

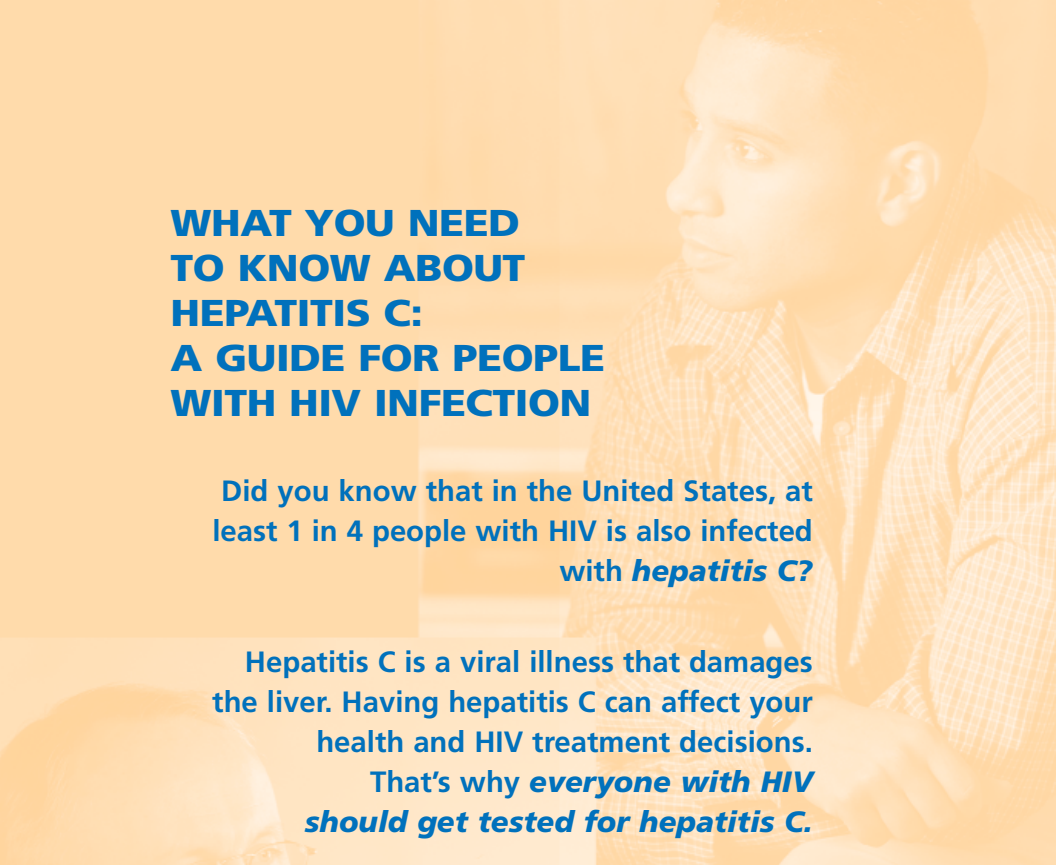
What you need to know about hepatitis C



*A guide for people
with HIV infection*



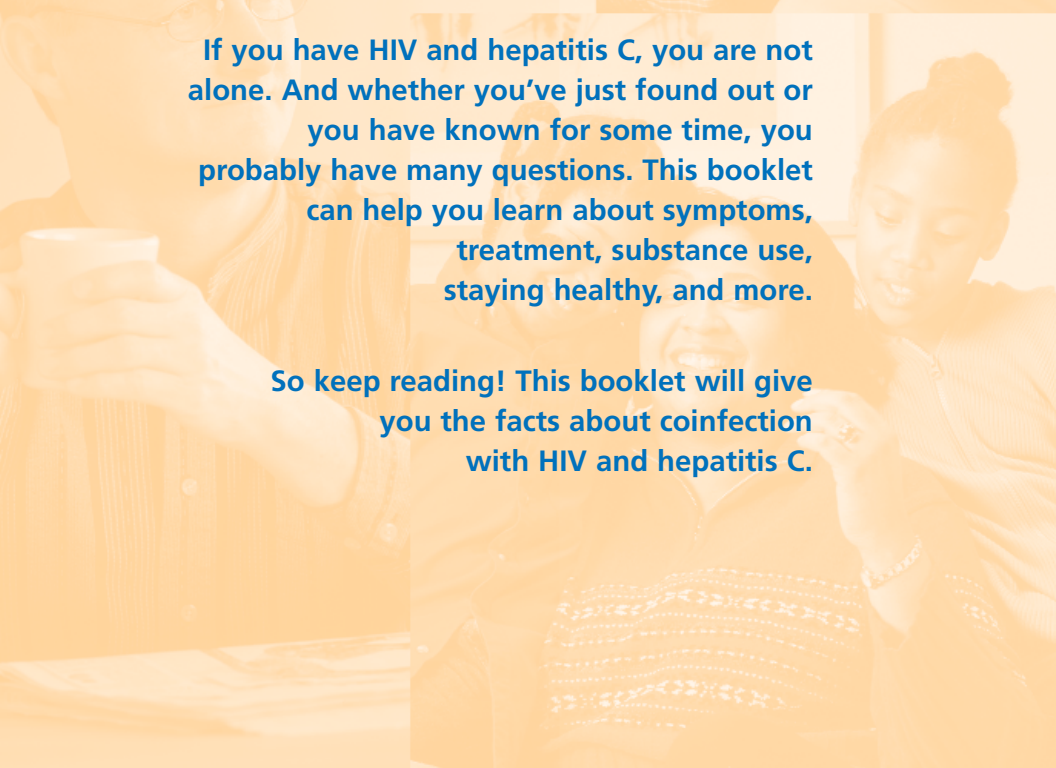
New York State
Department of Health



WHAT YOU NEED TO KNOW ABOUT HEPATITIS C: A GUIDE FOR PEOPLE WITH HIV INFECTION

Did you know that in the United States, at least 1 in 4 people with HIV is also infected with *hepatitis C*?

Hepatitis C is a viral illness that damages the liver. Having hepatitis C can affect your health and HIV treatment decisions. That's why **everyone with HIV should get tested for hepatitis C.**



If you have HIV and hepatitis C, you are not alone. And whether you've just found out or you have known for some time, you probably have many questions. This booklet can help you learn about symptoms, treatment, substance use, staying healthy, and more.

So keep reading! This booklet will give you the facts about coinfection with HIV and hepatitis C.

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HEPATITIS C: THE BASICS

What is hepatitis C?

“Hepatitis” means “liver disease.” Hepatitis C is a kind of liver disease caused by the Hepatitis C Virus (HCV). Up to 85% of people who are exposed to HCV develop chronic (long-term) hepatitis C infection. Chronic hepatitis C infection can lead to liver scarring (also called cirrhosis), liver disease, or liver cancer. People with HIV who are exposed to hepatitis C may be more likely to develop chronic infection. Other kinds of hepatitis can be caused by other viruses, by alcohol, or by medication. It is possible to have more than one kind of hepatitis at the same time.

What are the symptoms of hepatitis C?

Most people with hepatitis C have no symptoms for many years. Some never have symptoms at all. But some people have symptoms like:

- feeling very tired
- upset stomach
- stomach pain
- fever
- yellowish skin and/or eyes
- dark urine
- light-colored stools

The only way to know if you have hepatitis C is to have a blood test.



How is hepatitis C passed from one person to another?

Hepatitis C is passed through contact with infected blood. For example:

- sharing injection drug needles or works (spoons, cotton, cookers)
- needle-stick injuries in health care settings
- from mother to baby during birth
- unprotected sex

(See page 6 to learn more about how hepatitis C is passed from one person to another.)

What will hepatitis C do to my health?

Hepatitis C affects people differently: some have severe liver damage while others never have serious problems. In people infected only with hepatitis C, 5 to 15% will get severe liver damage and scarring (cirrhosis) or liver cancer.

This liver damage often happens slowly, over many years. Some people have no problems for 20 or more years after infection, while other people become sick much sooner.

