HCSP GUIDES

A publication of the Hepatitis C Support Project

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

A GUIDE TO:

UNDERSTANDING HEPATITIS C 2017

Alan Franciscus

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1945 TO 1965
GET TESTED

The Centers for Disease Control and Prevention (CDC) and the United States Preventive Services Task Force (USPSTF) recommend a one-time test for everyone born from 1945 to 1965.

FOREWORD

When I was diagnosed in 1996 there was almost no information about hepatitis C (HCV) available and the information that was available was often incorrect. At that time, treatment consisted of standard interferon monotherapy that you would inject under the skin three times a week for six months. For the most common strain of hepatitis C—genotype 1—there was only a 9% chance of being cured of hepatitis C.

Now it's 2017 and there is a wealth of information to help guide people with HCV. Treatments for hepatitis C have progressed to the point that more than 90% of the people who take the treatments can be cured, and, for many people, the treatment duration is usually 12 to 24 weeks. Now, we have interferon-free therapy. Importantly, the side effects of the newer treatments will be much less than the side effects of interferon-based therapies.

Today, medical providers are much more knowledgeable about diagnosis, management and treatment of hepatitis C. There is also a public campaign to raise awareness and test the largest patient population—Baby Boomers. In addition to testing Baby Boomers, we must test all people at risk for hepatitis C.

The most important steps that people can take are to learn as much as they can about hepatitis C and work with their medical provider to stay as healthy as possible—and that should include seeking HCV treatment now. This Guide is meant to help you understand hepatitis C and provide some strategies to become healthier and live longer.

I hope that you are as excited as I am about the future of hepatitis C. As I stated above, we have come a long way in our understanding of hepatitis C. Much more needs to be done to make sure that all of the people who are undiagnosed are tested and provided with care, support and have access to these life-saving medications that can cure almost everone with hepatitis C. Remember, everyone has the right to be treated and cured.

Stay tuned to the hepatitis C Support Project and our website www.hcvadvocate.org for the latest information about every aspect of hepatitis C.

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Alan Franciscus
Executive Director, Hepatitis C Support Project
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Get Tested. Get Treated. Get Cured.

INTRODUCTION

HCV is a blood-borne virus that was previously referred to as non-A/non-B hepatitis. HCV has seven genotypes, numbered 1–7. 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 75% 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 for HCV; however, treatment can cure most people of HCV and stop or slow disease progression.

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 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

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.

IMPORTANT NOTE

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 6% of births. 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 considered 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. Many experts recommend that 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

After exposure to HCV, the window period usually lasts 2–26 weeks. The initial phase of hepatitis C is called acute infection. Acute HCV can take up to 12 months to resolve. However, up to 75-85% 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% or more 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 to avoid 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; some 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. The type of liver cancer associated with HCV is called primary hepatocellular carcinoma (HCC).

SYMPTOMS OF HCV

People with HCV may experience mild flu-like symptoms including nausea, fatigue, fever, headaches, loss of appetite, abdominal pain, night sweats, and muscle or joint pain. Over time (often years) people with chronic HCV may develop various symptoms related to liver damage. Chronic HCV is also associated with a wide variety of related conditions.

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), Non-Hodgkin's Lymphoma (a form of cancer) 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.

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

DIAGNOSING HCV

Testing 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 liver test 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.

> 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.

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 waiver issued by the Food and Drug Administration (FDA).

HCV RNA or 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 and are performed before, during and after HCV treatment. An association between viral load and disease progression has not been established.

Genotype Tests

Genotype tests are used to determine what type ('strain') of HCV you have. This information is useful for making treatment decisions, such as 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 chemical tests includes measurements that may indicate liver function. The most common measurements are alanine aminotransferase (ALT) and aspartate aminotransferase (AST). 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 (ALP) and gamma-glutamyl transpeptidase (GGT). Abnormal levels may indicate cirrhosis or bile duct blockage, as well as other abnormalities.

