HEPATITIS B

INFORMATION GUIDE
If you have been diagnosed with hepatitis B, you are not alone. In fact, nearly 1 in 3 people worldwide will be infected with the hepatitis B virus in their lifetime. We know a hepatitis B diagnosis can be confusing, overwhelming, and distressing. We are here to help. We hope this guide will answer some of your questions and help you navigate living a healthy life with hepatitis B.

How to use this guide:

- Understand your diagnosis
- Find helpful resources
- Find support and connect with others
- Encourage others to get tested
- Get your questions answered
- Understand treatment options

Do you have additional questions or recommendations for this guide? Contact info@hepb.org
Knowing whether your hepatitis B is acute or chronic will help you and your doctor determine the next steps. When someone is first infected with hep B, it is considered an acute infection. Most healthy adults who are acutely infected are able to get rid of the virus on their own. If you continue to test positive for hepatitis B after 6 months, it is considered a chronic infection.

If you have been diagnosed with chronic hep B, it is important to find a doctor that has knowledge in treating liver disease. The Hepatitis B Foundation has a searchable physician directory to help you find a liver specialist near you.

Hepatitis B can be transmitted to others through blood and sexual contact. There is a safe and effective vaccine that can protect your loved ones from hep B.
Hepatitis B- What is it?

What does it do?

Hep B is the world’s most common liver infection. Almost **300 million** people are living with chronic hep B infections across the world.

- **A virus infects its host by attaching to the host cell and penetrating the cell wall or membrane.**
- **The virus’s genetic instructions is injected into the host cell.**
- **The virus hijacks the host cell’s machinery, forcing it to replicate and produce the virus.**

How does it spread?

- Mother to child transmission
- Unprotected sex
- Injection drug use
- Unsafe injections and medical procedures
- Contaminated blood and bodily fluids

Source: [https://www.nature.com/scitable/definition/virus-308/](https://www.nature.com/scitable/definition/virus-308/)
Addressing Myths

Is hep B spread by sharing food, bowls, utensils or chopsticks?

A. Hep B is NOT spread by sharing meals or food prepared by someone with hep B.

Is hepB spread by all body fluids?

A. Hep B is NOT spread by kissing, hugging, shaking hands, sweat, or saliva.

Can I get married or be in a relationship if I have hep B?

A. YES! People with hep B can get married & have children.

Can I have children without giving them hep B?

A. Yes, make sure your baby gets the HepB birth dose within 24 hours of delivery and then completes the vaccine series.

How can I prevent spreading Hep B to my sexual partner?

A. Ask your partner to be tested for hep B, if negative, use protection (condoms) until the vaccine is complete!
LIVING WITH HEPATITIS B: STAY HEALTHY!

Did you know? Everything you eat, drink, breathe or even absorb through the skin is eventually filtered by the liver. Here are some tips to make your life more liver-friendly.

KEEP YOUR LIVER HAPPY!

Schedule regular visits with your healthcare provider to keep yourself and your liver healthy.

Get the Hepatitis A vaccine to protect yourself from another virus that attacks the liver.

Avoid drinking alcohol and smoking since both will hurt your liver.

Tell your provider about herbal remedies or vitamins you take because some could affect your hep B medications or even damage your liver.

Tell your pharmacist about all medications you take (even over the counter) since most medications are processed through the liver. Remember to take your medicine on time!

Eat more fruit, whole grains, fish, lean meats, and LOTS of vegetables especially cabbage, broccoli, and cauliflower.

Limit foods and drinks with added sugar (like soda, juice & packaged snacks) or saturated fats (like fatty cuts of meat & fried food).

Check for mold on nuts and grains, especially if kept damp and unsealed since certain molds (like aflatoxins) are risk for liver cancer.

Avoid raw or undercooked shellfish (like clams, mussels, oysters and scallops) which may be contaminated with bacteria (vibrio vulnificus) which can hurt the liver.

Cook for mold on nuts and grains, especially if kept damp and unsealed since certain molds (like aflatoxins) are risk for liver cancer.

Reduce your stress levels by eating healthy foods, exercising regularly, and getting plenty of rest.

More resources
Understanding Your Hepatitis B Blood Tests

Hepatitis B Virus
Baltimore Group VII (dsDNA-RT)

Quantitative Hepatitis B Surface Antigen/qHBsAg
This blood test measures the amount of hepatitis B surface antigen in the blood. When used in combination with the HBV DNA test, qHBsAg can provide a liver specialist with additional insights to an individual's HBV infection. It can also be used in predicting and monitoring treatment response.

E antigen or HBeAg:
A negative test result means the virus may not be actively reproducing in the liver. In general, a person is considered very infectious when this test is positive, and less infectious when this test is negative.