Severe liver damage may be more likely and may happen faster in people who also have HIV.

Severe liver damage can lead to:

- problems with blood clotting
- swelling stomach and ankles
- not being able to think clearly
- liver failure

People with severe liver damage or liver cancer may need a liver transplant.

Remember that many people with HIV and hepatitis C are able to stay healthy for years. Not everyone with hepatitis C will have serious liver problems.

Will having hepatitis C make my HIV worse?

Doctors are not yet sure how hepatitis C affects HIV and AIDS. In most studies, people with HIV and hepatitis C did not have more serious HIV disease and did not get AIDS any sooner than people who only have HIV. In other studies, people with both hepatitis C and HIV seemed to develop AIDS more quickly than people with HIV alone. More research is being done to find out how hepatitis C affects HIV.

WHAT DOES MY LIVER DO, ANYWAY?

Your liver is one of the most important organs in your body. You cannot live without it. Some of its jobs are:

- processing some medications, including many HIV medications
- filtering poisons out of your blood
- helping to fight infection
- changing food into substances your body needs
- making substances that help your blood clot
- storing vitamins and sugar

Many medications that fight HIV are processed in the liver. If your liver is seriously damaged, you may not be able to take some medications that are used to treat HIV.

TRACKING HEPATITIS C IN YOUR BODY: BLOOD TESTS & BIOPSIES

Some people with hepatitis C get severe liver damage. Others never get very sick. Most do not have any symptoms until they have serious problems.

There are two kinds of blood tests to find out how hepatitis C is affecting your body.

- **viral load tests** measure the amount of hepatitis C virus in your body. You may be used to having viral load tests that measure the amount of HIV in your body. This test is similar, but your viral load for hepatitis C will probably be much higher than your viral load for HIV. For example, a viral load of 1,000,000 for HIV is very high. But, a viral load of 1,000,000 for hepatitis C is fairly low.

A viral load test is usually done once when you are diagnosed and once or twice when making treatment decisions. It does not need to be done regularly like an HIV viral load test.

- **liver function tests** measure substances in your blood to look for warning signs of liver damage. But hepatitis C can be tricky. A blood test may be normal even though your liver is being damaged. Or, a blood test may not be normal even though your liver is healthy. Liver function tests are most useful when done on a regular basis (once or twice a year) to look for long-term patterns in how your liver works.

To get a better idea of how hepatitis C is affecting you, your doctor may want to look at your liver directly by doing a **liver biopsy**.

In a liver biopsy, the doctor uses a long, thin needle to remove some tissue from your liver. The doctor will inspect the tissue for damage. This is the most exact way to find out what hepatitis C has done to your liver. Not everybody needs to have a liver biopsy, but it may be helpful if you are thinking about treatment.

A liver biopsy is not very painful for most people. You do not need to be “knocked out.” Instead, the doctor will numb your stomach area before the biopsy. Very rarely, a person may bleed or have severe pain after a biopsy. Although this does not happen often, the doctor will want you to stay at the hospital for a few hours after your biopsy—even if you feel fine—to make sure there are no problems.

WANDA:

“I need to stay healthy, because I have two little girls and they keep me busy! I’ve been lucky so far. My T-cells are good and my doctor says my liver is doing okay. I’m hanging in there.

But I worry about my family. My kids don’t have HIV, but what about hepatitis C? Could they get it from me? Sometimes I let them drink from my glass, or I forget to cover my mouth when I cough. I’m afraid I might be putting them at risk. And what about my partner? Can you get hepatitis C through sex?”



Like HIV, hepatitis C is **not** spread through casual contact like coughing, sharing cups or eating utensils, hugging, or kissing. Hepatitis C is **only** spread through direct contact with infected blood.

HOW IS HEPATITIS C SPREAD?

