

EASY A Guide to HIV and Hep C Coinfection

A publication of the Hepatitis C Support Project ●

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Introduction

HIV and Hepatitis C (HCV or Hep C for short) are viruses that live in the body. A virus is one of the smallest living things known to exist inside plants and animals. The term used when someone has two or more viruses is called coinfection.

HIV mainly attacks the body's immune system cells and Hep C mainly attacks liver cells. When someone has both HIV and Hep C together it can make it much harder for the body to fight HIV and Hep C. In fact, Hep C is the most common reason why people with HIV get sick and die.

HIV and Hep C are spread or transmitted in similar ways, such as by coming into contact with infected blood. However, there are differences in how they are spread by sexual contact. HIV is much easier to get from sexual contact. Getting Hep C from sex is not as easy, but recent reports from around the country and the world are finding that Hep C can be transmitted by sexual contact much easier in people with HIV. However, the most common way that people become coinfecting with HIV and Hep C is by sharing infected needles and works (cottons, cookers, ties, and water, etc.).

The good news is that most people can stay healthy when they have HIV and Hep C together. But the key to staying healthy with HIV and Hep C is to learn as much as you can about HIV and Hep C and to work as closely as possible with your medical care team. ■

- All people with HIV should be tested for Hep C.
- The government estimates that there are about 4 million Americans infected with hepatitis C and about 1 million Americans living with HIV. Up to as many as 300,000 Americans are coinfecting with HIV and Hep C.
- The liver can become very damaged and in a much shorter period of time in someone who is infected with both viruses.

Coinfection



FACTS

- Because Hep C damages the liver everyone with Hep C or coinfecting with HIV and Hep C should stop drinking alcohol or cut down as much as possible on the amount of alcohol they drink.
- Everyone with HIV and Hep C should be tested for Hep A and Hep B. If they have never been infected they should get vaccinated against Hep A and Hep B.

What is the Liver?



The liver is the largest organ in the body. It is reddish-brown and is about the size of a football. The really amazing thing about the liver is that if they removed half the liver, it would grow back in just a few weeks.

The liver's job is to run over 500 bodily functions to keep you healthy. It is also a very important organ because it filters everything you eat and breathe – even things that get on your skin. The problem is that things such as alcohol, street drugs, cigarette smoke, toxic fumes, some herbs and even some regular medicines people buy without a doctor's prescription can damage the liver.

The liver helps to keep the body healthy by taking certain foods and turning them into chemicals that give you energy and keep you healthy.

The liver also stores many important things such as vitamins. Sometimes you can take too much of these vitamins and this can damage the liver. ■

HEALTHY LIVER TIPS

- ✓ If you take medicines for HIV make sure that your liver is checked on a regular basis to be sure that the medications are not damaging the liver.
- ✓ Tell your doctor about all medicines you are taking, even if it's just an aspirin or Tylenol®.
- ✓ Stop drinking alcohol, smoking tobacco and taking street drugs. If you can't stop try to cut back – talk with a doctor, family or friends about getting some help to stop.
- ✓ Eat a healthy and well-balanced diet.
- ✓ Talk to your doctor about the hepatitis A and hepatitis B vaccines to help protect the liver from getting even more damaged.
- ✓ Try to exercise when you can – walking is one of the best exercises you can do.
- ✓ Drink lots of water.
- ✓ Stay away from raw or undercooked shellfish.
- ✓ Stay away from toxic fumes or liquids – protect yourself by wearing gloves and a mask and make sure the area is open and well-ventilated (lots of air in the room).

How Do You Give or Get Hepatitis C?

Hepatitis C is spread by direct blood-to-blood contact. This means that in order for someone to give hepatitis C to someone else they must get their blood into someone else's bloodstream. For this reason, it is difficult to get or give hepatitis C unless there is blood involved. So if you have hepatitis C, make sure that your blood does not come into contact with anyone else's blood. If you do not have hepatitis C, stay safe by making sure that you stay away from blood from other people. This will help to keep you healthier. ■

Common Ways to Give and to Get Hepatitis C

Getting Hepatitis C from Needles and Works

The most common way that people get hepatitis C is from sharing needles and anything else that is used to inject street drugs, hormones, steroids, vitamins or any other substance that is injected into the body. This is also the most common way that people get HIV and Hep C coinfection. Things Used to Inject Drugs – includes needles, cookers (to mix drugs), cottons (to filter drugs), and tourniquets or ties. Even the water used to clean drug equipment can have hepatitis C in it. It is also important to wash your hands to help reduce the risk of getting hepatitis C and other diseases.

