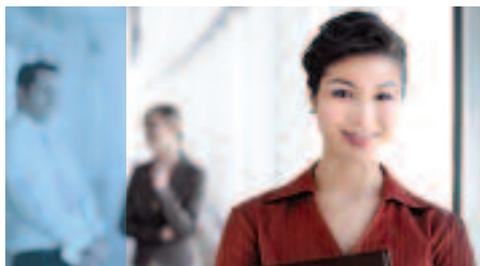


Newly Diagnosed: **HEPATITIS C**

American Liver Foundation Support Guide



Your Liver. Your Life.

The American Liver Foundation's mission is to facilitate, advocate, and promote education, support, and research for the prevention, treatment, and cure of liver disease.

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Introduction

Learning you have hepatitis C can be overwhelming. You may have a lot of questions and may wonder what the first step to take is. You are not alone. Over four million Americans have hepatitis C and the American Liver Foundation (ALF) is here to help. ALF provides individuals who have liver disease with the resources and information they need to care for their livers. Learn as much as you can about your liver, hepatitis C, and the resources available to you. Take steps forward equipped with information and support!

What is hepatitis C?

Hepatitis C is a liver disease caused by the hepatitis C virus (HCV). Hepatitis C is a form of viral hepatitis. Hepatitis A and hepatitis B are other common forms of viral hepatitis. Hepatitis A is transmitted through feces due to poor hygiene or contaminated food or water. Hepatitis B is transmitted through bodily fluids including blood.

HCV is transmitted when someone's blood comes into direct contact with HCV-infected blood. Common modes of transmission include unsafe injection practices, contaminated needles, needle sticks, and blood transfusions prior to July 1992.

HCV causes the liver to swell and prevents it from working well. Acute HCV occurs within six months after exposure and approximately 25% of people with acute HCV fully recover during this time as the virus goes away. About 75% of people with acute HCV develop long-term or chronic HCV.

Chronic HCV can lead to cirrhosis (scarring) of the liver, liver cancer, and liver failure. In the United States, more than 3.2 million people have chronic HCV. Globally, chronic HCV affects approximately 175 million people.



Symptoms of hepatitis C

Many people with acute or chronic HCV have no symptoms. When symptoms do occur, they may include tiredness, itchy skin, dark urine, muscle soreness, nausea, loss of appetite, stomach pain and jaundice (a yellowing of the skin and whites of the eyes). If symptoms occur, they usually appear within two weeks to six months after exposure. It is possible to have HCV for years or even decades without symptoms.

Treatment of hepatitis C

There is treatment available for HCV. Talk to your doctor about your treatment options.

Acute HCV

Doctors often recommend bed rest, drinking lots of fluids, eating a healthy diet and avoiding alcohol. Medicines may be used to treat acute HCV. It is important to see your doctor regularly to have tests done to make sure your body has fully recovered from the virus.

Chronic HCV

It is important to see a doctor who will recommend a treatment or management option that is right for you.

Doctors may recommend taking pegylated alpha interferon and ribavirin for chronic HCV:

- Pegylated alpha interferon is given by injection once a week, usually for six months to a year. Approved in 2005 and available only for adults.
For more information:
<http://www.nlm.nih.gov/medlineplus/druginfo/meds/a605029.html>
- Ribavirin is a pill usually taken twice a day for six months to a year. Ribavirin will not treat hepatitis C unless prescribed with interferon. Approved in 2004 and available only for adults.
For more information:
<http://www.nlm.nih.gov/medlineplus/druginfo/meds/a605018.html>

Two new oral medications that are protease inhibitors, Boceprevir and Telaprevir, were approved by the Food and Drug Administration (FDA) in May 2011 for patients with hepatitis C genotype 1. They will be used in combination with pegylated interferon and ribavirin. Boceprevir and Telaprevir cannot be taken together and are not monotherapies.

- Boceprevir FDA approval:
<http://www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/ucm255413.htm>
- Telaprevir FDA approval:
<http://www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/ucm256328.htm>

Pregnant women should not take these medicines as they may cause birth defects in babies.

The type and length of treatment can vary based on the patient's genotype. Genotypes refer to different strains of a virus. HCV genotypes are 1 (1a and 1b), 2, 3, 4, 5, and 6. About 75% of people with HCV in the United States have either genotype 1a or 1b. Between ten and twenty percent of people with HCV in the United States have either genotype 2 or 3.

These medicines may not work for all people with HCV and not everyone with HCV is eligible for treatment because of risks such as side effects and potential complications with other conditions. Individuals taking these medicines need to be monitored by their doctors.

