

# EASY A Guide to Hepatitis C

A publication of the Hepatitis C Support Project ●

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# Introduction

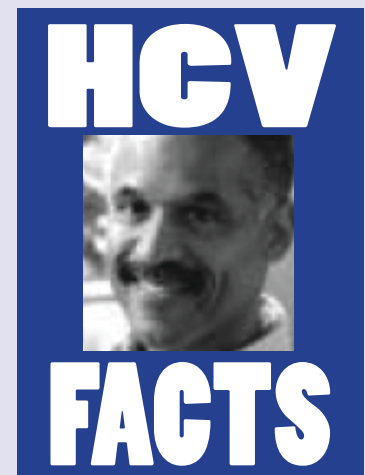
Hepatitis C (HCV for short) is a virus that lives in human blood. A virus is one of the smallest living things known to exist inside plants and animals. HCV makes new hepatitis C viruses by infecting the liver, and after many years the liver can become so damaged by hepatitis C that it cannot perform many of the important jobs that it must do to keep us healthy.

You can only get hepatitis C by getting HCV-infected blood from someone who has hepatitis C, and ONLY if that infected blood gets into your body.

Many people have hepatitis C so you are not alone. It takes many years for hepatitis C to cause damage to the liver and to make someone sick. There are many things that people can do to help fight hepatitis C, and the best time to start is early – before hepatitis C has a chance to damage your liver.

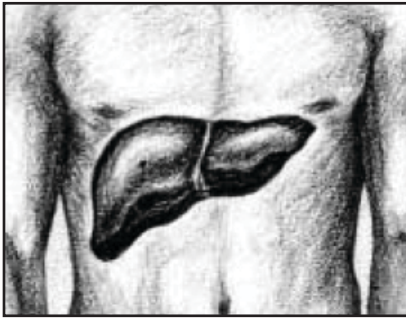
One of the most important things you can do is to stop or cut down on drinking alcohol and smoking tobacco. There are also medicines to get rid of hepatitis C and they work for about one half of the people who take them. Talk with your doctor or nurse about ways to stay healthy and about medications that can get rid of hepatitis C, and if you should be treated.

- The government estimates that there are about 4 million Americans infected with hepatitis C. However, some experts believe that the number of Americans infected with hepatitis C is closer to 5 to 6 million Americans.
- About 10,000 Americans die every year as the result of hepatitis C. It is expected that the number of people in the next 10 years who will die from hepatitis C will be 3 times more than now.



- Hepatitis C is so common that it is the main reason that people need liver transplants.
- Anyone with hepatitis C should try to stop drinking or cut down on drinking and smoking tobacco.
- People with hepatitis C should be given shots to protect them from hepatitis A and hepatitis B, if needed.

# What is The Liver?



The liver is the largest organ in your body. It is reddish-brown and is about the size of a football. The really amazing thing about the liver is that if they took away half the liver – it would grow back in 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 the body 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 many vitamins and this can damage the liver.

## HEALTHY LIVER TIPS

- ✓ Stay away from toxic fumes or liquids.
- ✓ Stop drinking alcohol, smoking tobacco and taking street drugs. If you can't stop, try to cut back – talk with a doctor, counselor, family or friends about getting some help to stop.
- ✓ Eat a healthy and well-balanced diet.
- ✓ Talk to your doctor about vaccines to help protect the liver, if needed.
- ✓ Tell your doctor about all medicines you are taking, even if it's just an aspirin, vitamin, herb or Tylenol.
- ✓ Drink lots of water.
- ✓ Stay away from raw or undercooked shellfish.

## 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. If you do not have hepatitis C, stay safe by making sure that you stay away from any blood from other people.

# Getting Hepatitis

## ***...from Needles & 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. Things used to inject drugs include 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.

## ***...from Sex***

Getting hepatitis C by having sex isn't very common, but it could happen if someone has sex with a lot of different people and/or engages in risky behavior – especially “rough sex” and other sexual practices that involve blood. Many experts believe that the risk of spreading hepatitis C is very low if people have sex with only one person over many years. But if the person with hepatitis C or the person you are having sex with is worried about catching hepatitis C then use condoms (rubbers) during sex. People

who have many sex partners or who have other sexual diseases should always use rubbers and take other precautions, such as covering any open cuts or wounds since these could pass hepatitis C during sex. Hepatitis C is also easier to spread while a woman is on her period. Remember to be safe if there is any blood during sex.

## ***...from Blood***

Another way that many people got hepatitis C is from having a blood transfusion or 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.