The most common ways that **hepatitis C** is spread are:

- sharing needles and works (like cookers and water) that are used to inject drugs, steroids, hormones, or vitamins
- mother to baby during birth
- accidental needle-stick injuries (mainly to health care workers on the job)
- unprotected sex (sex without using a condom)

It may also be possible to spread **hepatitis C** through:

- sharing razors, toothbrushes, or nail clippers with a person who has hepatitis C (because these items may have traces of blood on them)
- tattoos or piercing, especially if it is not done by a professional with sterile equipment
- sharing straws used to snort cocaine or other drugs

Before 1992, people also got hepatitis C through infected blood transfusions and organ transplants. Now, all blood and organ donations are tested for hepatitis C, so it is safe to receive blood or organs.

It is possible to spread hepatitis C during sex, but this is rare. On the other hand, HIV is easily spread during sex (vaginal, anal, and oral). Always use condoms to protect yourself and your partners.

A woman can pass hepatitis C to her baby during birth. This is more likely to happen if the woman is coinfectd with HIV: about 15 out of 100 babies born to coinfectd women will have hepatitis C. Talk to your child's doctor about when to test your child for hepatitis C.

KEEPING YOUR LOVED ONES SAFE

Hepatitis C is only spread through contact with infected blood. To avoid spreading hepatitis C to others:

- do not share needles, syringes, or other injection equipment (cotton, water, cookers, spoons, etc.)
- do not share razors, toothbrushes, nail clippers, or other household items that could have blood on them
- clean up blood spills right away with bleach
- keep cuts or sores covered with a bandage





CARLOS:

“When I found out that I had hepatitis C, I was really angry. I thought, first HIV and now this! I couldn’t believe it. I didn’t go back to the doctor for a while. I didn’t want to deal with it.

Later I realized that it wasn’t going to go away. When I found out about my HIV I was scared, too, but I learned more about it and I’m doing okay. I want to stay as healthy as I can. Is there a treatment for hepatitis C? Can I use it even though I also have HIV?”

WHAT ARE MY TREATMENT OPTIONS?

You are not alone! Having two serious illnesses can be scary and stressful. It may help to remember that many people in the U.S. who have HIV are also infected with hepatitis C. It’s very common.

The treatment most doctors recommend for hepatitis C is a combination of two medications: **pegylated interferon** and **ribavirin**. This treatment can be used by most people with HIV and usually does not interfere with HIV medications.

Pegylated interferon is injected under the skin (like a shot) once a week. Ribavirin is a pill that you swallow. Treatment usually lasts for 12 months; sometimes it is shorter.

Treatment with pegylated interferon and ribavirin works for some people, but not everyone:

- About half of people treated have healthier livers and no hepatitis C in their bodies at the end of treatment.
- Some people’s livers get healthier during treatment, but the hepatitis C is not completely removed from their bodies. They may still have liver damage from hepatitis C in the future.

Having HIV probably will not affect how well the treatment works, especially if your immune system is still strong.

Most people can take HIV and hepatitis C treatments at the same time. In some cases, doctors may suggest treating HIV first to strengthen the immune system before starting hepatitis C treatment. In other cases, doctors may suggest treating hepatitis C first so that the liver will be able to process more kinds of HIV medication. Work with your doctor or health care provider to make treatment decisions that are best for you.



“I’m also in a methadone program. Will I have to stop taking methadone if I want treatment for hepatitis C?”

No. You can be treated for hepatitis C while you are on methadone. Many people in recovery from drug addiction have been treated for hepatitis C while they were on methadone maintenance.

WHY DO SO MANY PEOPLE WITH HIV ALSO HAVE HEPATITIS C?

Hepatitis C and HIV can be spread in some of the same ways. HIV is spread through semen, vaginal fluids, or—like hepatitis C—through direct contact with infected blood (like sharing needles and works, or needle-stick injuries). HIV is more likely than hepatitis C to be spread during unprotected sex, but hepatitis C is sometimes spread in this way also. So, if you’re at risk for HIV, you’re also at risk for hepatitis C. That’s why co-infection is so common—and why everyone with HIV should get tested for hepatitis C.