Hepatitis C can lead to liver scarring (cirrhosis) or liver cancer. It is important to talk to your doctor about being screened for liver cancer every 6-12 months. Also, talk to your doctor about hepatitis A and hepatitis B vaccines.



Living with hepatitis C

It is possible for people with HCV to live healthy, active lives. You can take steps to keep yourself and those around you healthy.

What steps can be taken to prevent transmitting hepatitis C to others?

There is no vaccine to prevent HCV. The only way to stop the spread of HCV is to avoid direct contact with infected blood.

- Do not share needles
- Use recommended safety measures if you are exposed to blood or needle sticks
- Practice safe sex
- Use clean needles and equipment for tattoos or body piercings
- Do not share razors, toothbrushes, or other personal items with others
- Wear gloves if you have to touch someone's blood

HCV is not spread by sharing eating utensils, hugging, kissing, holding hands, coughing, or sneezing. It also is not spread through food or water.

Can I transmit hepatitis C sexually?

Yes, it is possible to transmit HCV sexually. HCV is transmitted when someone's blood comes into direct contact with HCV-infected blood. The risk of transmission from sexual contact is believed to be low. However, having multiple sex partners, a sexually transmitted disease, HIV, or engaging in rough sex can increase the risk of transmission. You can prevent transmitting HCV sexually by practicing safe sex.

Can I transmit hepatitis C to my baby?

Yes, it is possible to transmit HCV to your baby during childbirth. The risk of transmission is believed to be low. About 4 of every 100 infants born to mothers with HCV become infected with HCV. Mothers who have HCV and HIV are at greater risk of transmitting HCV to their babies.

HCV is not transmitted by breastfeeding. However, women who have cracked or bleeding nipples are advised to temporarily stop breastfeeding until the nipple is healed and is no longer bleeding.

How do I know if treatment is the best option for me?

The first step is to talk to your doctor to learn if current HCV medications are an option for you. Not everyone with HCV is eligible for treatment because of risks such as side effects and potential complications with other conditions.

If treatment is the right option for you, the next step is for you to decide with your loved ones about it. HCV treatment usually lasts for one year and can cause strong side effects, which may lead to needing assistance from family and friends to complete day to day activities. Some people on HCV treatment may need to take extra time off from work or may not be able to work at all during this time.

If treatment is not an option for you, talk to your doctor about other steps you can take to manage your hepatitis C. It is important to see your doctor regularly and have your hepatitis C monitored even if you are not experiencing symptoms or undergoing treatment.

What are the potential outcomes of hepatitis C treatment?

The potential outcomes of treatment are:

- Sustained virologic response (SVR) – Treatment for hepatitis C is considered successful when HCV cannot be detected in the body six months after the medication has been completed. This is called sustained virologic response (also known as SVR).
- Improved response, but no SVR – The amount of HCV in the body is significantly lower than before treatment, but HCV is detectable in the body.
- No response – The medications had minimal or no effect.
- Incomplete treatment – Treatment ended earlier than the prescribed duration.



Once I start medical treatment for hepatitis C, do I have to finish it?

Your doctor will discuss with you the importance of completing treatment (full duration and appropriate dose) to enable the medications to work best. However, serious side effects and complications with other health conditions may require you to stop treatment. With the current standard treatment of pegylated interferon and ribavirin, it is possible to repeat treatment, if unsuccessful the first time.

Boceprevir and Telaprevir are different types of medications from pegylated interferon and ribavirin. If Boceprevir and Telaprevir are not taken for the recommended period of time at the correct dosage, individuals can develop resistance to HCV treatment that prevents similar future treatments from working.

Can people with chronic hepatitis C continue to work and do everyday activities?

People with chronic HCV can continue to work and perform everyday activities. The Centers for Disease Control and Prevention's recommendations state that people should not be excluded from work, school, play, child care, or other settings because they have HCV.

People with chronic HCV can take the following steps to take care of their livers:

- Eat healthy meals
- Exercise
- Rest when tired

- Take only the medications recommended by a healthcare professional
- Avoid alcohol and drugs
- See a liver doctor regularly (hepatologist or gastroenterologist)
- Keep all medical appointments
- Talk to a healthcare professional about hepatitis A and hepatitis B vaccines
- Be screened for liver cancer regularly

What are the possible complications of chronic hepatitis C?

Chronic HCV is a serious disease that can result in long-term health problems, including liver damage, liver failure, liver cancer, or even death. HCV is the leading cause of cirrhosis and liver cancer and the most common reason for liver transplantation in the United States. Approximately 10,000 people die every year from HCV-related liver disease.

What is the outlook for people with chronic hepatitis C?

The effects of chronic HCV vary greatly from individual to individual. Some people with chronic HCV can go decades without liver injury, while others progress to more severe disease including liver scarring (cirrhosis), liver failure, or liver cancer during this time.

