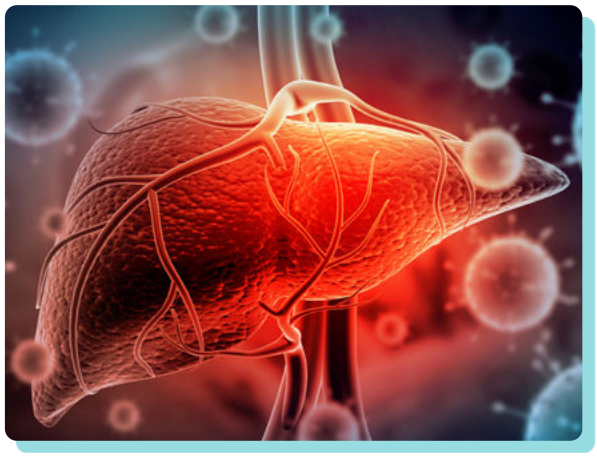
CME OUTFITTERS

A Guide for People Living with Hepatitis B and Hepatitis D

This handout is for general information only and does not replace advice from your own doctor or nurse.

Why should I care about Hepatitis D (Hep D)?



- Some people who have Hepatitis B (Hep B) can also get Hep D
- Hep B is a common liver infection around the world
- In 2022, about **254 million people** were living with long-term (chronic) Hep B, and deaths from all types of viral hepatitis increased from **1.1 million in 2019** to **1.3 million in 2022**
  - Most of these deaths—**about 8 out of 10**—were caused by hepatitis B
- Globally, Hep D affects nearly 5% of people (an estimated 12 million) who have a chronic infection with Hep B
- Global Hep D prevalence among Hep B-positive patients is estimated to be 4.5%, while the prevalence is around 16.4% among Hep B-positive hepatology clinic patients
- Hep D can make liver problems worse and develop faster, so it's important to know about it and get tested, if appropriate (ask your clinician)

First things first: Your liver and hepatitis

Your liver is like your body's "filter" and "chemical factory." It:

Cleans your blood

Helps digest food

Stores energy

Hepatitis literally means "swelling or inflammation of the liver." It is derived from the Greek prefix "hepat-" meaning "liver" and the suffix "-itis" meaning "inflammation." Hep B is caused by the hepatitis B virus (HBV).

What is Hep D?

Hepatitis delta virus (HDV) is another virus that can infect the liver — but only in people who already have Hep B.

Think of it this way:

- Hep B is the main virus
- Hep D is a "helper virus" that needs Hep B to survive
- If you don't have Hep B, you cannot get Hep D

How can someone get Hep D?

There are two main ways:

	COINFECTION	SUPERINFECTION
What it means	You get hepatitis B and hepatitis D at the same time from one exposure.	You already have long-lasting (chronic) hepatitis B and later get hepatitis D.
How you get it	Both viruses enter your body together, usually through blood or body fluids.	You are living with chronic hepatitis B, then have another exposure that brings in hepatitis D.
How common it is	Less common than superinfection.	More common than coinfection.
Chances it becomes long term	Only a small number of people (less than 5 out of 100) keep both infections long term.	A large number of people (about 7–9 out of 10) go on to have long-term infection with both viruses.
What it means for your liver	If it does become long term, it can cause serious liver damage, including scarring and liver cancer.	Because long-term infection is so common, the risk of serious liver damage, scarring, and liver cancer is very high.
Key message	Getting both viruses at once can be serious. You need close follow-up to watch your liver and plan care.	Getting hepatitis D when you already have chronic hepatitis B is very serious and often lifelong. Regular liver checkups and treatment discussions are very important.

Hep B and Hep D spread in similar ways:

- Sharing needles or equipment to use drugs
- Contact with blood or certain body fluids
- From mother to baby during birth in some cases
- Less often: unprotected sex with an infected partner

What are the Symptoms of Hep D?

CO-INFECTION:

You can get **hepatitis B and hepatitis D together** in one new infection.

- This can cause **hepatitis that ranges from mild to very serious**
- The symptoms look like other kinds of **acute (short-term) hepatitis** and usually start about **3–7 weeks** after infection:
  - Fever
  - Fatigue
  - Loss of appetite
  - Nausea and vomiting
  - **Dark urine**
  - **Pale or clay-colored stools**
  - **Yellow skin or eyes (jaundice)**
  - In rare cases, **sudden, life-threatening liver failure** (fulminant hepatitis)
- **Most people recover fully**
- It is **uncommon** for this short-term infection to turn into long-term hepatitis D

SUPERINFECTION:

- Hepatitis D can also infect someone who already has **chronic (long-term) hepatitis B**
- Superinfection is **much more dangerous**:
  - It speeds up liver damage at any age
  - About **70–90 out of 100 people** with superinfection develop **chronic hepatitis D** and more severe liver disease
- Compared to people who only have hepatitis B:
  - People with **Hep B + Hep D** are more likely to develop **cirrhosis** (serious scarring of the liver)
  - They are also at **higher risk of hepatocellular carcinoma (HCC)**