HBsAg (Hepatitis B surface antigen)
A "positive" or "reactive" HBsAg test result means that the person is infected with hepatitis B. This test can detect the actual presence of the hepatitis B virus (called the "surface antigen") in your blood.

HBV DNA
This test measures the amount of hepatitis B DNA in the blood, which tells how actively the virus is replicating.

Understanding your hepatitis B blood test results can be confusing. It is important to talk to your doctor so you understand your test results and your hepatitis B status. This fact sheet can help you understand and answer questions about what your blood tests mean and if you are infected, protected or at risk for hepatitis B. Be sure to ask for a printed copy of any blood tests so you can understand your results.
Managing Hepatitis B

If you have chronic hepatitis B infection, your provider should monitor your hepatitis B infection and the health of your liver with **regular check-ups every 3 to 6 months**, using the following tests:

- Physical exam
- Blood tests for liver enzymes
- Blood tests indicating liver function
- Blood tests for liver cancer screening
- Blood tests for hepatitis B markers
- Complete Blood Count (CBC)
- Imaging studies of the liver

### Liver Enzymes

These blood tests measure potential liver damage caused by the hepatitis B virus. When the liver is injured, the liver enzymes can leak into the bloodstream. The larger the number, the greater the potential liver damage.

### Alanine Aminotransferase (ALT or SGPT)

This enzyme is monitored closely with a hepatitis B infection and is found almost exclusively in the liver. This test is useful in deciding whether a person would benefit from treatment or for evaluating how well a person is responding to treatment.

### Alpha-Feto Protein (AFP)

This blood test is used to screen for the development of primary liver cancer in those living with chronic hepatitis B and should be tested at every visit for this. If an individual does have elevated AFP, then more tests and imaging studies should be ordered.

### Imaging Studies of the Liver

Your doctor may order an ultrasound, FibroTest, or transient elastography to evaluate or monitor liver damage (e.g., inflammation, fibrosis, cirrhosis) and to screen for primary liver cancer. Be sure to talk to your doctor about liver cancer screening. Generally, imaging of the liver and blood tests at least every 6-12 months is recommended.

More Resources
Talking to your provider - Questions to ask

- **What kind of hepatitis B infection do I have: a new "acute" infection or a "chronic" infection?**

  A new infection is one that has recently occurred and is called an **acute infection**. This means you were recently exposed to hepatitis B. Most adults who are exposed to hepatitis B (about 90% of them) are able to recover from the acute infection. The acute infection generally lasts less than 6 months. There is no specific treatment for people who have acute infection. **Chronic infection** is one that has been in your body for more than 6 months. Chronic infection is a lifelong infection that will require monitoring your liver health at least every 6-12 months with a liver specialist.

- **Where can I get my family, spouse or sexual partner tested and vaccinated for hepatitis B? What do I need to do to protect them until they are completely vaccinated?**

  Your household members and sexual partners should be tested for hepatitis B. Ask your doctor for local clinics or you can tell your household members or partners to talk to their primary care doctors and ask to be tested for hepatitis B.

- **Am I a good candidate for treatment? If not, why not? If yes, please explain why and tell me about the treatment options?**

  **Not everyone is a good fit for hepatitis B treatment.** Treatment for hepatitis B is based on many things, including age, family history, liver enzyme test results, hepatitis B DNA levels, and other things. Talk to your doctor to see if treatment is right for you. Keep in mind that currently, **treatment is a long-term commitment**, and you should expect to be on treatment for the rest of your life or until a cure is available.

- **If I am not eligible for medical treatment, what do I need to do to monitor my hepatitis B?**

  **People on treatment and not on treatment need monitoring for hepatitis B.** Monitoring for hepatitis B could include HBV DNA testing, ALT testing, and ultrasound or some type of imaging of the liver.

- **Could you tell me about clinical trials? Do you offer any clinical trials for hepatitis B? If so, could you please explain them to me?**

  Every drug must go through a testing process, which involves three phases of clinical trials, to evaluate its safety and effectiveness before being approved. Volunteering for a clinical trial program can be very beneficial to the patient and very valuable to research, and other patients.
Talking to your provider- questions to ask

- **If I want to have children, should I wait to start treatment? If I need to start treatment now, at what point can I consider having children?**

If you test positive for hepatitis B infection while pregnant, your doctor also should do a hepatitis B viral load blood test (HBV DNA) during your pregnancy. In some cases, the laboratory test results may show a very high viral load. In these cases, your physician may recommend that you take an oral antiviral drug in your third trimester to reduce the risk of infecting your newborn at birth. Your baby will need a hepatitis B birth dose within the first 24 hours of birth followed by childhood immunizations (at least 2 doses of hepatitis B vaccine) within their first year of life. This can prevent hepatitis B transmission during the birthing process.