Glossary

The following is a list of hepatitis C-related terms you may hear or read about:

Antibody: An antibody is a protein found in the blood that is made by the body to fight germs such as viruses or bacteria. Antibodies can be a result of receiving a vaccine or coming into contact with a virus. They protect the body against future infections.

Ascites: Ascites is the build up of fluid in the abdomen that can occur due to liver failure, cirrhosis and liver cancer.

Cirrhosis: Cirrhosis is extensive scarring of the liver — hard scar tissue replaces soft healthy tissue. Severe scarring of the liver can prevent the liver from working well.

Clinical trial: A clinical trial is a medical research study conducted to find answers to health questions. Clinical trials often are conducted to evaluate new medications, combinations of medications, or new ways to use current treatments. Also, clinical trials are conducted to evaluate new tests, equipment, and procedures for diagnosing and detecting health conditions and to find vaccines to prevent illnesses.

Edema: Edema is the build up of fluid in the legs that can occur due to liver failure, cirrhosis, and liver cancer.

Fibrosis: Fibrosis is the initial scarring of the liver.

Gastroenterologist: A gastroenterologist is a doctor who specializes in the study of digestive organs including the liver.

Genotype: A genotype is the genetic makeup of a cell, an organism, or an individual. In the study of liver diseases, the term genotype is used often to describe different strains of viruses.

Hepatitis: Hepatitis means “inflammation of the liver.”

Hepatitis A: Hepatitis A is a liver disease caused by the hepatitis A virus (HAV). HAV causes the liver to swell and prevents it from working well. HAV is passed from person to person through fecal matter. Most often it is transmitted because of poor hand washing after using the bathroom or changing a diaper, or before preparing and eating food.

Hepatitis B: Hepatitis B is a liver disease caused by the hepatitis B virus (HBV). HBV causes the liver to swell and prevents it from working well. HBV is passed from person to person through bodily fluids such as blood, semen, or vaginal secretions. Most often it is transmitted through sexual contact or from an infected mother to her infant during birth.

Hepatitis C: Hepatitis C is a liver disease caused by the hepatitis C virus (HCV). HCV causes the liver to swell and prevents it from working well. HCV is passed from person to person by blood. It is most often transmitted when a person's blood comes into direct contact with infected blood.

Hepatitis C antibody tests: Hepatitis C antibody tests detect the presence of HCV antibodies in a blood sample; the following tests are used to detect HCV antibodies:

- **ELISA (enzyme-linked immunosorbent assay):** a blood test used to detect antibodies in the blood
- **RIBA (recombinant immunoblot assay):** a blood test used to confirm antibodies in the blood after an ELISA test indicated a positive result for antibodies

Hepatitis C RNA: Hepatitis C RNA indicates a high level of HCV replication. It is used to help determine how a doctor will treat a patient with chronic HCV infection.

Hepatologist: A hepatologist is a doctor who specializes in the study of the liver.

Interferon: Interferon is a protein used by the body to fight infection. It is prescribed as an injected medication for people with hepatitis B and hepatitis C.

Jaundice: Jaundice is the yellowing of the skin and white part of the eyes.

Liver: The liver is the second largest organ in your body. It processes what you eat and drink into energy and nutrients your body can use. The liver also removes harmful substances from your blood.



Glossary *continued*

Liver biopsy: A liver biopsy is a medical procedure used to remove a small piece of liver tissue that is studied in the lab to determine the liver's condition.

Liver cancer: Liver cancer is the growth and spread of unhealthy cells in the liver.

Liver failure: Liver failure is the inability of the liver to function and perform its jobs.

Liver function tests: Liver function tests help check the liver's health and detect liver damage. These blood tests measure the levels of certain proteins and enzymes in the blood.

- **ALT:** Alanine transaminase (ALT) is an enzyme mainly found in the liver. The ALT test measures the level of ALT in the blood. Consistently high levels of ALT can be a sign of liver damage.
- **AST:** Aspartate transaminase (AST) is an enzyme found in large amounts in the liver and other parts of the body. The AST test measures the level of AST in the blood. High levels of AST can be a sign of liver damage.

Liver transplant: A liver transplant is the process of replacing a sick liver with a donated, healthy liver.

Ribavirin: Ribavirin is an oral medication that is prescribed together with interferon for some people with hepatitis C.

Sustained virologic response: Sustained virologic response (SVR) is a person's successful response to antiviral medications when the virus is not present in the blood six months after treatment has been completed.

Vaccine: A vaccine is a medication that stimulates the production of antibodies to protect against a specific disease.