Getting Hepatitis C from Blood – Another way that many people got Hep C was from having a blood transfusion or receiving an organ transplant before 1992. This can include having an operation that required someone to receive blood from another person or any other way where a blood product was used.

Getting Hepatitis C from Sex – Getting hepatitis C from having sex with someone

who has hepatitis C does not happen very often in people with Hep C alone. But people who have sex with a lot of different people and have high risk sex are more likely to get Hep C by sexual contact. Other ways that increase the chances of getting Hep C from sex include having sex partners who have other sexually transmitted diseases – herpes, HIV, Hep B, open cuts or wounds and when there is any blood during sex. In people who are HIV and Hep C coinfecting the chance for giving Hep C to someone else while having sex is also higher. For this reason people with HIV and Hep C should practice safer sex – use condoms (rubbers) and stay away from any blood during sex. And everyone with HIV should be tested for hepatitis C.

Other Ways to Get Hepatitis C – Some experts believe that you can get hepatitis C in other ways, such as by getting a body tattoo or piercing or sharing personal hygiene items (toothbrushes, razor blades, nail clippers). The chances of getting or giving HCV in these ways is much higher if safety is not followed carefully. ■

The Good News

The good news is that you can not get or give hepatitis C by sneezing, hugging, breast feeding, sharing eating utensils or drinking glasses. It is just not spread by this type of casual contact.

What Are the Tests for Hepatitis C?

There are various blood tests used to find out if you have hepatitis C. The first test is to find out if you have ever been infected with hepatitis C. This is called an antibody test. This test only tells you if you have ever been infected. It does not tell you if you actually have the hepatitis C virus in your blood now. Another blood test called an HCV RNA or viral load test looks for the Hep C virus in your blood. There are other tests used to help find out what is going on in your liver and how sick or healthy you may be.

Antibody Test

When the hepatitis C virus enters your body, your immune system releases chemicals or proteins into your bloodstream to help fight off the hepatitis C virus. These are called antibodies. If you have hepatitis C antibodies it means that you have been infected with hepatitis C at one time, but it does not mean that you have active hepatitis

C. For some people (about 2 to 4 people out of 10) the body's natural defenses can rid the body of the virus, but for the other 6 to 8 people the body cannot kill off the virus – these people have chronic long-term hepatitis C. Hepatitis C antibodies do not protect against getting infected with the same or a different strain of Hep C in the future.

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SAFETY TIPS

- ✓ Do not share needles or works (cottons, cookers, ties) used to inject drugs, hormones, steroids and vitamins. Do not even share the water. Wash hands before injecting.
- ✓ Make sure that in healthcare settings standard safety precautions are being carefully followed.
- ✓ Do not share any personal hygiene items such as razors, toothbrushes, nail clippers or pierced earrings. If you live with someone else, make sure that your personal hygiene items are covered and kept in a different area of the bathroom so that someone doesn't accidentally pick up and use an item.
- ✓ Make sure tattoo and piercing equipment is sterile – a tattoo or piercing shop will have a machine called an autoclave that will sterilize equipment using

heat and steam. For a tattoo – make sure that a new needle and ink pot are used for each person. For a piercing – make sure that a new needle is used and that the package that contains the needle is opened up in front of you.

- ✓ Cover any open cuts or wounds.
- ✓ If you are coinfecting with HIV and Hep C use condoms and barriers to help prevent transmission.
- ✓ Mothers with HIV and Hep C can transmit hepatitis C to their babies during pregnancy or birth so talk to your doctor or nurse for advice on what to do.
- ✓ Do not share straws to snort drugs, or pipes to smoke crack.

What Are the Tests for Hepatitis C?

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Hepatitis C Viral Load Test

There is a blood test that looks to see if it can find the virus in you. It is called a hepatitis C viral load or HCV RNA test. There are two reasons this test is done. The first reason is to tell you if you still have the virus in your body.

The other important reason for having a viral load test is for treatment. It can help to tell you the chances of getting rid of the hepatitis C virus from your body with HCV medicines and whether the medicines are working.

The really important thing to remember about the viral load is that the amount of hepatitis C virus you have in your body does not mean how sick you are. For example, having a lot of virus (high viral load) does not mean that you will get sicker more quickly. For this reason the viral load test is not a very good test for monitoring or telling you how much the hepatitis C virus is damaging your body.

