTING ANTIVIRALS (DAA'S):** There are 3 categories of direct antivirals—protease inhibitors, polymerase inhibitors and NS5a. DAA's target viral enzymes that are important for replication of hepatitis C and block these enzymes from allowing the hepatitis C virus to replicate.

**EARLY VIROLOGICAL RESPONSE (EVR):** 2 log<sub>10</sub> drop in HCV RNA at treatment week 12.

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

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

**ENCEPHALOPATHY:** disease of the brain.

**END-OF-TREATMENT RESPONSE (EOT OR ETR):** undetectable HCV RNA at the completion of treatment.

# Glossary

**EXTENDED RAPID VIROLOGICAL RESPONSE (eRVR):**

HCV RNA negative at treatment week 4 and 12.

**EXTRAHEPATIC:** outside the liver.

**FDA:** see Food and Drug Administration.

**FIBROSIS (ADJECTIVE FIBROTIC):** liver damage in which fibrous tissue develops and replaces normal cells.

**GENOTYPE:** the genetic makeup of an organism. HCV has six major genotypes (designated by the numbers 1 through 6). In the U.S., genotype 1a/b is most prevalent.

**HCV RNA:** the genetic material of the hepatitis C virus. A detectable level of HCV RNA on a viral load test indicates that HCV is actively replicating.

**HEPATIC:** having to do with the liver; also, an herbal remedy used to treat liver conditions.

**HEPATIC ARTERIAL STENOSIS (HAS):** narrowing of the hepatic artery.

**HEPATIC PANEL:** see liver function tests.

**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.

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

**HISTOLOGY (ADJECTIVE HISTOLOGICAL):** the study or examination of body tissues. In people with HCV, histological improvement refers to improved liver tissue health, including decreased inflammation and reduced fibrosis or cirrhosis.

**HISTOLOGICAL RESPONSE:** an improvement in liver tissue condition (e.g., reduced inflammation) in response to treatment.

**INCIVEK (TELAPREVIR)** an HCV protease inhibitor developed by Vertex to treat hepatitis C.

**INTERFERON (IFN):** a cytokine (messenger protein) that plays a role in immune response. The three major classes of interferon are alpha, beta, and gamma.

**JAUNDICE:** (icterus, itcteric) 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. Monotherapy for HCV (interferon alone) is no longer considered standard treatment. Contrast with combination therapy.

**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:** person who does not show improvement while undergoing treatment. In HCV, a nonresponder does not achieve normal ALT levels or an undetectable viral load.

**NULL RESPONDER:** – a person who does not achieve a 2 log<sub>10</sub> drop of HCV RNA by treatment week 12.

**PEGYLATED INTERFERON (PEGINTRON, PEGASYS):** a recently developed form of interferon that has a long half-life in the body and can be injected less often (typically once per week). Pegylated interferon (brand names Peg-Intron, Pegasys) appears superior to standard interferon as a treatment for HCV.

**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.

**POLYMERASE INHIBITOR:** an agent that inhibits viral replication by interfering with the polymerase enzyme.

**PRIOR PARTIAL-RESPONDER:** a person who has a 2 log<sub>10</sub> drop in HCV RNA by treatment week 12, but who does not become HCV RNA negative by end of treatment. (*Example 2 log<sub>10</sub> drop: 1,000,000 to ≤ 10,000*).

**PROTEASE INHIBITOR:** an agent that inhibits viral replication by interfering with the virus' protease enzyme.

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

**PSORIASIS:** a skin condition characterized by scaling and red patches, due to the overproduction of skin cells.

**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.

**RAPID VIROLOGICAL RESPONSE (RVR):** HCV RNA negative after 4 weeks of treatment. RVR is used to predict treatment response and to dictate how long people with HCV genotype 1 should be treated.

**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.

**RELAPSER:** a person who becomes HCV RNA negative at end of treatment, but becomes HCV detectable within 24 weeks from the end of treatment (EOT).

**RESPONSE-GUIDED TREATMENT:** Response-guided therapy uses HCV RNA testing during treatment to predict response and guide treatment duration for patients with chronic hepatitis C.

**RESPONSE TO TREATMENT:** see treatment response.

**RIBAVIRIN (RBV)—BRAND NAME REBETOL, COPEGUS, RIBASPHERE:** an antiviral medication approved for use in combination with interferon to treat chronic HCV infection.

**STEATOSIS:** buildup of fat tissue 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 response (e.g., normal ALT levels, undetectable HCV RNA) that persists after treatment is stopped.

**SUSTAINED VIROLOGICAL RESPONSE (SVR):** HCV RNA negative 24 weeks after completion of treatment (CURE).

**TELAPREVIR (INCIVEK)** an HCV protease inhibitor developed by Vertex to treat hepatitis C.

**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 easy bruising.

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

**TREATMENT-NAIVE:** a person who has never been treated.

**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.

**VICTRELIS (BOCEPREVIR):** an HCV protease inhibitor developed by Merck to treat hepatitis C.

**VIRAL LOAD:** the amount of virus in the blood or other tissues, usually expressed in terms of copies of viral genetic material (RNA or DNA). The presence of genetic material indicates that a virus is actively replicating.



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



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*Executive Director*  
Editor-in-Chief, HCSP Publications  
Alan Franciscus

*Authors*  
Alan Franciscus  
Liz Highleyman

*Managing Editor / Webmaster*  
C.D. Mazoff, PhD

*Design and Production*  
Paula Fener

*Contact Information*  
Hepatitis C Support Project  
PO Box 427037  
San Francisco, CA 94142-7037  
alanfranciscus@hcvadvocate.org

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

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