

What you need to know about hepatitis C testing and prevention



You've been given this fact sheet from your medical provider because you're getting a hepatitis C (HCV) test. This is a very important step for you in terms of taking care of your health.

People living with HIV should get tested for HCV when they start their medical care and then discuss routine testing thereafter, which depends upon your risk factors as detailed below. But for now, let's focus on the fact that you're taking the test and explain what the testing process is.

Within this fact sheet, you'll find information about HCV infection, testing and prevention. It's written for people who are HIV-positive, but who so far are HCV-negative.

If you test HCV-negative, most of this information may be helpful to you, especially the section towards the end called, "If I test negative for HCV, what are my next steps?" You may also want to read Project Inform's fact sheet, *Sexual Transmission of HCV: A guide for HIV-positive gay men*, available from your provider or at www.projectinform.org/pdf/hcvtoolkit_patient_transmission.pdf.

If you test HCV-positive or already know you have hepatitis C, then the section at the end called "If I test positive for HCV, what are my next steps?" may be helpful. Also, Project Inform's publication series, *Hepatitis C & HIV Co-infection*, could be another resource for you at www.projectinform.org/coinfection. And, your provider may offer you a HCV/HIV Resource Guide, or find it at www.projectinform.org/pdf/hcvtoolkit_resourceguide.pdf.

What is hepatitis C?

Hepatitis C is a virus that infects the liver; in fact, "hepatitis" means "inflammation of the liver". Over time, it can begin to scar the liver, and the more severe the scarring the more health problems one can have. With time, there is increased risk of developing liver cancer and/or liver failure.

There are two important things to be aware of when it comes to living with HIV and HCV:

- (1) HCV progresses faster in people with HIV, and can complicate treatment for both.
- (2) For reasons that are not fully understood, HIV-positive people are at greater risk for the sexual transmission of HCV (see the fact sheet, *Sexual Transmission of Hepatitis C: A Guide for HIV-positive Gay Men*).

There are other concerns as well, but these two are especially important. So, catching HCV early is extremely important as it offers the best hope for being able to deal with it effectively.

The good news is that HCV can be cured. It can be more challenging in people who are HIV/HCV co-infected, but it can and does happen.



How is HCV spread?

HCV is spread predominantly by blood-to-blood exposure. If you inject drugs or have ever injected (and especially if you've shared syringes and injection equipment), it carries a high risk of HCV transmission with it.

Transmission from mother to child during pregnancy and childbirth happens around 4-5% of the time in women with HCV only. However, it goes up to 25% in women who are co-infected with HIV/HCV.

Another emerging risk for people with HIV — one that is not the same as for those who are HIV-negative — lies in the sexual transmission of HCV. People with HIV are at greater risk of sexual transmission of HCV than are those who are HIV-negative, and it doesn't matter if you're male, female or transgender, or gay or straight.

What is involved in HCV testing?

Hepatitis C testing can be pretty complicated. It's also different from HIV, so that can be confusing as well. It's a two-step process: first, you take an HCV antibody test; and second, you confirm the result with a viral load (HCV RNA) test.

ANTIBODY TESTING

The HCV antibody test will come up either negative or positive. If you're negative, you probably don't have HCV at this time. However, there's a "window period" with HCV antibodies similar to HIV. It may take up to 12 weeks to develop HCV antibodies. Therefore, if your most recent exposure for HCV occurred in the past 12 weeks, or if you have a low CD4 cell count, you should talk to your provider about getting a viral load test to look for the virus directly (see below).

If your antibody test comes back positive, then you may have HCV, and "may" is the important word here. That's because some people with HIV (about 1 in 5) will clear hepatitis C on their own within six months of infection, but they'll still always show "positive" on an antibody test. Therefore, you'll need to get a viral load test too (see below).

However, if you clear HCV like this during early infection, then these antibodies cannot protect you from another hepatitis C infection. People have and can get re-infected! So it's important to protect yourself from re-infection (read page 4).

VIRAL LOAD TESTING

If you get a positive HCV antibody test, the next step is to get a viral load test to confirm it. If that test comes back negative, then you've cleared the virus. If it comes back positive, then you are chronically infected with HCV, meaning that you will have it for the rest of your life until you get treated and cured.

The other possibility is to have a negative HCV antibody test result with a positive viral load test. This means one of two things: (1) you were very recently infected with HCV and your body hasn't yet produced enough antibodies to come back antibody-positive; or (2) you have a weakened immune system (low CD4 cells) and your body may not be able to produce enough antibodies in response to HCV. In either situation, it's important to talk with your medical provider about what these results mean and what next steps you should take.

