



Your Liver. Your Life.

Newly Diagnosed Hepatitis B



American Liver Foundation Support Guide

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Newly Diagnosed: Hepatitis B

Learning you have hepatitis B can be overwhelming. You may have a lot of questions and may wonder what the first step to take is. You are not alone. 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 B, and the resources available to you. Take steps forward equipped with information and support!

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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Hepatitis B

Hepatitis B is a liver disease caused by the hepatitis B virus (HBV). Hepatitis B is transmitted by direct contact with an infected person's bodily fluid (blood, semen, or vaginal secretions). Common modes of transmission include unprotected sex, mother to child during birth, unsafe injection practices, contaminated needles and needle sticks.

HBV causes the liver to swell and prevents it from working well. About 95% of adults who are exposed to HBV fully recover within 6 months (acute hepatitis B) without medication. About 5% become infected with HBV (chronic hepatitis B). Infants born to mothers infected with HBV are at high risk of developing chronic HBV infection.

Chronic hepatitis B can lead to cirrhosis (scarring) of the liver, liver cancer, and liver failure. In the United States, more than 1 million people have chronic HBV infection. Globally, chronic HBV infection affects approximately 350 million people and contributes to an estimated 620,000 deaths each year.

Symptoms of hepatitis B

Many people with acute or chronic hepatitis B have no symptoms. When symptoms do occur, they may include tiredness, fever, loss of appetite, nausea, headache, muscle soreness, pain near the liver, and jaundice (yellowing of the skin and whites of the eyes). Symptoms often begin two to five months after acute infection. Symptoms usually last for several weeks, but can last up to six months.

Treatment of hepatitis B

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

Acute hepatitis B

Doctors often recommend bed rest, drinking lots of fluids, eating a healthy diet and avoiding alcohol. Medicines are not used to treat acute hepatitis B. It is important to see your doctor regularly to make sure your body has fully recovered from the virus.

Chronic hepatitis B

Treatment options for chronic HBV include oral medications such as adefovir dipivoxil, entecavir, interferon alfa 2a, lamivudine, telbivudine, tenofovir, and peginterferon alfa 2a, which is given by injection.

Hepatitis B medications should not be taken by pregnant women unless recommended by their

doctors. Some pregnant women with HBV may be treated to prevent transmitting HBV to their babies.

The following is a list of commonly prescribed medicines for individuals with chronic HBV:

Oral Medications

- Adefovir dipivoxil (Hepsera) is a pill taken once a day for at least one year or longer. Approved in 2002 for adults. Pediatric clinical trials are in progress. For more information: <http://www.nlm.nih.gov/medlineplus/druginfo/meds/a605024.html>.
- Entecavir (Baraclude) is a pill taken once a day for at least one year or longer. Approved in 2005 for adults. Pediatric clinical trials are in progress. For more information: <http://www.nlm.nih.gov/medlineplus/druginfo/meds/a605028.html>.
- Interferon alfa 2b (Intron A) is given by injection several times a week for six months to a year, or sometimes longer. Approved in 1991 and available for both children and adults. For more information: <http://www.nlm.nih.gov/medlineplus/druginfo/meds/a690006.html>.
- Lamivudine (Epivir-HBV, Zeffix, or Heptodin) is a pill that is taken once a day for at least one year. Approved in 1998 and available for both children and adults. For more information: <http://www.nlm.nih.gov/medlineplus/druginfo/meds/a696011.html>.
- Telbivudine (Tyzeka, Sebivo) is a pill taken once a day for at least one year or longer. Approved in 2006 for adults. For more information: <http://www.nlm.nih.gov/medlineplus/druginfo/meds/a607045.html>.
- Tenofovir (Viread) is a pill taken once a day for at least one year. Approved in 2008 for adults. For more information: <http://www.nlm.nih.gov/medlineplus/druginfo/meds/a602018.html>.

Injection Medications

- Peginterferon alpha 2a (Pegasys) 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>.

These medicines may need to be taken long-term, and may not work for all people with hepatitis B. People taking these medicines need to be monitored for side effects by their doctors.

If you have HBV, it is important to talk to your doctor about treatment options and to discuss the need for regular liver cancer screenings. Also, talk to your doctor about the hepatitis A vaccine.

Living with hepatitis B

It is possible for people with hepatitis B to live healthy, active lives. You can take steps to keep yourself and those around you healthy. Talk to your doctor about treatment options and diet recommendations.

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

Hepatitis B vaccination in people who have not been exposed to HBV is the best way to prevent infection. Other ways to stop the spread of HBV are:

- Get tested if you are pregnant or want to become pregnant
- Do not share needles
- Practice safer sex
- Do not share razors, toothbrushes, or other personal items
- Do not donate blood, organs, or tissue
- Use only clean needles and equipment for tattoos or body piercings
- Tell your doctors, dentists, and other healthcare providers

Can I transmit hepatitis B sexually?

