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Hepatitis C Information Sheet.

What you should know about having HCV infection:

HCV infection is a chronic viral infection of the liver. That means HCV virus is in you, residing mostly in your liver. It causes low grade (small amount) inflammation in your liver. It is neither "active" nor "inactive". Rather, everyday, week after week, year after year, the virus is residing in your liver and your immune system is trying to get rid of it. That is where the inflammation comes from and inflammation causes damage to your liver. Even though you feel perfectly fine and have no symptoms, this is going on. For some people, the inflammation is so mild, that after 20 years of infection, they only have a small amount of damage and fibrosis (scarring) of the liver. And the fact that they have HCV infection is not a big deal. It will probably not harm them. For other people, after 20 years of infection, they have already developed cirrhosis of the liver, and eventually they will develop end stage liver disease with early death. But you cannot tell the difference between the people who will never be harmed by HCV from the person who will die young from HCV infection just by looking at them

Most people will not develop cirrhosis. We say, although it is only guess, that about 20 per cent of people with HCV infection will develop cirrhosis. That means 80% of people will not develop cirrhosis. We do know that people who drink alcohol are more likely to get cirrhosis than those who do not, and the more you drink, the more likely you are to get cirrhosis. To really know how your liver is doing requires a liver biopsy.

Transmission of HCV.

Most people became infected from HCV by IV drug injection or having received a blood transfusion before 1992. Other ways of getting infected such as tattoos, sexual transmissions, contact with another person, or getting it from your mother at birth are possible but less likely ways of getting it. Snorting cocaine may be a way of getting it, but we are not sure.

Preventing Transmission of HCV infection.

It is very hard to give HCV to another person. You do NOT have to worry about sharing food, cooking utensils, plates, forks or knives with other people. You do not have to worry about hugging or kissing anyone; you will not give them HCV. When it comes to sex, we tell people who are in a monogamous relationship that they do not have to do anything different than what they have been doing. If not in a monogamous relationship we tell people to always use condoms. (That is what we tell everyone with or without HCV). People with HCV should be

careful about any wounds, scrapes or abrasions they may have. You should cover up any wounds.

What about using Tylenol (acetaminophen)?

You can use Tylenol in small amounts. Do not take more than six, regular strength Tylenol per day. People often ask about using Tylenol (acetaminophen) or aspirin products. Examples of aspirin products are Motrin (ibuprofen), Aleve, Naprosyn, and Anacin. Aspirin products are different than Tylenol. Tylenol is acetaminophen. Sometimes it is called non-aspirin. You may have heard that Tylenol is bad for your liver. In low doses Tylenol is very safe; safer than aspirin products. But in high doses or even in medium doses it can hurt your liver. Tylenol is safe to take, but use regular strength Tylenol, not extra strength Tylenol and do not take more than six Tylenol in one day.

You can take aspirin products, but remember any dose of aspirin can sometimes harm people. One of the most concerning risks of aspirin is a bleeding ulcer. Aspirin can also hurt your kidneys and this is especially true if you have advanced liver disease. If you have advanced liver disease you should not take ANY aspirin product.

Alcohol

The single most important thing you can do to help your liver is not drink alcohol. People who drink heavily are much more likely to develop cirrhosis of the liver than those who do not drink. But even moderate alcohol use can harm your liver when you have hepatitis C. Think of HCV infection as being a mild fire in your liver, and alcohol as being gasoline. Stop using alcohol.

Vaccination against Hepatitis A and Hepatitis B:

As part of your evaluation you will most likely be tested to see if you have been exposed to hepatitis A or hepatitis B. If you have not, then we would recommend you be vaccinated against those viruses. This is done at the Snohomish County Health Department. Please ask your doctor about this and ask for an information sheet on how to get vaccinated.

Taking over the counter supplements:

Many people are tempted to take supplements, especially those that are advertised to improve your liver or boast your immune system. We do not recommend any supplements because the advertising claims of all these supplements are not true. There is no information to show that they work (despite their claims), and in fact the more we know about hepatitis and the liver the more we understand that supplements DO NOT work to help the liver. Supplements are foreign chemicals that the liver must metabolize and get rid of; even the "all natural" ones are foreign chemicals as far as your liver is concerned. Some supplements are toxic to the liver.

What about Milk Thistle?

Many people take Milk Thistle (silymarin) for the treatment of hepatitis C. Studies done so far do not show any benefit by taking Milk Thistle, but there is no harm in taking Milk Thistle either.

Vitamins and minerals

Do not take any vitamins with iron. Do not take any iron pills such as ferrous sulfate or ferrous gluconate. Do not take multi-vitamins that have iron. Other vitamins such as Vitamin B and Vitamin C are okay to take. We do not recommend any vitamin supplements. Vitamin A can cause liver damage if taken in large amounts. We do not recommend any Vitamin A supplements except what is found in a typical multivitamin pill. Vitamin E is being studied as a treatment for liver disease.

Diet and exercise

There is not a special diet for people with hepatitis C, and people who tell you there is are wrong. When it comes to diet common sense applies. A well rounded diet with fresh fruits and vegetables is what we recommend. People who have advanced liver disease are sometimes placed on a low protein and low sodium diet. Moderate daily exercise is highly recommended. The only exception this is people with advanced liver disease

Tobacco

Smoking is doing to your lungs exactly what hepatitis C is doing to your liver. It causes constant low grade inflammation which leads to fibrosis and scarring of you lungs. We recommend stopping smoking. The University of Washington will not do a liver transplant on anyone who is smoking.