Here's a chart to show the range of HCV test results and what they mean:

HCV antibody result		Viral load result	What it means ...
Negative	+	Negative	You do not have HCV.
Positive	+	Negative	You do not have HCV: you have cleared the virus, either through treatment or as one who naturally clears the virus.
Positive	+	Positive	You have chronic HCV.
Negative	+	Positive	You have early HCV infection OR your immune system cannot produce enough HCV antibodies.

If you have questions about testing, don't hesitate to ask your medical provider what it all means or call HELP-4-HEP (877-435-7443) and talk with a counselor.

How often should I get tested?

As an HIV-positive patient, you should at least get an HCV antibody test during the first couple of visits with your medical provider. If you've never had one done, request one. And then, depending upon your risk factors, you may need to get routinely tested thereafter.

For example, a person who injects drugs should get tested more often than a person in a monogamous relationship with an HCV-negative partner. If you develop unexplained elevated liver enzyme tests (ALT and AST), then it would be worth taking an HCV test to rule that out as the cause.

Finally, as we discussed above, the type of routine testing will depend upon your earlier HCV status. If you have never tested HCV antibody positive, then routine antibody testing will suffice. If you have tested antibody positive, but cleared the virus naturally or were successfully treated and cured, then routine viral load testing is needed to detect re-infection.

If I test HCV-negative, what are my next steps?

If you test negative for HCV, then you most likely are not infected at this time. However, depending upon how long ago your last possible exposure to HCV occurred, you may still be in the window period so a follow-up HCV antibody test may be in order. Talk with your medical provider about this, and schedule a follow-up test as needed.

If you're HCV antibody negative and outside of the window period, there are several things you can do to minimize your risk of infection going forward. The list below is not exhaustive. For more info, check out the *Sexual Transmission of HCV* fact sheet (www.projectinform.org/pdf/hcvtoolkit_patient_transmission.pdf).

1. **Screen for HCV routinely.** Don't wait for symptoms as there may not be any. You should screen for HCV at least annually, but for some, more frequent screening may be necessary. If you are sexually active with multiple partners or use drugs (injection or non-injection), testing every 6 months may be in order. Talk with your medical provider about the best option for you.
2. **If you inject drugs, don't share anything that could have blood on it.** This means syringes, but also all other "works" including cookers, cotton, water, alcohol wipes and ties.
3. **Practice safer sex.** Ask your partners about their HCV status while being open and disclosing your own. Be aware of sex practices that can lead to bleeding, such as anal sex, fisting, sex toys and sex that could injure skin or tissue and expose blood. Use barriers like condoms or latex gloves to minimize the risk of transmission. Screen for STDs regularly, and if you have with herpes, keep an eye out for outbreaks and abstain from sex when you have one.

If I test HCV -positive, what are my next steps?

If you test positive for HCV, there are several things you can do to deal with it. First, talk with your medical provider. Most HIV providers know a lot about HCV, and even if they don't, they know how to get the information or refer you to a specialist who does.

Next, take some time to learn more about the disease. Look for information that focuses on HIV/HCV co-infection as it can be a very different course of disease than HCV alone. You might want to find a support group, read educational materials or even call the HELP-4-HEP support line. Your medical provider has fact sheets and booklets to offer you to learn more about HIV and HCV co-infection. If they don't, then again call HELP-4-HEP (877-435-7443).

In the meantime, there are a few things you can do:

1. Keep taking your HIV meds.

The longer HIV is well controlled, the slower HCV progresses and better off you'll be overall. Most HIV medications are safe for people with HCV, but check with your medical provider to make sure. If you decide to start HCV treatment, then be aware of possible drug interactions. And while we're at it: Make sure all of the medications you're taking are safe for people with liver disease.

2. Quit or reduce your alcohol intake.

Quitting is best, as alcohol and HCV do not mix. But quitting can be hard (and in some cases deadly, if you're alcohol dependent), so get the support you need to cut it down, and work towards quitting entirely when you're ready.

3. Get vaccinated for hepatitis A and hepatitis B.

You may have gotten these already, but check with your medical provider to make sure.

4. Drink lots of water and eat as healthy as you can.

Drink 8–10 glasses of water per day. For food, cut down on your fat intake and look for foods that are low-fat, low in sodium and low in salt. While you're at it, have a couple of cups of coffee. Some good research shows that it can reduce liver inflammation and slow down cirrhosis.

5. Get support.

Testing positive for HCV can feel very isolating, so reach out for support. You know yourself and what works for you. Some people like support groups, while others prefer one-on-one therapy. Some people find help in faith-based organizations, while others can turn to family or friends. You can also call the HELP-4-HEP support line: 877-435-7443.