HCV Facts

- The Centers for Disease Control and Prevention (CDC) estimates that 3.5 million Americans have chronic hepatitis C. Many experts believe the actual number is much higher.
- More than 19,000 Americans die annually of complications related to HCV. This figure is expected to triple in the next 10 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, if not already immune.

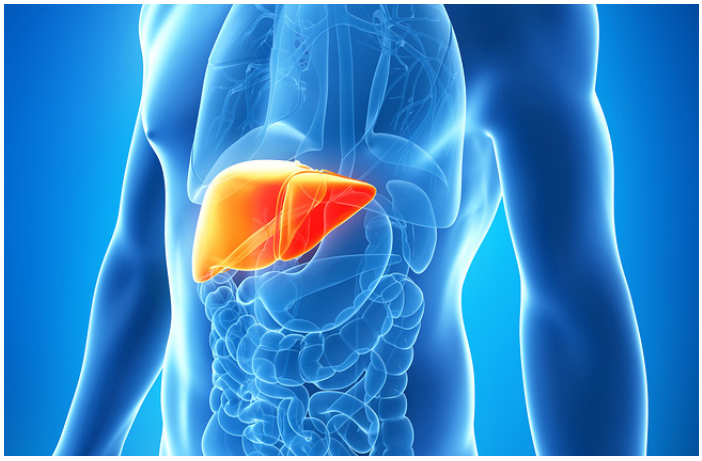
In addition, your doctor may measure prothrombin time (an indication of blood clotting speed) and bilirubin levels. Bilirubin is a pigment that is often present in the blood of people with liver inflammation; high bilirubin levels result in jaundice. Many factors such as the use of medications and alcohol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

Liver Biopsy / Fibroscan

Biopsies are done to measure the severity of inflammation, the amount of scarring, and the general health of the liver.

The Fibroscan is another diagnostic tool that is used to evaluate liver health. The Fibroscan is based on a technology using a machine that sends a vibration wave through the liver to detect and analyze any fibrosis.

These and other diagnostic tests are discussed in a fact sheet from the HCV Advocate website.



HCV TREATMENT OPTIONS

Until 1998, interferon alone (monotherapy) was the only approved treatment for HCV infection. Today, there are interferon- and ribavirin-free medications that can cure most patients who take the medications. The newer medications also have fewer side effects than the older medications and they are taken for a shorter period of time.

There are currently three types of HCV inhibitors protease, polymerase and NS5a. They 'inhibit' the hepatitis C virus from replicating (making more viruses).

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

Approved Pharmaceutical Treatments

There are currently many medications approved to treat hepatitis C. These include direct-acting antiviral medications with and without ribavirin that inhibits the replication process of the hepatitis C virus. Ribavirin is not effective when used alone.

- *A DAA* is a pill that may or may not need to be taken with food.
- *Ribavirin* is a pill taken orally twice a day with food.

Genotype 1

People with HCV genotype 1 who have never been treated (treatment-naïve) or who have had a previous of course treatment (treatment-experienced) are treated with a combination of an HCV inhibitor(s) and for some ribavirin (pills). People who take the combinations have more than a 90% chance of curing hepatitis C.

Treatment duration is 8 to 24 weeks, but most people are treated for 12 weeks.

Genotypes 2,3,4,5, and 6

People with genotype 2,3,4,5 and 6 are treated with a combinaton of an HCV DAA

with or without ribavirin. The treatment duration is 12 to 24 weeks. The cure rates are 80 to 100%. However, people with genotype 3 and who have cirrhosis do not respond as well.

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.

Investigational Pharmaceutical Therapies

HCV therapy has seen impressive advances, given that the virus was only identified in 1989. There are many clinical studies underway with investigational drugs and different combinations of existing drugs that have the potential to cure everyone with hepatitis C in the near future. For more information about these studies visit the HCV Advocate Drug Pipeline. http://hcvadvocate.org/treatment/drug-pipeline-monthly-report/

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, if ever.

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).