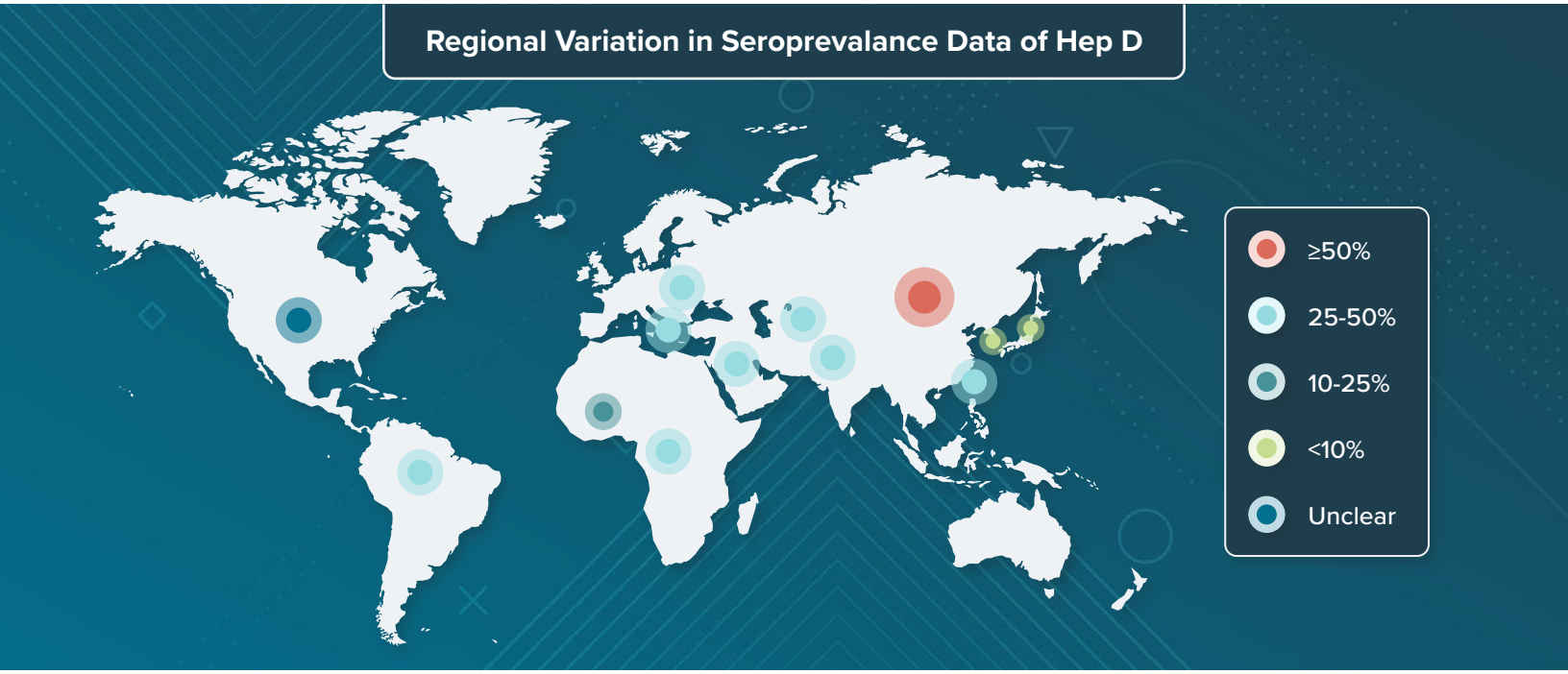
Doctors still do not fully understand why Hep D causes more severe hepatitis and faster scarring (fibrosis) than Hep B alone, but they know the risk is clearly higher.

Why do doctors take Hep D so seriously?

1. Hep D can speed up damage to the liver

- It can cause more scarring of the liver
- Cirrhosis means the liver becomes stiff and scarred and doesn't work well
- This can happen faster in people with Hep B + Hep D than with Hep B alone

Good news: *Testing and treatment can slow or help prevent serious liver damage.*



Where is Hep D more common?

HDV infection remains endemic in many areas, including Central and West Africa, the Mediterranean Basin, the Middle East, Eastern Europe, Northern and Southeast Asia, and the Amazon Basin of South America.

1. While Hep D is found worldwide, it is more common in:

- Europe
  - Hep D is seen more often in **Eastern Europe** and around the **Mediterranean**
  - The prevalence of Hep D is around 3% among Hep B positive patients and 19.5% among Hep B positive hepatology clinic patients
- United States
  - It is currently unclear how common hepatitis D is in the United States
  - Many people with hepatitis B are **not tested** for hepatitis D
  - In some large U.S. data sets, only about **6–19 out of 100** adults with chronic hepatitis B have ever been tested for hepatitis D
- Africa
  - HDV seroprevalence in the general population is around 6%
  - The seroprevalence of Hep D is around 7.33% in Western Africa, 25.6% in Central Africa
  - The seroprevalence data was higher in populations with confirmed active liver disease, reaching around 9.6% in Western Africa and 37.8% in Central Africa
- Asia
  - Hepatitis D is more common in places like Mongolia, Uzbekistan, Kyrgyzstan, the Punjab region of India, and Pakistan

