

Spend time with these resources to continue to learn more and share what you've learned with others.

HEPATITIS C RESOURCES:

Hepatitis C Support Project/HCV Advocate Website

www.hcvadvocate.org

Provides resources and information about every aspect of hepatitis C, from living with hepatitis C, clinical trials, HCV management, HCV treatment to alternative treatments. Included on the website are over 150 fact sheets and comprehensive guides about hepatitis C and HIV/HCV coinfection

American Liver Foundation

1-800-GO-LIVER (1-800-465-4837)

www.liverfoundation.org

Information on liver diseases, including hepatitis C

Caring Ambassadors Hepatitis C Program

1-503-632-9032

www.hepcchallenge.org

Hepatitis C Choices book (free PDF); information and awareness

Centers for Disease Control and Prevention (CDC)

1-800-CDC-INFO (1-800-232-4636)

www.cdc.gov/hepatitis/index.htm

Fact sheets and answers to frequently asked questions about hepatitis

Hepatitis Education Project

www.hepeducation.org

A website for people with hepatitis C and their friends, family members, and healthcare providers. It has hepatitis information about advocacy and support, as well as other resources

Hep C Connection

1-800-522-HEPC (1-800-522-4372)

www.hepc-connection.org

Resources and support for people affected by the hepatitis C virus

Hepatitis Foundation International

1-800-891-0707

www.hepfi.org

Information on liver disease and viral hepatitis

Mayo Clinic

www.mayoclinic.com

Up-to-date information and tools that reflect the expertise and standards of the Mayo Clinic

MedicineNet (owned by WebMD)

www.medicinenet.com/hepatitis_C/

Medical information on hepatitis C

MedlinePlus Health Information

www.nlm.nih.gov/medlineplus/hepatitisc.html

An extensive health information website that includes a medical dictionary, information on prescription and nonprescription drugs, and an overview of hepatitis C

National AIDS Treatment Advocacy Project (NATAP)

www.natap.org

Educates people about HIV and hepatitis treatments, and advocates for those with these conditions. Provides hepatitis C news and extensive conference coverage. This site is one of the most comprehensive websites about HIV and HCV that is geared towards medical providers

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

www.niddk.nih.gov

National Institutes of Health (NIH)

www.nih.gov

*Comprehensive health website with links to health publications and current research***United States Department of Veterans Affairs (VA)**

www.hepatitis.va.gov

*Information, brochures, and manuals on hepatitis C***Drug Manufacturers and Other Resources:**

Umbrella Organizations		
Chronic Disease Fund	1-877-968-7233	www.cdfund.org/Default.aspx
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
Pharmaceutical Companies		
AbbVie	1-844-2proCeed	www.viekira.com/proceed-program
Patient Outreach Program	1-844-428-4357	www.hepceducate.com/
Genentech	1-866-422-2377	www.genentech-access.com/hcp
Gilead	1-855-769-7284	www.mysupportpath.com/
Johnson & Johnson Patient Assistance Foundation	1-800-652-6227	www.jjpaf.org
Olysio Support (Co-pays)	1-855-5-OLYSIO	www.olsio.com
Kadmon Pharmaceuticals (Keys Program)	1-888-668-3393	www.hcvadvocate.org/community/community_pdf/Riba_CoPay_Cards.pdf
Moderiba Ribavirin	1.844.MODERIBA (1.844.663.3742)	www.moderiba.com/patient-support/financial

Other Resources

Affordable Care Act

Information about the national health insurance/coverage and if your state is participating.

<http://www.hhs.gov/healthcare/rights/>

Rules and regulations regarding medical conditions and the workplace can be obtained from:

Federal Equal Employment Opportunity Commission (EEOC)

www.eeoc.gov/facts/qanda.html

Federal Family and Medical Leave Act of 1993 (FMLA)

www.afm.ars.usda.gov/hrd/payleave/family/FMLAentitlements.htm

New privacy laws about medical information and records can be found at:

US Department of Health and Human Services (HHS) Health Insurance Portability and Accountability Act (HIPAA)

www.hhs.gov/ocr/privacy

GLOSSARY:

Acetaminophen: The generic name for over-the-counter pain and fever relievers, such as Tylenol®. Large doses can cause liver failure. Ask your healthcare provider if you can take acetaminophen. It should never be taken with alcohol.