Clinical trials can be an excellent way to obtain free medications; 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. It is also important to understand that the study drug(s) could potentially cause you harm. For more information about clinical trials go to our Clinical Trials Reference Guide http://hcvclinical.hcvadvocate.org/

TREATMENT CONSIDERATIONS

Direct-Acting Antivirals

The most common side effects of HCV inhibitors and ribavirin include mild flu-like symptoms, muscle and joint pain, nausea, headaches, fatigue, loss of appetite, dry skin, rashes, anxiety, and insomnia. Some physical symptoms may be reduced with ibuprofen or acetaminophen in low doses. High doses of acetaminophen can be toxic to the liver. High doses of non-steroidal anti-inflammatory drugs

WWW.

For the most current information about investigational pharmaceutical therapies visit

http://hcvadvocate.org/treatment/drug-pipeline-monthly-report/

(NASIDs) should also be avoided. People experiencing anxiety, or irritability, may be helped with mild tranquilizers. Check with your doctor before taking any of these medications for any of the side effects listed above.

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.

Regular exercise may help alleviate some side effects, such as fatigue.

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

- 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 taking the medications.
- 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.

HCV MANAGEMENT

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 medical provider, 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.choosemyplate.gov is generally recommended. Such a diet is low in fat and sodium, high in complex carbohydrates, and has adequate protein.

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. Although these options are not available to everyone with hepatitis C, any action that will reduce the harm is beneficial. Read all labels to acquaint yourself with the 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 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 over-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, almond, cashew, coconut, hemp 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 with HCV 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.

People with hepatitis C should have their fat soluble vitamin (A,D,E & K) levels checked.

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 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.

- Exercise
  Moderate exercise is generally 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 medical provider 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 guide.

Social Media

Social Media such as Facebook provides many groups that provide support to people with hepatitis C.

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.

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.

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 websites 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 website at www.hcvadvocate.org for recommended sites.

CONCLUSION

Chronic hepatitis C is a liver disease that can have serious consequences. It is important to remember that not everyone experiences every symptom or severe disease progression. Those who do eventually experience disease progression may remain symptom-free for many years. However, many people develop serious liver disease that can result in liver failure and death. There are effective treatments now and everyone with hepatitis C should talk with a medical provider about treatment. Additionally, lifestyle changes such as good nutrition, exercise, and stress management can help alleviate some side effects and may slow disease progression.

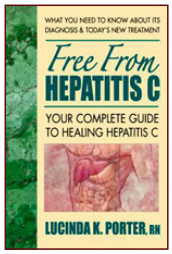
We hope this information has helped you to understand the hepatitis C virus and how it can affect your physical and emotional health. We welcome any suggestions or ideas for improving this guide.

PATIENT ASSISTANCE PROGRAMS

There are many assistance programs that can help you with the cost of the medicines including the insurance co-payments. Talk to and work closely with your medical provider to access these programs.

Umbrella Organizations		
Good Days	1-877-968-7233	www.mygooddays.org
HealthWell Foundation	1-800-675-8416	www.HealthWellFoundation.org
Needymeds.org	1-800-503-6897	www.needymeds.org
Partnership for Prescription Assistance	1-888-477-2669	www.pparx.org
Patient Access Network Foundation	1-866-316-PANF (7263)	www.panfoundation.org/
Patient Advocate Foundation Co-Pay Relief	1-866-512-3861	www.copays.org/diseases/hepatitis-c
Vaccines		
Merck-VAQTA – hepatitis A vaccine; RECOMBIVAX HB – hepatitis B vaccine	1-800-293-3881	www.merck.com/merckhelps/vaccines/home.html
GSK - HAVRIX – hepatitis A vaccine; ENGERIX-B – hepatitis B vaccine; TWINRIX – combination hepatitis A and hepatitis B vaccine	1-877-822-2911	www.gsk-vap.com/
Pharmaceutical Companies		
AbbVie	1-844-2proCeed	www.viekira.com/patient-support
BMS	1-844-442-6663	www.daklinza.bmscustomerconnect.com/support
Gilead	1-855-769-7284	www.mysupportpath.com/
Merck	1-800-727-5400	www.merckhelps.com
Ribavirin patient assistance programs		http://hepatitiscmedications.hcvadvocate.org/patient-assistance-programs/

SUGGESTED READING



Free from Hepatitis C: Your Complete Guide to Healing Hepatitis C

By Lucinda K. Porter, RN.
Square One Publishers.