MICHAEL:

“The first HIV meds that I took made me so sick and tired I didn’t even want to get out of bed. So I got switched to another kind. But I still felt sick, and there were so many pills to take that I had trouble remembering all my doses. Then I got resistant. That means there’s a bunch of HIV drugs that don’t work for me at all. After more than a year of this, they finally got me on some meds that I can live with and that seem to work. My viral load is down and I only feel sick in the morning.

Now my doctor says I should think about getting pegylated interferon/ribavirin treatment for my hep C. She says it has a good chance of helping my liver. But I’ve heard that the side effects of interferon really mess you up. That’s not what I need right now. Are the side effects bad? Do most people get them?”



Pegylated interferon and ribavirin are strong drugs. Many people treated with them get side effects like:

- flu-like symptoms (fever, chills, headache, muscle pain)
- feeling very tired (fatigue)
- mood changes (depression, bad temper)
- temporary hair loss (alopecia)
- anemia (reduced red blood cells)

Some people have mild or no side effects. Some people have very severe side effects. For many people, the side effects become less severe over time.

RIBAVIRIN & BIRTH DEFECTS

Ribavirin can cause birth defects in unborn babies. Women on ribavirin who could become pregnant, as well as men on ribavirin who have a female partner who could become pregnant, must use 2 reliable forms of birth control during and for 6 months after treatment with ribavirin.

“I don’t know if I’m ready for that. Do I have to start treatment for hepatitis C right away?”

This is not an easy question. There are good reasons to delay treatment—and good reasons to start treatment sooner:

Reasons to delay hepatitis C treatment

- Side effects from interferon and ribavirin could make you sick.
- Better treatments may be available in the future.
- Your hepatitis might not get worse—some people never have serious liver problems.

Reasons to start hepatitis C treatment sooner

- Treatment might not work as well later.
- Your hepatitis C could get worse very fast.
- Liver damage from hepatitis C might limit the HIV medications you can take.

When and how to treat your hepatitis C is a hard decision. Family needs, side effects, work, substance use, health issues, and many other parts of your life will affect your choice. Your doctor, nurse, or another health professional you trust can help you look at all of the factors to decide what is best for you.



DEPRESSION: A COMMON SIDE EFFECT OF INTERFERON

Depression is a common side effect of interferon. Severe depression can happen to anyone who is taking interferon. But it is more likely in people who have a history of depression or other mental illness.

If you have a history of any mental illness or substance abuse, tell your doctor before you begin treatment with any type of interferon. Your doctor may want to prescribe an antidepressant before you begin your hepatitis C treatment. Your doctor can also refer you to support services like hotlines or counseling so that if you have mood changes, you can get help right away.



IF YOU USE DRUGS, HERE'S WHAT YOU NEED TO KNOW:

The healthiest choice is to stop using. Drug use can cause many health problems, and you need to keep your body as healthy as possible. Also, you don't always know what you are getting when you buy street drugs. They may be cut with substances that can hurt your liver. If you can't quit, reduce your drug use as much as you can.

If you inject drugs, you may be putting yourself at risk for many infections, including reinfection with HIV and/or hepatitis C. If you are sniffing drugs, do not share straws (hepatitis C may be spread in tiny drops of blood from the nose that stay on the straw).

If you are going to inject drugs, do it as safely as you can:

- **Use a new needle and syringe every time.**

Through the New York State ESAP (Expanded Syringe Access Demonstration Program), you can buy up to 10 new syringes at many pharmacies. You do not need a prescription. You can also trade used syringes for new syringes at syringe exchange programs. To find a syringe exchange program or a pharmacy that sells syringes without a prescription, call:

1-800-541-AIDS (English)
1-800-233-SIDA (Spanish)
1-800-369-AIDS (Deaf/TDD)

ALCOHOL & THE LIVER

Alcohol is very hard on your liver. If you have hepatitis C, alcohol could make your hepatitis get worse, and get worse faster. If you drink while in treatment for hepatitis C, the treatment may not work as well for you. The less you drink, the better. Quit if you can.

- **Don't share needles or works—including cookers (spoons, bottle-caps), cotton, tourniquets, and water.**

You might think that if you don't share needles and syringes, you are not at risk. But you can also get hepatitis C, HIV, and other infections from tiny traces of blood in water, cotton, cookers (spoons, bottle-caps, etc.), or anything else you share when you shoot up.