Viral load: A viral load is the amount of a virus, such as hepatitis B or hepatitis C virus, in the blood.

Questions to ask your healthcare provider

Having a list of questions to ask a healthcare provider during an appointment can be a helpful tool to remember the important questions to ask. Be sure to bring a pen, this sheet and the notes pages at the end of the guide, or other device (notebook, phone) to write down the answers.

1. Do I have acute or chronic hepatitis C?
2. What is my current virus level? What does that mean?
3. What is my genotype? What does my genotype mean?
4. Do I have liver damage? If so, how much liver damage is there?
5. Do you recommend treatment? What treatment do you recommend? What do I need to know about my treatment?
6. Do I need to start treatment for hepatitis C now?
7. How will this treatment interact with my other medications?
8. How will you assess whether the treatment is working for me?
9. What should I do if I have side effects? How can I manage the side effects?
10. What are symptoms to pay attention to and look out for?
11. Do I need to be vaccinated for hepatitis A and hepatitis B?
12. How likely is it that I will develop cirrhosis or liver cancer?
13. If I do not start treatment now, how often should my liver be monitored for liver damage?
14. What medications or other substances should I avoid?
15. Does my family need to be tested for hepatitis C? Should they be vaccinated for hepatitis A and hepatitis B?
16. How often should I see a liver specialist? Primary care physician?



Resources

The following is a list of resources you might find helpful:

Hepatitis C Information

- American Association for the Study of Liver Diseases:
<http://www.aasld.org/patients/Pages/default.aspx>
Phone: 703-299-9766
- American Liver Foundation:
<http://www.liverfoundation.org/abouttheliver/info/hepatitisc/>
Phone: 800-465-4837 (800-GO-LIVER)
- Centers for Disease Control and Prevention:
<http://www.cdc.gov/hepatitis/C/index.htm>
Phone: 800-232-4636 (800-CDC-INFO)
TTY: 888-232-6348
- Hepatitis Foundation International:
<http://www.hepfi.org/education/index.htm>
Phone: 800-891-0707
- HCV Advocate:
<http://www.hcvadvocate.org/hepatitis/factsheets.asp>
- National Institutes of Health:
http://digestive.niddk.nih.gov/ddiseases/pubs/hepc_ez/
Phone: 800-891-5389
TTY: 866-569-1162
- Parents of Kids with Infectious Diseases (PKIDS):
http://www.pkids.org/dis_hep.php
Phone: 877-557-5437 (877-55-PKIDS)

Medical Referrals

- American Association for the Study of Liver Diseases:
<http://www.aasld.org/patients/Pages/PhysicianReferralService.aspx>
Phone: 703-299-9766
- American College of Gastroenterology:
<http://www.acg.gi.org/patients/phylocator.asp>
Phone: 301-263-9000
- American Liver Foundation:
<http://www.liverfoundation.org/chapters/>
Phone: 800-465-4837 (800-GO-LIVER)
- Hepatitis B Foundation:
http://www.hepb.org/resources/liver_specialist_directory.htm
Phone: 215-489-4900
- Hepatitis Foundation International:
http://www.hepfi.org/support/support_physician.html
Phone: 800-891-0707
- Medicare:
<http://www.medicare.gov/find-a-doctor/provider-search.aspx>
Phone: 800-633-4227 (800-MEDICARE)
TTY/TDD: 877-486-2048



Resources *continued*

Medication Assistance Programs

- Chronic Disease Fund:
<http://www.cdfund.org/>
Phone: 877-968-7233

- Healthwell Foundation:
<http://www.healthwellfoundation.org/>
Phone: 800-675-8416

- Needy Meds:
<http://www.needymeds.org/>

- Partnership for Prescription Assistance:
<http://www.pparx.org/>
Phone: 888-477-2669 (888-4PPA-NOW)

- Patient Access Network Foundation:
<https://www.panfoundation.org/>
Phone: 866-316-7263

- Together Rx Access:
<http://www.togetherrxaccess.com/Tx/jsp/home.jsp>
Phone: 800-444-4106

ALF Support Services

- National helpline: 800-465-4837 (800-GO-LIVER)
- Support guides:
<http://www.liverfoundation.org/>
- Resource referrals: 800-465-4837 (800-GO-LIVER)
- Online support communities:
<http://www.liverfoundation.org/>

Clinical Trials

- NIH hepatitis C clinical trials:
<http://clinicaltrials.gov/ct2/results?term=hepatitis+C>

Research

- NIH PubMed hepatitis C search:
<http://www.ncbi.nlm.nih.gov/sites/entrez>



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www.liverfoundation.org

1-800-GO-LIVER

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Read more at www.allabouthepc.com.