Acute: A term used to describe disease symptoms of a short period of time.

Acute hepatitis C: A short-term illness that usually occurs within the first 6 months after someone is exposed to the hepatitis C virus. Up to 85% of people who become infected with the hepatitis C virus will develop chronic, or long-term, hepatitis C.

Adverse event (side effect): An unwanted reaction you get from taking a medicine.

Alanine aminotransferase (ALT): A liver enzyme that plays a role in building up and breaking down protein. Healthcare providers check the serum level as part of a liver function test. If your liver cells are damaged, the serum levels of ALT may be high. Hepatitis C can cause your ALT level to go up.

Anemia: A condition in which your blood has a lower-than-normal number of red blood cells. Symptoms include feeling tired, having a shortness of breath, having a headache, and having your heart beat too fast or too slow for no reason.

Antiviral drug: A medicine that fights a virus.

Aspartate aminotransferase (AST): An enzyme normally present in liver, heart muscle, and red blood cells. It is released into the blood when you've been injured (including getting infected with the hepatitis C virus). Higher levels of AST in your blood may mean you have the hepatitis C virus.

Blood transfusion: The transfer of blood from one person into the bloodstream of another person. Before July 1992, people were at risk of getting infected with the hepatitis C virus through blood transfusions. Since then, blood is screened more carefully.

Blood-borne virus: A virus in your blood that can infect someone else through blood-to-blood contact (through shared needles when blood is exchanged, for example).

Body mass index (BMI): A measurement of body fat. It is calculated by the weight of your body and your height. Your healthcare provider can use it to help find out if you are overweight.

Chronic: A permanent or reoccurring disease or condition.

Chronic hepatitis C (CHC): A serious condition that inflames and damages the liver. It can lead to potentially fatal liver diseases, such as cirrhosis, liver failure, and liver cancer. Up to 85% of the people who are infected with the hepatitis C virus will develop chronic, or long-term, hepatitis C.

Cirrhosis: The late stage of liver disease. It's when the liver has scar tissue that has replaced normal liver tissue. As a result, the liver does not have enough blood flowing through it. The liver has fibrosis (scar tissue that has replaced normal liver tissue), and has a bumpy surface from new growth. There are 2 types of cirrhosis—compensated and decompensated:

- *Compensated cirrhosis means that the liver is very scarred but can still do what it is supposed to do. People who have compensated cirrhosis can be treated with hepatitis C medicines*
- *Decompensated cirrhosis (also known as end-stage liver disease) means that the liver is so scarred that it can't work properly. The liver can no longer keep the person healthy. Decompensated cirrhosis is a life-threatening condition*

Clearing the virus (or being cured of the virus): Describes the best result after treating hepatitis C. You are cleared of the virus, or cured of the virus, when no virus is detected in your blood 12 weeks after you finish all treatment. This is also called a **Sustained Virologic Response (SVR)**.

Combination therapy: 2 or more drugs used at the same time to treat a disease or condition.

Direct-acting antiviral (DAA): A type of medicine used in combination with other medicines to treat hepatitis C. It is a class of medicine that you swallow as a pill. DAAs directly target the hepatitis C virus as it multiplies. Also known as HCV inhibitors.

Depression: A state of being when you may have problems concentrating, lose interest in things you once enjoyed, feel guilty or hopeless, or have thoughts about death or suicide.

End-stage liver disease: The last stage of liver disease. It happens when the liver is not getting enough blood flowing through it, when the liver has *fibrosis* (scar tissue that has replaced normal liver tissue), and when it has a bumpy surface from new growth. This disease is also known as *decompensated cirrhosis*, and it can cause death.

Fatty liver: Too much fat in the liver cells. It is the most common type of liver disease in the United States. Having diabetes, being overweight, and eating a diet with too much cholesterol (fat in food), all increase chances for getting fatty liver disease.

Fibrosis: Scar tissue that replaces healthy liver tissue. It can lead to cirrhosis, liver cancer, and even death.

Gastroenterologist: A medical doctor who is an expert on the digestive system, which includes the stomach, intestines, and liver.

Genotype: A virus type that has a special genetic makeup. There are at least 7 genotypes for hepatitis C. In the United States, genotype 1 is the most common: genotypes 2 and 3 are found in a smaller number of people with hepatitis C. Genotypes 4, 5, 6 and 7 are not common in the United States.