## ***...other Ways to Get Hepatitis C***

Some experts believe that you can get hepatitis C in other ways, such as by getting a tattoo or piercing or sharing personal hygiene items (toothbrushes, razor blades, nail clippers). Although there has never been a proven case of this happening, it remains a very real concern.

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## **The Good News**

The good news is that you can not get or give hepatitis C by sneezing, hugging, breastfeeding, 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 tests to find out if you have hepatitis C. The first test is to find out if you have ever been infected with HCV. 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. There are many 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 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 the hepatitis C virus in your body now. For some people (about 2 to 3 people out of 10) the body's natural defenses can get rid of the virus, but for the other 7 to 8 people the body cannot kill off this virus.

## **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 test. There are two reasons this test is done. The first reason is to tell you whether you still have the virus in your body. The other important reason for having a viral load test is for treatment. It can help tell you the chances of getting rid of the hepatitis C virus from your body with HCV medicines and whether or not the medicines are working.

The really important thing to remember is that the amount of hepatitis C virus you have in your body is not a sign of how sick you are. For example,

*CONTINUED ON PAGE 6*

## **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.
- ✓ Cover any open cuts or wounds.
- ✓ Sexual transmission is low, but the use of condoms and barriers will help reduce the risk even more.
- ✓ A mother can transmit hepatitis C to her baby during pregnancy or birth, but this doesn't happen very often.
- ✓ Do not share any straws to snort drugs, or pipes to smoke crack.
- ✓ 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. Cover personal items and keep them separate from other people you live with.
- ✓ Make sure tattoo and piercing equipment is sterile. For a tattoo – make sure that a new needle and ink pot is 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.

## **What Are The Tests For Hepatitis C?**

CONTINUED FROM PAGE 5

having a lot of virus (high viral load) does not mean that you will get sicker more quickly. For this reason it is not a very good test to monitor or tell 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, it is not a perfect test for people with HCV – most people with what we call “normal” ALT levels will have little damage, but some people can still have ongoing liver damage. In the past, if people with HCV had normal ALT levels they were not treated with HCV medications, but now doctors will treat hepatitis C if there are other signs that the liver is damaged.

### **Genotypes: Different Kinds of Hepatitis C**

Not everyone with hepatitis C has the same kind. In fact, there are six different kinds of hepatitis C. These different kinds of hepatitis C are called genotypes and are numbered 1 to 6. The genotype test is a blood test.

Knowing which genotype you have is really important to your doctor because some genotypes are easier to treat with HCV medications. For example, genotype 1 is a little harder to treat than genotypes 2 or 3. Also, the kind of genotype you have will tell your doctor how much and what type of medicine to give you and how long and how often you should take the medicines.

Just because you have a certain genotype does not mean that you will get less or more sick. It is important to remember that most people with hepatitis C never develop symptoms – no matter which type they have.

### **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 that the liver produces and releases into your bloodstream.

### **Liver Biopsy**

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 other liver conditions.

During a liver biopsy, a needle is put into your liver and a small sample of liver tissue is 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 performed to take a picture of the liver. This will help to decide where to put the needle for the biopsy.

Most people are really concerned about having a biopsy because of the pain. The good news is that only about half of people who have biopsies done have some brief pain that may spread to the right shoulder. Although rare, some people will have to be hospitalized after a biopsy due to pain or from another organ being accidentally hit during the test.

After the biopsy is performed the 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 advise you about 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 biopsies. Some of these new blood tests measure certain blood chemicals. These new tests can tell if the liver has no damage or there is a lot of damage to the liver, but unfortunately, they do not tell your doctor if you have moderate damage to the liver – for this reason blood tests can not replace the liver biopsy at this time. ■

# What Are The Symptoms?

Some people with hepatitis C have no symptoms but others can have many symptoms. The most common symptom people with hepatitis C say they have is feeling tired a lot (fatigue). Other symptoms people with hepatitis C report are feeling sick to the stomach, and aches and pains in their muscles, joints, stomach, and liver. Some people have fevers and may sweat in their sleep. 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 your doctor to make sure that they are from hepatitis C and not from another illness or condition. The good news is that for most

people with these types of symptoms it may not mean that you are getting any sicker – it may just mean that your body is fighting the hepatitis C. But talk to your doctor about any of these symptoms you are having 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**

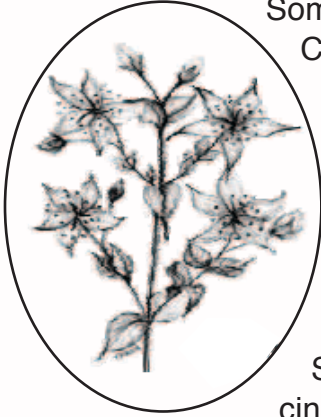
### **COMPENSATED CIRRHOSIS**

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

### **DECOMPENSATED CIRRHOSIS**

means that there is so much scarring that the liver can no longer do its job without help. 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, and even a type of brain disease that causes severe mental confusion.