Yes, it is possible to transmit hepatitis B sexually. Hepatitis B is transmitted by contact with infected bodily fluid (blood, semen, and vaginal secretions). Among adults in the U.S, hepatitis B is most commonly spread through sexual contact and accounts for nearly two-thirds of acute hepatitis B cases. You can help to prevent transmitting hepatitis B sexually by practicing safer sex. It is important to talk to your healthcare provider about whether your partner should be vaccinated for hepatitis B.

What is the hepatitis B vaccine?

The hepatitis B vaccine is a series of three shots to protect the human body against HBV. After the vaccine is given, the body makes antibodies that protect a person against HBV. An antibody is a substance in the blood that is made by the body to fight a virus or bacteria. These antibodies are stored in the body and will fight the infection if a person is exposed to HBV in the future. The hepatitis B vaccine is given in 3 doses. The first 2 doses are given one month apart and the final dose is given 6 months later.

Can I transmit hepatitis B to my baby?

Yes, it is possible to transmit hepatitis B to your baby during childbirth. However, HBV transmission to babies can be prevented through a series of vaccinations and hepatitis B immune globulin that are given at birth. Hepatitis B immune globulin is a medication that is given after a person has been exposed to infected blood or bodily fluids to prevent hepatitis B infection. Without vaccination, babies born to women with HBV can develop chronic HBV, which can lead to serious health problems.

Can people with chronic hepatitis B continue to work and lead healthy, active lives?

People with chronic HBV can continue to work and perform everyday activities. The Centers for Disease Control and Prevention's recommendations for HBV prevention and control state that people should not be excluded from work, school, play, child care, or other settings because they have hepatitis B. People with chronic hepatitis B can take the following steps to take care of their liver:

- Be monitored regularly by a healthcare provider
- Check with a health professional before taking any prescription or over-the-counter medications, vitamins, or supplements
- Avoid alcohol
- Eat a healthy diet

What are the possible complications of chronic hepatitis B?

Chronic hepatitis B is a serious disease that can result in long-term health problems, including liver damage, liver failure, liver cancer, or even death. Approximately 2,000 to 4,000 people in the U.S. die every year from hepatitis B-related liver disease.

What is the outlook for people with chronic hepatitis B?

The majority of people with chronic hepatitis B feel healthy their entire lives and do not experience ongoing liver damage. However, in some people with chronic hepatitis B, the infection causes liver damage and liver scarring (cirrhosis), liver failure, or liver cancer develops. It is important for people with chronic hepatitis B to be screened for liver cancer every 6-12 months as liver cancer can develop in those with chronic hepatitis B without liver scarring or liver damage.

Glossary

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

Antibody: An antibody is a protein 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.

HBeAg: HBeAg indicates a high level of HBV replication. It is used to help determine how a doctor will treat a patient with chronic HBV infection.

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 B blood panel: A hepatitis B blood panel usually is made up of the following three hepatitis B tests:

Hepatitis B surface antigen (HBsAg): HBsAg is the surface protein of the hepatitis B virus that is used to detect infection. If this blood test is positive, then the hepatitis B virus is present.

Hepatitis B surface antibody (HBsAb): HBsAb is the antibody formed in the blood of someone who has the hepatitis B virus. It can be produced in response to vaccination or recovery from hepatitis B infection. If this test is positive, then the immune system has successfully developed an antibody to protect the body from the hepatitis B virus.

Hepatitis B core antibody (HBcAb): HBcAb refers to a specific part of the hepatitis B virus. This test is often used by blood banks to screen blood donations. A positive test result means a person may have been exposed to the hepatitis B virus and requires additional confirmation.

Hepatitis B immune globulin (HBIG): Hepatitis B immune globulin is a medication that is given after a person has been exposed to infected blood or bodily fluids to prevent hepatitis B.

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.

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

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.

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. Proteins are large molecules that make sure the body's organs function properly. Enzymes are protein cells that help important chemical reactions to occur in the body.

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 swelling or injury.

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.

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

Resources

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

Hepatitis B 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/education/info/hepatitisb/>
Phone: 800-465-4837 (800-GO-LIVER)
- Centers for Disease Control and Prevention:
<http://www.cdc.gov/hepatitis/HepatitisB.htm>
Phone: 800-232-4636 (800-CDC-INFO) TTY: 888-232-6348
- Hepatitis B Foundation: http://www.hepb.org/learning_guide/index.htm
Phone: 215-489-4900
- Hepatitis Foundation International: <http://www.hepfi.org/education/index.htm>
Phone: 800-891-0707
- HBV Advocate: <http://www.hbvadvocate.org/hepatitis/factsheets.asp>
- Immunization Action Coalition: <http://www.vaccineinformation.org/hepb/qandadis.asp>
Phone: 651-647-9009
- National Institutes of Health: http://digestive.niddk.nih.gov/ddiseases/pubs/hepb_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

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 B clinical trials:
<http://clinicaltrials.gov/search/open/condition=%22Hepatitis+B%22>

Research

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

Notes

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