ALT Levels

One of the most common blood tests used is a blood test that measures a certain chemical in your blood called ALT. This chemical is released by the liver into the blood when the liver is damaged or sick. High levels of ALT can be caused by many things like alcohol, drugs, toxins, and viruses such as hepatitis C.

Unfortunately, ALT measurement is not a perfect test for people with HCV or people who are coinfecting with HIV and Hep C. Most people with what we call “normal” ALT levels will have little damage, but some people can still have ongoing liver damage.

If people are taking medicines for treating HIV it is important that the liver is monitored regularly since some HIV meds can be hard for the liver to process safely.

Genotypes: Different Kinds of Hepatitis C

Not everyone with Hep C has the same kind. In fact, there are six different kinds or strains of Hep C. These different kinds of Hep C are called genotypes and are numbered 1 to 6. A person’s genotype is found by checking the blood. The genotype a person has stays the same over time unless someone gets re-infected with another genotype.

Knowing the genotype you have is really important to your doctor because some genotypes are somewhat easier to treat with the medications used to treat Hep C. Also, the kind of genotype you have will tell your doctor how much of one of the medicines – ribavirin – to give you and how long you should take the medicines. If you have genotype 1 your doctor may treat you with an HCV protease inhibitor.

Just because you have a certain genotype does not mean that you will get less or more sick. This is the same for people with HIV/HCV coinfection.

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What Are the Tests for Hepatitis C?

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Other Blood Tests

There are many blood tests that are used to see how well your liver is working. These tests will look at many types of chemicals or markers that the liver produces and releases into your bloodstream. So in addition to the blood test you take to monitor your HIV there are other blood tests to see how well the liver is working.

Liver Biopsy

Right now, a liver biopsy is the best way to find out if your liver is healthy or damaged. It is also the best way for your doctor to know whether you have any other liver conditions.

During a liver biopsy, a needle will be put into your liver and a small sample of liver tissue taken out. Try not to worry too much because most people only have mild to moderate pain. If you are nervous about the test, ask your doctor for some medicine to help you relax. The liver biopsy is done while you are awake. Sometimes an ultrasound is also done before the biopsy to take an image or picture of the liver. This will help to decide where the needle needs to be inserted and if there are certain other problems with the liver.

Most people are really concerned about having a biopsy because of the pain. The

good news is that although most people who have a liver biopsy have some pain, it is usually mild to moderate pain. A few people have severe pain and may need to be watched closely to make sure that there are no other problems.

After the biopsy is performed a patient will lay on the right side of the body and will be checked for several hours to make sure nothing serious happens.

Talk with your doctor or nurse about having a biopsy. They will tell you what to do before and after the test.

After the biopsy is done the liver tissue will be sent to another medical person to look at under a microscope and issue a report on the health of the liver.

Scientists are studying other ways to get the same information that they now get from a liver biopsy. These are different types of blood tests that measure certain blood chemicals. There are also tests where radio waves are bounced off the liver to find out if the liver is scarred. The new tests can tell if the liver has no damage or if there is a lot of damage to the liver, but, unfortunately, they do not tell you whether the liver has moderate damage. For this reason blood tests cannot replace the liver biopsy – at least at this time. ■

What Are the Symptoms?

There are many people with Hep C who have no symptoms. Some of the symptoms of Hep C are similar to the symptoms of HIV. The most common symptom is feeling tired a lot (fatigue). Another symptom of Hep C that is like HIV symptoms is having fevers and night sweats. Other symptoms people with hepatitis C report is feeling sick to their stomach, aches and pains in their muscles, joints, stomach, and liver. Others say that they feel depressed or worried all the time. Still others say that they can't think or remember as well as they used to before getting hepatitis C. These types of symptoms can be very troubling and they should be reported to a doctor or nurse to make sure that they are from hepatitis C or HIV and not from another illness or condition. The good

news for most people with these types of Hep C symptoms is that it may not mean that you are getting any sicker – it may just mean that your body is fighting the Hep C. But talk to your doctor or nurse about any of these symptoms to make sure they are not serious.

There are other symptoms that people can have if their liver is really damaged and scarred. The term for this condition is called cirrhosis (sir-oh-sis). When you develop cirrhosis the liver cannot perform many of its important functions. There will be many warning signs and symptoms that your doctor will need to know about. For this reason it is important to have regular check-ups with your doctor to keep an eye on you more closely and treat you for some of the symptoms. ■

CIRRHOSIS OF THE LIVER

COMPENSATED CIRRHOSIS

means that the liver is scarred but can still do many of its important functions to keep you healthy; people with compensated cirrhosis may have few or no symptoms.