Hepatitis C Treatment One Step at a Time.

By Lucinda K. Porter, RN.
Demos Health.

RESOURCES

For more information about HCV, contact the following organizations

- HIVandHepatitis.com
  www.hivandhepatitis.com/
- National AIDS Treatment Advocacy Project (NATAP)
  www.natap.org/
- National HCV Helpline
  877-HELP-4-HEP (877-435-7443)

HEPATITIS C SUPPORT PROJECT
HCV Advocate
Get Tested. Get Treated. Get Cured.

Visit the HCV Advocate Website for information about hepatitis C including:

- HCV Advocate Website: www.hcvadvocate.org for information about hepatitis C
- Newly Diagnosed: Information and a printable brochure to help newly diagnosed patients http://hcvadvocate.org/newly-diagnosed/
- Treatment Issues: Treatment-related information: fact sheets about approved medications, side effects, and more http://hcvadvocate.org/treatment/
- Fact Sheets: This lists all of our fact sheets including our Easy C Facts, HCSP Fact Sheets, FAQ, Guides, Coinfection Facts, Chinese Easy C's, and Tattoos http://hcvadvocate.org/publications/fact-sheets/
- Resources: Disability Benefits, Glossaries (Medical & Herbal), Helpful links including support groups http://hcvadvocate.org/resources/
- Espanol: Fact Sheets in Spanish http://hcvadvocate.org/spanish/
- HBV: A web page dedicated to hepatitis B http://hcvadvocate.org/hbv/
- Newsletter: http://hcvadvocate.org/publications/newsletter/
- Clinical Trial Reference Site: http://hcvclinical.hcvadvocate.org/
- HCV Drug Pipeline and Conference Coverage Site: http://hcvdrugs.com/

GLOSSARY

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.

ALT (**ALANINE AMINOTRANSFERASE**; **formerly SGPT**): an enzyme (also called alanine transaminase) produced in the liver when the membranes of liver cells break down. ALT levels are measured to help assess the degree of liver damage and determine how well HCV treatment is working. A normal level is below 48 IU/L.

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 that the body makes to fight specific invaders. The antibody attaches itself to the invaders and targets 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.

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.

BRAIN FOG: mild mental confusion, memory loss, and/or lack of concentration and alertness.

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.

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.

EXTRAHEPATIC: outside the liver.

FDA: 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 seven major genotypes ('strains') designated by the numbers 1 through 7. In the U.S., genotypes 1a and 1b are most prevalent.

HCV INHIBITORS: There are 3 categories of HCV inhibitors—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. Also known as HCV inhibitors.

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 PANEL: 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.

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GLOSSARY

HISTOLOGY (ADJECTIVE HISTOLGICAL): 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.

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.

MYALGIA: muscle pain.

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

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.

NS5A INHIBITOR: an HCV medication that inhibits viral replication.

NULL RESPONDER: a person who does not achieve a 2 $\log_{10}$ drop of HCV RNA by treatment week 12.

ONCE-A-DAY: taken once a day.

PLATELET: see thrombocyte.

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

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.

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).

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 12 weeks after completion of treatment (CURE).

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

TID: taken tree times a day.

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.

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.

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

VIRUS: a microscopic infectious organism that is unable to grow or replicate outside of a host cell. Viruses integrate their genetic material (DNA or RNA) into a host cell and take over the cell's biological mechanisms to reproduce new virus particles.

WESTERN MEDICINE: allopathic medicine; the type of medical practice.

WHITE BLOOD CELL (WBC): leukocyte.

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

NOTES

MANAGING HCV

HCSP GUIDES

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A GUIDE TO:

UNDERSTANDING HEPATITIS C

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

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