Liver enzymes.

There are several blood tests that your doctor will check to evaluate your condition. One set of numbers is your ALT and AST. Other names for these blood tests are: liver enzymes, LFTs, transaminases, SGOT, SGPT. These liver numbers are important because they can indicate how inflamed your liver is at the moment. BUT these numbers DO NOT tell us anything about the condition of your liver. They do not tell us how scarred or fibrotic or damaged your liver is after many years of infection. To find out how damaged your liver is after many years infection requires a liver biopsy.

Viral load.

One of the tests for hepatitis C is to measure the amount of virus in your blood. This is called the viral load or quantitative PCR. This test is important because people with a low viral load are more likely to respond to HCV treatment with interferon/ribavirin and people with a high viral load are less likely to respond to treatment. BUT viral load does not tell you how damaged your liver is; it does not tell you if you are getting worse if the number goes up or better if the number goes down. The response to treatment with interferon/ribovirin between a high viral load and a low viral load is not large, not nearly as large as the difference in response to treatment between different hepatitis C genotypes (see next paragraph).

Hepatitis C genotype.

There are slightly different types of hepatitis C that we call genotypes. The majority of Americans have HCV genotype 1 (Ia or Ib). Some people have HCV genotype 2 or genotype 3.

Genotypes are important because the average person who has HCV genotype 1 has about a 45% chance of having complete success during treatment with Interferon/ribovirin, but people with HCV genotype 2 or genotype 3 have an 85% chance of successful treatment with interferon/ribavirin. This is a big difference.

Liver biopsy

Your doctor will talk with you about a liver biopsy. The decision to get a liver biopsy is your decision. When we say that about 80% of people will get not get cirrhosis and 20% of people will get cirrhosis of the liver, this is a guess. It does not say anything about how damaged your liver is. Generally people become infected with the hepatitis C virus when they are young, and they come to see us when they are middle aged. The question is: how damaged is their liver? The answer is we do not really know unless they get a liver biopsy. Some people look and feel well and on liver biopsy they have only a tiny amount of damage and scarring in their liver, other people look and feel well, but on liver biopsy they already have cirrhosis of the liver. Most people fall somewhere in between.

A liver biopsy involves going to the hospital as an outpatient. An IV is placed in your arm, medicine is given to relax you and for pain. They do not "put you to sleep", but you very comfortable. A needle is inserted between your lower ribs on your right side. You have to stay at the hospital for four hours after the biopsy so they can observe you (so bring a book). The next day it feels like you got kicked in the side. The risks of a liver biopsy are bleeding that may require a blood transfusion, getting a hole in some other organ that would require surgery to fix, collapsing a lung that would require a tube to re-expand your lung or other things. The chance of anything bad happening is small. The most common complication is bleeding and the chance of that happening is about one in 500 or one in a 1000, the chance of other things happening is even less.

Treatment of hepatitis C with interferon and ribavirin.

There is treatment for hepatitis C, but it is a difficult treatment that often fails. Interferon is a substance that your immune system makes to fight infections; the interferon that we give you is the exact same stuff that your immune system makes. We are just giving you more of it so hopefully your immune system can get rid of the hepatitis completely. Interferon is given as an injection, like giving insulin injections. You give yourself an injection once a week or three times per week depending on what type of interferon is being used. Ribavirin is a pill that helps interferon work well. The Ribavirin pill you take everyday. Treatment is a difficult experience because:

1. You feel like you have the flu when you are on treatment, you will have headaches, muscle aches, fatigue, joint aches. Generally you feel bad.
2. You can have hair thinning or hair loss (this usually gets better after treatment is over.
3. You have to do the treatments for a year! (Unless you have genotype 2 or 3).

4. You have to have your blood checked once a month and you have to come in and be seen by us once month for the whole year. (To start treatment you get your blood checked the first week and the second week).
5. Worsening depression can be an issue. If you have tried to hurt yourself in the past you have to talk with your doctor. If you have thought about hurting yourself recently you should not undergo treatment with interferon/ribovirin and you should tell your doctor!
6. Treatment will lower your red blood cells, white blood cells and platelets, we expect this to happen. But we need to follow these counts closely and if necessary we will lower the dose of your medicine.
7. The chance of successful treatment for most people is about 45%. Success means the virus goes away and stays away. We call this a "sustained response" but really this is a cure of your hepatitis C infection.
8. Treatment is expensive.

There are good things about treatment:

1. Hepatitis C is the most common cause of cirrhosis and death from liver disease in the United States. It is also the number one reason for liver transplantation. Successful treatment will prevent your liver disease from progressing and to some degree your liver will improve. You will not have to worry about your liver any more (assuming you are not drinking heavily or doing other things to hurt your liver).
2. While a 45% success rate is terrible, it is also really fantastic. There is no other chronic virus that we can successfully treat medically.

Remember, there is no right or wrong answer when it comes to treatment. It is something that you need to decide for yourself after you have thought about the risks, benefits and trouble of treatment. Our job is to provide you with information, not tell you what to do. One exception though is people who have heavy scarring, or bridging fibrosis or early cirrhosis on liver biopsy. People with this type of liver biopsy are likely to go on and develop cirrhosis or end stage liver disease, so we would recommend treatment (but of course it is still your choice).