# What About Herbs?



Some people with hepatitis 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 can damage the liver.

Since herbs are like medicines it is very important that you talk with your doctor 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 – but just because an herb is natural does not mean that it is safe. Some herbs can make you sick and damage the liver.
- ✓ 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 of any problems or symptoms you are having. Talk to them about medicines to treat hepatitis 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 should be avoided.
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 illness that might make your hepatitis C worse so ask your doctor or nurse if you need to be vaccinated.
6. Cut down 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. Try not to worry too much. Learn as much as you can about hepatitis C so that you know what you are facing.

## Will I Get Sick?

Many people with hepatitis C can lead normal lives and will die of something other than hepatitis C. However, some people with hepatitis C will get very sick, but this usually takes many years (up to 40 years). The damage caused by hepatitis C usually 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 a few people hepatitis C can lead to a form of cancer of the liver. There is a simple way to estimate how many people will get sick from hepatitis C:

About 75 out of 100 people who get hepatitis C will develop chronic (long term) infection.

About 20 people out of the 75 people who have chronic hepatitis C will become very ill or sick. It usually takes many years to severely damage the liver.

About 2-3 people out of the 75 people who have chronic hepatitis C will get liver cancer.

The important point to remember is that hepatitis C usually takes a long time to damage the liver and many people will never get sick from hepatitis C. There are also many things that you can do to stay healthy such as eating a healthy diet, getting lots of exercise, cutting down or stopping drinking alcohol, joining a hepatitis C support group, taking HCV medicines – and many other ways to stay healthy.

## What About Treatment?

If you are thinking about being treated for hepatitis C, there are many things to think about. The decision to treat should be made by you and your doctor based on how hepatitis C is affecting you. You will need to know your viral load, genotype and how much your liver is damaged. The good news is that there are medicines to treat hepatitis C that can get rid of the virus in up to about 70% (7 out of 10 people) of the people who have genotype 1. For people with genotypes 2 or 3, treatment works for about 70-90% (7 to 9 people out of 10). However, treatment is

not easy and the decision is a difficult one for most people. Talk to your doctor about the possible benefits as well as the treatment side effects you might get. There are three medicines (called combination therapy) to treat hepatitis C – interferon, ribavirin and a protease inhibitor. The best way to treat HCV is with a combination of pegylated (peg-ated) interferon and ribavirin for people with genotypes 2 and 3 and the triple combination of pegylated interferon, ribavirin, and an HCV protease inhibitor for people with HCV genotype 1.

## Resources

### ***For more information about HCV, contact the following organizations***

- Hepatitis Foundation International  
1-800-891-0707, [www.hepfi.org](http://www.hepfi.org)
- American Liver Foundation  
1-800-465-4837, [www.liverfoundation.org](http://www.liverfoundation.org)
- Hep C Connection  
1-800-522-4372, [www.hepc-connection.org](http://www.hepc-connection.org)

### ***Suggested Reading***

- *The Hepatitis C Help Book*, by Misha Cohen, OMD, LAc, and Robert Gish, MD. St. Martin's Press.
- *Living with Hepatitis C: A Survivor's Guide*, by Gregory T. Everson, MD, and Hedy Weinberg. Hatherleigh Press. 800-367-2550.
- *The First Year—Hepatitis C: An Essential Guide for the Newly Diagnosed*, by Cara Bruce and Lisa Montanartelli. Marlow and Co.

### ***Pharmaceutical resources***

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



# Bottom Line

It is important, 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 website – [www.hcvadvocate.org](http://www.hcvadvocate.org) – contain information about all of these things in much greater detail.

## Easy C Facts

- 100 People
- African Americans & HCV
- Alcohol and HCV
- Antibody Test
- Biopsy
- Diet
- Feeling Tired
- Genotype
- Get Healthy
- Herbs
- HIV-HCV Coinfection
- Hygiene Items
- Immune System
- Liver
- Mother-to-Child
- Natural & Alternative Medicine
- Needle Exchange
- Piercing
- Prevention
- Ribavirin Warning
- Sex and Hep C
- Sleep
- Tattoos
- Treatment
- Viral Load
- What Is ALT?
- What Is Cirrhosis?
- What Is Hepatitis C?
- Whom Should I Tell?