DECOMPENSATED CIRRHOSIS

means that there is so much scarring that the liver can no longer do its job. People who have this type of severe scarring can develop many signs and symptoms, such as bleeding from the blood vessels in the throat, retaining a large amount of fluid or liquid around the stomach, legs and feet and even a type of brain disease that causes changes in the way people act and severe mental confusion.

Will I Get Sick?

Many people with hepatitis C and HIV can lead normal lives; however, some people with hepatitis C and HIV will get sick. The damage caused by hepatitis C mostly takes place in the liver. When the hepatitis C virus gets into the liver it can irritate it and cause it to become inflamed like a sore. The inflammation can lead to the liver becoming scarred, and for some people this can lead to a form of cancer of the liver.

The important point to remember is that hepatitis C usually takes time to damage the liver. In people with HIV and Hep C coinfection the damage caused to the liver can happen more quickly than in someone with just hepatitis C. Some studies have found that it could happen in about 7 years.

That's why it is so important to take really good care of yourself and talk with your doctor or nurse about ways to stay healthy and whether treatment is needed. But there is good news that in some people who are living well with HIV their HCV disease is similar to someone who has Hep C alone. That's why it's so important to make sure to work as closely as possible with a medical team to stay as healthy as possible.

There are also many other things that you can do to stay healthy, such as eating a healthy diet, getting regular exercise, cutting down or stopping drinking alcohol, joining a hepatitis C or HIV/Hep C support group, taking HIV and HCV medicines – and many other ways to stay healthy. ■

What about Hep C Treatment?

There are three medicines (called combination therapy) to treat hepatitis C – interferon, ribavirin and an HCV protease inhibitor.

Interferon is taken as a shot given under the skin, and ribavirin comes in pills that are taken twice a day. Today, a longer acting (time-released) form of interferon – pegylated (peg-a-lated) – is more commonly used.

An HCV protease inhibitor is a pill that is either taken three times a day or every 8 hours. The addition of an HCV protease inhibitor to the combination of pegylated interferon and ribavirin therapy has been approved for people with genotype 1 who are HCV mono-infected, but not for people with HCV who are also infected with HIV. There are studies now looking at treating HCV in people who also have HIV, and more information is expected within a year. Talk with your doctor about whether it is safe to take the HCV protease inhibitors now or if you can wait.

More about Treatment

It is important to know what type of hepatitis C (genotype) you have because it will tell you how much ribavirin to take and help your doctor to decide if you should take an HCV protease inhibitor.

Everyone with HIV and Hep C should be checked to see if they need to be treated for their Hep C because the liver will become more damaged and it will happen sooner in someone who also has HIV. The chances for someone coinfecting with HIV and Hep C of getting rid of Hep C is less than for someone who has Hep C alone. But many people with HIV and Hep C have been able to rid their bodies of hepatitis C.

There are many reasons to be treated, such as getting rid of the Hep C virus, and improving the way you feel. There is also the added benefit that getting rid of Hep C

can make the liver healthier and reverse the liver scarring due to Hep C. For people with HIV this may mean that because the liver is healthier it will be easier for the liver to process HIV drugs.

Hep C medications can cause side effects, some of which are like the side effects of HIV drugs. The side effects may get worse or happen more often when HIV and Hep C drugs are used at the same time. The best way to handle these side effects is by trying to treat the side effects before they become worse. For this reason it is really important that you work closely with your doctor and nurse. Getting support from every area of your life – support groups, family, friends and co-workers – is one of the most important things you can do to help with the side effects. ■

What about HIV Treatment?

HIV can be treated effectively in most people with Hep C. The medicines for HIV have to be processed by the liver and some HIV medicines may be hard for the liver to process. If the liver is severely damaged it can affect how well the HIV drugs are handled by the liver. Some HIV medicines can cause ALT and other liver chemicals or enzymes to increase, but usually the enzyme levels will even out over a period of time. Damage to the liver from HIV medicines is most often

seen in people who already have a lot of liver damage, but even in this group it is not very common.

Most people with Hep C can take HIV medicines if their liver health is watched closely. It may be necessary to change to a different type of HIV drug. If possible it may be better to have a doctor for HIV and another doctor for Hep C, but some doctors are very good at taking care of both diseases. ■

What about Herbs?



Some people with HIV and Hep C take herbs and vitamins. There are some herbs and vitamins that some doctors consider “safe” and other herbs and vitamins that should not be taken because they may interfere with the way the body processes HIV and Hep C drugs and could possibly damage the liver. Since herbs are like medicines it is very important that you talk with your doctor or nurse before taking any herbs or high doses of vitamins.