Genotype 1: The most common type of the hepatitis C virus in the United States.

Hepatic portal vein: The main vein that carries nutrients from the digestive tract to the liver where the nutrients are processed. Liver disease, such as cirrhosis, increases blood pressure in the portal vein, which can lead to complications and even death.

Hepatitis: Inflammation (swelling) of the liver.

Hepatitis C disease: A liver disease caused by the hepatitis C virus. The hepatitis C virus lives in a person's blood. It inflames and can damage the liver, sometimes without any symptoms. It can only be transmitted through blood-to-blood contact. Hepatitis C is a major public health problem and the leading cause of chronic liver disease in the United States.

Hepatitis C virus: A virus that lives in a person's blood. It inflames and can damage the liver, sometimes without any symptoms. It can only be transmitted through blood-to-blood contact. Hepatitis C is a major public health problem and the leading cause of chronic liver disease. It is also called *hep C* or *HCV*.

Hepatologist: A gastroenterologist who is an expert in treating people with liver diseases, such as hepatitis C.

Interferons: Proteins that our immune system makes to fight viruses and other inflammatory diseases. Interferon can also be a **synthetic** (man-made) medicine. It is an injection and is part of the treatment for hepatitis. One type of interferon is called peginterferon alfa that is often combined with the drug ribavirin. They are both used together to treat hepatitis C, genotypes 2 and 3. Those 2 medicines are also used with another medicine, a DAA (direct-acting antiviral), to treat people who have genotype 1.

Jaundice: A yellow coloring of the skin and eyes. Jaundice can appear when the liver is not working normally. It is also one of the signs of end-stage liver disease.

Liver biopsy: A procedure where a small piece of liver tissue is taken out of the body by a long needle. Healthcare providers then study the tissue under a microscope to see if it is diseased.

Liver cancer: Develops when a cell or group of cells becomes damaged and begins growing in an unusual way. It often causes **liver tumors** (lumps of tissue). People with hepatitis C are at a higher risk of getting liver cancer. Between 1 and 5 people out of every 100 get liver cancer after having cirrhosis. Liver cancer is also called **hepatocellular carcinoma** (HCC).

Liver enzymes: These are proteins that the liver makes to help do some important tasks. We all have some enzymes in our blood, but too many enzymes may be a sign that the liver is damaged or sick.

NS5A Inhibitor: A class of compounds that work by inhibiting or stopping the NS5A enzyme from working, in order to prevent the hepatitis C virus from replicating.

Peginterferon: A type of synthetic interferon. It is given as a weekly injection.

Polymerase inhibitor: A class of compounds that work to inhibit (stop) the polymerase enzyme from working, in order to prevent a virus from multiplying.

Protease inhibitor: A class of compounds that is still being studied. They work to inhibit (stop) the protease enzyme from working, in order to prevent a virus from multiplying.

Prothrombin time (PT): A test that measures blood clotting.

Rapid virological response (RVR): A term used for a blood test results after 4 weeks of treatment that shows that the hepatitis C virus can no longer be detected.

Relapse: An instance in which illness symptoms of a disease return after showing improvement. A relapse of hepatitis C can happen after reducing the virus or after stopping therapy.

Ribavirin (RBV): A medicine used in combination with peginterferon alfa to treat hepatitis C. When used alone, it is not effective in the treatment of hepatitis C.

Ribonucleic acid (RNA): Genetic material. Hepatitis C virus RNA can be detected in the blood within 2 to 3 weeks after a person is infected. After treatment, if a blood test shows no hepatitis C virus RNA, the person is considered clear of the virus.

Support group: Small meetings of people who have hepatitis C. The people share information and help each other deal with the challenges of life and having hepatitis C.

Sustained virologic response (SVR): A term used when the hepatitis C virus does not show up in blood tests taken 12 or 24 weeks after treatment has stopped. SVR is also called “a cure,” or “clearing the virus.”

Undetectable: When the virus can't be detected or found in viral blood tests.

Viral load: A measure of the amount of hepatitis C virus in the blood. Test results are usually written in international units per milliliter (IU/mL).

Virus: A tiny infectious “agent” or “germ” that causes diseases.