- **Here are the names of the medications that I currently take – are they safe for my liver?**

The liver is one of the most important organs in our bodies and can absorb medications you might take. It is important that your doctor is aware of any medications you are taking, particularly if you have hepatitis B because it impacts your liver. Bring a list of all medications (herbals, vitamins, included) to your doctor so they know what you are taking.

- **What over the counter medications or herbal supplements can I safely take for pain, cold symptoms, etc.?**

Many people are interested in using herbal remedies or supplements to boost their immune systems and help their livers. The problem is that there is no regulation of companies manufacturing these products, which means there is no rigorous testing for safety or purity. So the quality of the herbal remedy or vitamin supplement may be different from bottle to bottle. Some herbal remedies could interfere with your prescription drugs for hepatitis B or other conditions; some can even actually damage your liver. Talk to your doctor first before starting herbals.

- **Should I be tested for other liver diseases, such as hepatitis C or D?**

Yes, it is recommended that if you test positive for hepatitis B, you also get tested for hepatitis C and hepatitis D or Delta. These are simple blood tests that can be done at your doctor’s office.

- **Should I be vaccinated to protect myself against hepatitis A?**

Yes, the hepatitis A vaccine is recommended for people with hepatitis B. Ask your doctor about getting the hepatitis A vaccine today.

More Resources
There is medicine for both adults and children that control the hep B virus, which helps reduce the risk of developing more serious liver disease, but there is still no complete cure for hepatitis B.

Current treatments for hepatitis B fall into two general categories:

**Immune modulator Drugs** — These are interferon-type drugs that boost the immune system to help get rid of the hepatitis B virus. They are given as a shot (similar to how insulin is given to people with diabetes) over 6 months to 1 year.

**Antiviral Drugs** — These are drugs that stop or slow down the hepatitis B virus from reproducing, which reduces the inflammation and damage of your liver. These are taken as a pill once a day for at least 1 year and usually longer.

It is important to know that not everyone with chronic hepatitis B infection needs to be treated. This can be difficult to accept when first diagnosed because taking a drug to get rid of the virus seems like the first step to getting better.

<table>
<thead>
<tr>
<th>Medication Name</th>
<th>Year Approved</th>
<th>Description</th>
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<tbody>
<tr>
<td>Tenofovir disoproxil (Viread)</td>
<td>2008</td>
<td>a pill taken once a day, with few side effects, for at least one year or longer. This is considered a first-line treatment with an excellent resistance profile</td>
</tr>
<tr>
<td>Tenofovir alafenamide (Vemlidy)</td>
<td>2016</td>
<td>a pill taken once a day, with few side effects, for at least one year or longer. This is considered a first-line treatment with an excellent resistance profile</td>
</tr>
<tr>
<td>Entecavir (Baraclude)</td>
<td>2005</td>
<td>a pill taken once a day, with few side effects, for at least one year or longer. This is considered a first-line treatment with an excellent resistance profile</td>
</tr>
<tr>
<td>Telbivudine (Tyzeka or Sebivo)</td>
<td>2006</td>
<td>a pill taken once a day, with few side effects, for at least one year or longer. This is considered a second-line treatment option</td>
</tr>
<tr>
<td>Adefovir Dipivoxil (Hepsera)</td>
<td>2002</td>
<td>a pill taken once a day, with few side effects, for at least one year or longer. This is considered a second-line treatment option and patients must have their kidney function monitored regularly</td>
</tr>
<tr>
<td>Lamivudine (Epivir-HBV, Zeffix, or Heptodin)</td>
<td>1998</td>
<td>a pill that is taken once a day, with few side effects, for at least one year or longer. This is generally not used in the U.S. because it is less potent than the newer drugs and most people develop drug resistance within a year or two</td>
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**More Resources:**

If you live in the United States and need help to pay for your hep B medication, learn more about patient assistance programs here.
LIVING WITH HEPATITIS B: HAVE A HEALTHY SEX LIFE

Although hep B may change your relationship and approach to sex, your diagnosis doesn’t mean you can’t have intimacy. There are ways to make sure that you and your partner(s) stay safe in bed, while making sure everyone still has a good time.

MOST IMPORTANTLY: PRACTICE SAFE SEX

KNOW YOUR STATUS

- It can be an awkward conversation, but to keep your loved and not-so-loved ones safe, you should tell any sex partners that you have hep B. Find tips online about how to talk about it.
- Know your partner’s status. This can be an awkward conversation, but it should also happen. Talk to your sexual partner and encourage them to get regularly tested for sexually transmitted infections (STIs). Make sure they are vaccinated against hep B and immune against the virus.

USE PROTECTION

- Always use condoms and dental dams during oral, anal, and vaginal sex — whether or not you have an STI. You can get a dozen free condoms at your nearest planned parenthood.
- Know how hep B is spread. You can find specifics here: https://www.hepbpositive.org.uk/hepatitis-b-and-sex

LEARN ABOUT STIS

- Keep yourself and your partner(s) safe by learning about how different STIs are spread and about risk factors. Planned Parenthood and your local health department may be good resources for this.