SOME TIPS ABOUT HERBS & VITAMINS

- ✓ Some people think that since herbs are natural that they can take them safely – but just because an herb is natural does not mean that it is safe. There have been deaths of people reported from taking certain herbs.
- ✓ Do not take more herbs or vitamins than you are instructed to take.
- ✓ Get advice about herbs from experts – medical doctors and herbal doctors.

How Do I Stay Healthy?

There are many ways to stay healthy. Here's our top ten list of things you can do to stay healthy

1. See your doctor and nurse for regular check-ups. Make sure you tell them about any problems or symptoms you are having. Talk to them about medicines to treat HIV and Hep C.
2. Eat a healthy and balanced diet with lots of vegetables and fruits, and try to stay away from too much sugar, salt and fatty food. Balance the amount of food you eat with regular exercise such as walking. Walking will help to make you feel less tired.
3. Stay away from or protect yourself from chemicals. Everything you breathe or absorb through the skin must be filtered by the liver. Fumes from paint thinners, pesticides, and aerosol sprays can damage your liver and you should be careful around these products.
4. Rest when you are tired. Try to find time during the day for a short nap or times you can unwind and relax.
5. Get the hepatitis A and hepatitis B vaccines if you have not already been infected. You won't want to get another liver disease that might make your hepatitis C worse so ask your doctor or nurse if you need to be vaccinated.
6. Cut down on or stop drinking alcohol. Alcohol can harm the liver so it is important that you try to stop drinking. If you can't stop drinking, cut down on the amount of alcohol you drink and ask for help on ways to stop drinking alcohol.
7. Be careful when mixing alcohol, drugs or herbs or when using over-the-counter drugs such as Tylenol® and ibuprofen.
8. Join a support group. People in a support group can help you with emotional problems and give you information about how best to take care of yourself.
9. Try to do things that help you cut down on stress and to keep a positive attitude, such as meditation and prayer.
10. Do not eat raw or undercooked shellfish because these can harm the liver of someone with Hep C.

Making Changes

After reading about all the ways to stay healthy you are probably thinking that you can't do all of these things – most people would feel this way! But remember it is not an all or nothing situation. Anything you can do to become healthier is a success! Remember to take small or simple steps when making any major change. Start slowly and congratulate yourself on any success along the way. Even if you do not succeed at first, congratulate yourself that you are trying to make these very difficult changes in your life. When it comes right down to it, you are the person who is in control of making the needed changes and when you feel that it can be done. But remember that you do not have to go it alone – get as much support from your family, friends, doctor, nurses and counselors as possible.

Bottom Line

It is important that if you have ever been in a situation where you may have caught hepatitis C that you are tested. If you have hepatitis C there are many things that you can do to stay healthy. One of the most important things that you can do is to find out as much as you can about hepatitis C and work with your medical team to make the best choices to keep you healthy. There many more things that you can do to educate yourself. The Hepatitis C Support Project and our web site www.hcvadvocate.org contain information about all of these things in much greater detail.

Resources

Recommended HIV Resources Include:

- Project Inform:
www.projectinform.org
Hotline: 800-822-7422
- National AIDS Treatment
Advocacy Project:
www.natap.org
- San Francisco AIDS
Foundation:
www.sfaf.org
Hotline 900-367-2437
- Aidsmed.com:
www.Aidsmeds.com
- HIV and Hepatitis.Com
www.hivandhepatitis.com

Hep C Resources

- Hepatitis C Support Project / HCV Advocate
www.hcvadvocate.org
- American Liver Foundation
800-465-4827
www.liverfoundation.org
- Hep C Connection
800-522-4372

Pharmaceutical resources

- **Genentech** (Member of the Roche Group):
1-877-PEGASYS (1-877-734-2797)
www.genentechaccesssolutions.com/portal/site/AS/
- **Merck** (includes Schering-Plough subsidiary):
1-866-939-HEPC (4372)
www.merck-cares.com
- **Kadmon Pharmaceuticals** (formerly 3 Rivers Pharmaceuticals) 1-800-405-8506
www.3riverspharma.com
- **Vertex:**
1-888-552-2494
Patient Assistance: www.vrtx.com/patients.html

Tattoo resources

If you are thinking about getting a tattoo it is important to realize that there is a very real chance that you could get hepatitis B, hepatitis C or another infection while having a tattoo if safety practices are not followed very carefully. Find out more at: www.hepatitistattoos.org