- **If you have to re-use a needle and syringe, first clean it with bleach and water.**

These steps may help reduce your risk from spreading hepatitis C, but injecting drugs is never safe. To clean a needle and syringe:

- 1) Wash your hands and try to clean your works in a space that is separate from others.
- 2) Fill the syringe half full with clean water; pull back on the plunger. Shake the syringe and squirt the water through the needle. Repeat 2 times with new water, or until all the blood is gone.
- 3) Fill the syringe with full strength bleach. Shake. Squirt the bleach out through the needle. Repeat.
- 4) Rinse the syringe 3 more times with clean water.

Do not re-use water or bleach. Be sure to keep the rinse water apart from water used to prepare drugs.



Hepatitis C treatment for drug users

The National Institutes for Health says that you should stop using all drugs and alcohol for 6 months before and during treatment. This is good advice for keeping your liver healthy and giving treatment the best chance of helping you. Your doctor, nurse, case manager, or counselor can help you find a drug treatment program. Or, you can call one of the phone numbers on page 20 of this booklet for a referral.

If you can't quit using drugs, treatment may still be an option. Many experts, including the New York State AIDS Advisory Council, say that no one should be denied hepatitis C treatment just because they use drugs. Your doctor, case manager, or other people on your health care team can help you decide if hepatitis C treatment is right for you.

STAYING HEALTHY: YOUR CHOICES MAKE A DIFFERENCE!

Even if you have HIV and hepatitis C, there are many things you can do on your own to keep your liver healthy:

- **Get hepatitis A and hepatitis B vaccines.**
Hepatitis A and hepatitis B are liver diseases similar to hepatitis C. Hepatitis A, especially, can be very serious in someone with hepatitis C. Protect yourself! Most doctors and clinics have these vaccines.
- **Avoid alcohol.**
Alcohol hurts your liver and will probably make your hepatitis C worse. The less alcohol you drink, the better. The healthiest choice is not to drink any alcohol at all.

- **Tell your doctor about every medication or drug that you are taking.**

This includes:

- prescription medications
- herbal pills or extracts
- over-the-counter medications like headache pills or cold medicine
- street drugs

One of your liver's jobs is to process medications. Your doctor needs to know everything that you take in order to help your liver work and keep you healthy.

- **Always use a male latex condom or a female condom when you have sex.**

This will reduce your risk of getting other sexually transmitted diseases and reduce your partner's risk of getting HIV.

TO FIND OUT MORE . . .

For more information about HIV and AIDS, to find HIV testing sites, syringe exchange programs, and pharmacies that sell syringes without a prescription, and to access services near you, call the toll-free New York State Department of Health HIV/AIDS Hotline:

1-800-541-AIDS English
1-800-233-SIDA Spanish
1-800-369-AIDS Deaf/TDD

You can listen to taped messages or speak to a phone counselor. You can ask them anything, and you do not need to give your name.



For more information about hepatitis C, call toll-free:

**1-888-4-HEP-CDC
(1-888-443-7232)**

CDC Hepatitis Hotline

For help quitting or reducing your alcohol and drug use, call:

1-800-522-5353

**New York State Office of
Alcohol & Substance Abuse
Services (OASAS)
Monday – Friday,
9 a.m. – 5 p.m.**

**1-800-LIFENET
(1-800-543-3638)**

**New York City only
24 hours a day,
7 days a week**

1-800-LIFENET also offers confidential help with depression and other mental health problems.

There are also many resources on the Internet. If you do not have access to a computer, try your local library. Most libraries have Internet access that you can use free of charge, and they can show you what to do if you need help. (Librarians are not required to keep information confidential. If you prefer to keep your HIV status private, you don't need to tell them what information you are looking for or which websites you plan to view.) Try these websites:

www.cdc.gov

www.hivandhepatitis.com

www.thebody.com

www.niddk.nih.gov/index.htm

www.hepfi.org