- Asia (Cont.)
  - Travel, migration, changes in drug use, and low testing rates all affect who gets hepatitis D and where it is found
  - When broken down into different subregions:
    - Central Asia
      - HDV seroprevalence in the general population is 8.3%
      - Among people who were Hep B positive, HDV seroprevalence is 51.3%
    - South and East Asia (overall)
      - In the general population, HDV seroprevalence ranges from 0.36% to 0.69%
      - Among Hep B positive patients, HDV seroprevalence ranges roughly from 10.1% to 17.5%
    - Mongolia
      - HDV seroprevalence in the general population is around 8%
      - Among Hep B positive patients, HDV seroprevalence is around 83.3%
      - Mongolia has the highest reported prevalence of HCC worldwide
    - Uzbekistan
      - About 80% of patients with HBV-related cirrhosis are coinfected with HDV
      - HDV is a leading cause of liver-related illness and death.
    - Taiwan, Japan, and Korea
      - HDV prevalence is high in Taiwan
      - HDV prevalence is very low in nearby Japan and Korea, despite similarly high rates of HBV
      - This pattern suggests that HDV may differ in its ability to superinfect different populations of hepatitis B virus (HBV) carriers

How do doctors test for Hep D?

Testing is done with blood tests.

Usually it happens in two steps:

1. Screening test

- This tells your doctor if you've ever been exposed to Hep D
- It looks for antibodies against Hep D (anti-HDV antibodies: your body's "memory" of the virus), which tells if you have prior or present infection

2. Confirming test

- If the first test is positive, a second test checks for active virus in your blood by checking for HDV RNA levels with molecular biology tests such as polymerase chain reaction (PCR)
- This shows whether the virus is currently active and needs treatment or closer follow-up

Important: Not all labs and clinics have easy access to Hep D tests, so you might need to see a liver specialist (hepatologist) or go to a larger center.

Who should ask about Hep D testing?

1. Anyone who has Hepatitis B should talk to their health care team about Hep D testing — especially if:

- You have unexplained liver problems (high liver tests, worsening liver disease)
- You inject drugs or have in the past
- You also have HIV or Hepatitis C (Hep C)
- You were born in or lived for a long time in areas where Hep D is more common (parts of Eastern Europe, the Mediterranean, Central and East Asia, parts of India and Pakistan)

Note: If any of these risk factors pertain to you, it's extra important to ask about Hep D testing.

2. You do not need to remember the test names. You can simply say:

"I have hepatitis B. Should I be tested for hepatitis delta (Hep D)?"

What happens if my Hep D test is positive?

If your test shows you have active Hep D, your care team will likely:

1. Check how healthy your liver is, using:

- Blood tests
- Ultrasound or other scans
- Simple "risk stratification" scores based on your lab results
- Your Hep B status (how active the Hep B virus is)

2. Talk with you about treatment options and follow-up visits

- In some places (such as parts of Europe), there are newer medicines that can help block the virus from entering liver cells
- Other medicines, like certain forms of interferon, may also be used for some people
- Treatment is complex, which is why seeing a liver specialist is important

Your care team: You are not alone

1. Caring for Hep B and Hep D often involves a team:

- Liver specialist (hepatologist)
- Primary care provider (family doctor, internist, nurse practitioner, physician assistant)
- Addiction or mental health specialists, if needed

- Case managers or patient navigators who can help with appointments and insurance
- Community or harm-reduction programs, especially for people who inject drugs

2. These supports can help with:

- Getting to appointments
- Understanding your test results
- Starting and staying on treatment
- Getting help for substance use, housing, or other social needs

If you inject drugs or face other challenges

If you use drugs, have been in jail, are experiencing homelessness, or face stigma, you still deserve high-quality care.

1. Helpful services may include:

- Needle and syringe programs
- Medication treatment for opioid use disorder (like methadone or buprenorphine)
- Peer navigators – people with similar life experiences who help you through the health system
- Nonjudgmental counseling focusing on your goals and choices

2. You can say to your care team:

> *"I want help with my hepatitis and my other health needs, but I need support that is respectful and nonjudgmental."*

The Bottom Line: What can you do to protect your liver?

Here are some practical steps:

1. Ask about testing

- If you have Hep B, ask: "Have I been tested for Hep D?"

2. Take your medicines as prescribed

- Don't stop or change medicines without talking to your provider

3. Avoid alcohol

- Alcohol can speed up liver damage

4. Avoid unnecessary herbal supplements or over-the-counter pills

- Some can hurt the liver; always ask your provider first

5. Get vaccinated, if recommended

- For example, vaccines for hepatitis A or other infections may be appropriate, if you are not already vaccinated. There is also a vaccine for hepatitis B, if you are currently not infected with it

6. Keep your appointments

- Regular checkups catch liver problems early

KEY TAKE-HOME MESSAGES

Hep D only occurs alongside Hep B.

It can cause faster and more serious liver damage, but testing and treatment help.

If you have Hep B, it's reasonable to ask: *"Should I be tested for Hep D?"*

You deserve respectful, patient-centered care—no matter your background, how you got hepatitis, or whether you use drugs.

Your voice and choices matter in every step of care.

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