Sexual stigmas and sex-negativity are common experiences faced by people living with hep B.

In the words of the late HIV-positive artist and activist David Wojnarowicz:

"[How do you tell someone recently diagnosed that they] can’t have desire, he can’t touch others, he can’t express his sexuality? [...] A condom, if used correctly, will prevent transmission of disease. There’s a full range of sexual expression that I’ve always tapped into [...] step back a few hundred miles into space; in the air above all this it all looks like ants in a clockwork maze of pre-invented structures. By mixing variations of sexual expressions there is the attempt to dismantle the structures formed by category; all are affected by laws and policies"
How will having hepatitis B affect my job or ability to work?

Around the world, millions of people with chronic hepatitis B face discrimination that limits their dreams, education, careers, income and access to medicine. The stigma that persists is based on ignorance and it impacts millions around the world daily. Hepatitis B is simply not transmitted through casual contact, and should not prevent anyone from attending school, working, having a family, or traveling. If you are faced with discrimination due to hepatitis B, it is important to know your rights and to have information to support your case. Use the information on our site to help advocate for yourself, or contact the Hepatitis B Foundation at info@hepb.org or 215-489-4900 if you need additional assistance.

Fighting Stigma

Stigma refers to irrational or negative attitudes, behaviors, and judgments towards people living with or at risk of hepatitis B. It can negatively affect the health and well-being of people living with hepatitis B by discouraging some individuals from learning their hepatitis B status, accessing treatment, or staying in care. Hepatitis B stigma can also affect those at risk of hepatitis B by discouraging them from seeking hepatitis B prevention tools and testing.

You can play an important role in reducing stigma and discrimination by offering support and speaking out to correct myths and stereotypes about hepatitis B that you hear from others.

Connect with others living with hepatitis B through support groups like the Hep B Community
FIGHTING HEPATITIS B: BECOME A LOCAL CHAMPION

Ignorance about transmission of hep B affects people’s lives at home and in the community

People living with hep B are often subject to discriminatory policies which impact their right to work, study, and travel

Hep B has a disproportionate impact on people belonging to racial, sexual, and ethnic minorities

Not everyone has equal access to care. Many people face geographical, financial, and legal barriers to obtaining care

The Americans with Disabilities Act protects people living with hep B in the U.S. from discrimination

Raise awareness about hep B on World Hepatitis Day (July 28). Be an advocate for those living with hep B by encouraging community members and policymakers to prioritize hep B research, prevention, and treatment

Work towards a cure by learning about current research, providing feedback, and participating in clinical trials
LIVING WITH HEPATITIS B: FIND SUPPORT

It is important to prioritize your mental and social wellbeing along with your physical health. We know that it can be challenging to understand your diagnosis and find support. Remember that you are not alone and there are many resources to help connect you with reliable community and social support networks,

Online Communities

- **HepBcommunity.org**
  - A free forum dedicated to supporting to those living with and affected by hep B by connecting them with each other and with verified experts
- **Hep Free Hawaii Slack**
  - A safe space with support and resources around Hep B for sexual and gender minorities.
- **SF Hep B Free Support Group**
  - A safe community network which provides access to reliable information, links to care services, and a strong support system to promote emotional wellbeing
- **Facebook**
  - A private social network group with over 14,000 members for people interested in, suffering from or caring for individuals with Hepatitis B.
  - [https://www.facebook.com/groups/hepatitisfoundation](https://www.facebook.com/groups/hepatitisfoundation)
- **Reddit**
  - A small community of active members where people can share news, tell stories, and ask questions about Hep B
  - [https://www.reddit.com/r/hepatitisB/](https://www.reddit.com/r/hepatitisB/)

In-person Communities

**Hep B support groups**

- A great way to make friends who support you and understand what you’re going through!

Mental Health Support

- Connect with health professionals and therapists to educate yourself on hep B and mental health
- Tune in to the Heppy B podcast to listen to people as they share their experiences living with hep B
- Check out inspiring stories from people in Hawaii living with Hep B on the Hep Free Hawaii Youtube

More Resources
[https://www.hepb.org/resources-and-support/online-support-groups/](https://www.hepb.org/resources-and-support/online-support-groups/)
FIGHTING HEPATITIS B: SHARE YOUR STORY

YOUR STORY MATTERS

By sharing stories about hep B, you can promote understanding, reduce stigma, and empower other people living with hep B.

justB storytelling campaign raises the profile of hep b as an urgent public health priority and helps put a human face to the disease.

Hep Free Hawai’i centers its work on the ideas and voices of people living with viral hepatitis as they share their stories of bravery, resilience, and honesty to make Hep Free 2030 a reality.