
a series of fact sheets written
by experts in the field of liver
disease

HCV Education & Support: Testing Positive – Now What?

Heather Lusk Hepatitis C Coordinator
Hawai'i Department of Health

Testing positive for antibodies to the hepatitis C virus (anti-HCV) may be scary, but now you have information that can improve your health and well-being. This brochure will explore what testing positive means, and what you can do about it. Don't panic – the knowledge you now have will help you make healthier decisions for you and your liver. Information is the key to living well with hepatitis C.

Testing positive for antibodies doesn't necessarily mean you have hep C

When you test positive for anti-HCV, it means that you have been infected with the hepatitis C virus (HCV). What the test doesn't tell you is whether you currently have HCV. About 55–85% of people with anti-HCV still have

the virus in their body six months after infection. This means that 15–45% people (about 1 in 4) have antibodies, but not the virus. In these people, their immune system was able to “clear,” or get rid of, HCV. If you test positive for anti-HCV, you need to get a confirmatory viral load test to see if you still have HCV. This test measures HCV RNA, or genetic material in the blood. If you have “cleared” or “resolved” the virus, this test will come back “undetectable.” If the test comes back “detectable,” then you are living with chronic (long-term) hepatitis C.

If you don't know whether you still have HCV, live like you do

If you know you have antibodies to HCV but have been unable to get the additional confirmation test, you are not alone. The viral load tests are expensive and hard to get without insurance. Since most people who have anti-HCV do have HCV, the best thing to do while you wait for the test is to live like you have hepatitis C, taking good care of yourself and protecting the health of your liver.

If you have hep C, you have time

Once you are confirmed as having hepatitis C, there will probably be many things running through your mind. Hepatitis C is a slow-moving disease, so most likely you will have a lot of time to make decisions about your health. Take the time to learn about hepatitis C and make the right decisions for yourself. Don't make any snap decisions in the moment. In fact, you shouldn't make any important decisions right away – you may still be in shock. There may be some days when you feel balanced and ready to take steps towards a healthier life, and other days when you don't

want to deal with your hepatitis – this is normal. Take the time to think about what is important for you now, and remember you will have time to make all the decisions you need to make.

Your body, your liver, and hepatitis C

Your liver is the largest internal organ and has over 500 important functions. Almost everything that we eat, drink, smoke, swallow, or absorb through the skin goes through the liver. Since hepatitis C affects the liver and can cause liver damage, you may want to think about what you put into your body so you can minimize the harm to your liver. The most harmful thing for your liver is alcohol, so it's important to reduce your alcohol intake as much as you can. Eating a healthy, low-fat, low salt diet, drinking lots of water, and getting enough rest and moderate exercise will help your liver do its job.

Disclosure: telling others you have hepatitis C

You may be wondering how to tell others that you have tested positive for HCV. First, you don't have to tell anyone until you are ready. If you have only a positive antibody test result, you'll have to decide if you want to disclose now or after your confirmation test. There are two main reasons to tell others: support for yourself and because you think they should get tested for hepatitis C. Think about whom you want to tell, why you want to tell them, how you will tell them, and when and where you will tell them. Make sure you have support by first telling someone who will be there for you.

Preventing transmission to others

While it is important to take care of yourself, you may also have questions about how to make sure you don't transmit HCV to someone else. HCV is transmitted through direct blood contact

– someone else has to get your blood directly into their blood through sharing a needle, a razor, nail clippers, a toothbrush, or anything that may have your blood on it. HCV has been found to survive outside the body for up to four days. Even when blood is present, there also has to be an opening for the blood to get into the other person's body. It is also possible for HCV to be transmitted through sex or from a mother to her baby during pregnancy or birth, but this is rare. You cannot transmit HCV through hugging, kissing, sharing eating or drinking utensils, or sharing a bathroom.

Next steps: medical care for hepatitis C

In addition to getting your positive antibody test result confirmed, it is important to get additional testing and vaccinations once you know you have HCV. You need to be vaccinated against hepatitis A and hepatitis B if you have hepatitis C to avoid getting more than one type of hepatitis, which will be hard on your liver. Your doctor will do more tests to see how your liver is doing, and may do a biopsy (removal of a small liver tissue sample) to see if your liver is damaged. You may also want to find out what kind of HCV you have (called genotype) and how much HCV you have in your blood (called viral load). Getting all of these tests will give you and your doctor information so that you can make the best treatment decisions.

Deciding about treatment

There are treatments that may get rid of HCV, but they aren't for everyone, and some people don't need treatment. Treatments work better for some people than others. How well it works depends on the genotype of HCV you have, how long you have been infected, how much your liver is damaged, and other factors. Also, HCV treatment is very expensive and can have significant side effects. Pegylated interferon (an injection) plus ribavirin (a pill) is the most common treatment

combination available; treatment usually lasts 6 to 12 months. Talk to your doctor and people who have tried the treatment to help make your decision. Many people find that complementary therapies such as acupuncture, massage and herbs are helpful in managing their hepatitis C. It is important that you talk with an expert and consult with your doctor since some herbs can be harmful to the liver.

Experimental drugs to treat hepatitis C

There have been many advances in the treatment of HCV since the virus was first identified over a decade ago. However, current treatment options can have many undesired side effects and treatment success cannot be achieved in everyone. There is much research underway to develop new and better HCV treatment options without the serious side effects of current medications.

Researchers are studying a variety of new drugs to treat hepatitis C, such as medications that directly attack the hepatitis C virus and which will be used in combination with pegylated interferon. It is estimated that these newer drugs will be available in 2-4 years. Talk to your doctor or nurse about whether it is safe for you to wait or if you need to be treated before the newer drugs become available.

Getting support

If you have hepatitis C you are not alone – there are more than four million others in the U.S. Many people find it helpful to join a support group or connect with people on the Internet who also have hepatitis C. Talk with people who care about you and ask for support. For more information on support groups in your area, visit www.hcvadvocate.org.

Be Sure to Check Out the Following HCSP Publications

Basic Information:

- *Easy C - A Guide to Understanding Hepatitis*
- *A Guide to Understanding Hepatitis C Basics*

General Topic Specific Guides:

- *A Guide to Understanding Clinical Trials and Medical Research in Hepatitis C*

HCV and Work-Related Issues:

- *A Guide to HCV Disclosure*
- *A Guide to Hepatitis and Disability*

Managing HCV:

- *A Guide to Healthy Living with HCV*
- *A Guide to Understanding and Managing Fatigue*
- *Coping with Depression and Hepatitis C*

Newly Diagnosed:

- *First Steps with HCV for the Newly Diagnosed*

Treatment Issues:

- *A Guide to Hepatitis C: Preparing for Treatment*

For more information about hepatitis C, hepatitis B and HCV coinfections, please visit www.hcvadvocate.org.

• *hcsPFACTsheet* •

A publication of the Hepatitis C Support Project

Executive Director
Editor-in-Chief, HCSP Publications
Alan Franciscus

Design
Paula Fener

Production
C.D. Mazoff, PhD

Contact information:
Hepatitis C Support Project
PO Box 427037
San Francisco, CA 94142-7037
alanfranciscus@hcvadvocate.org

The information in this fact sheet is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

This information is provided by the Hepatitis C Support Project • a nonprofit organization for HCV education, support and advocacy • © 2008 Hepatitis C Support Project • Reprint permission is granted and encouraged with credit to the Hepatitis C Support Project.

