



HCSP FACT SHEET

HCV ADVOCATE

• HCV EDUCATION AND SUPPORT •

Dispelling HCV Myths

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Foreword

As the saying goes, “knowledge is power.” This is particularly true when it comes to living with a chronic illness such as hepatitis C. In this day and age of managed health care, it is extremely important that people learn as much as possible about any healthcare issue so that they can advocate for themselves in order to get the best medical care possible. Conversely, misinformation about a condition like hepatitis C can be especially dangerous, and could potentially lead to living in fear and isolation, making life with HCV even more difficult.

Considering that the hepatitis C virus was only identified in 1989, it is incredible how far we have come in our understanding of hepatitis C, and remarkable that we have medications that can eradicate the virus in the majority of people who are treated. However, we have some way to go before we can completely understand hepatitis C.

This fact sheet will focus on some of the most common myths.

Myth – Hepatitis C is a death sentence

After an initial diagnosis of hepatitis C, one must confront his or her mortality. Many people believe that every HCV-infected person will die of hepatitis C, and that it will happen very soon. This is one of the biggest fears that people with HCV face, especially those who are newly diagnosed. In recent years we have studied many different populations that have acquired hepatitis C within the last 10, 20, or 30 years or more, and it has been well-documented that only 10-25% of people chronically infected with HCV will experience serious liver disease progression that may result in death. The remaining 75-90% of people with chronic hepatitis C will live long and productive lives. However, we can not predict who will and who will not have serious disease progression. That is why it is so important that people with chronic hepatitis C are seen regularly by their medical providers to monitor their HCV health and status. There are

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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.

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also many strategies to stay healthy with hepatitis C that include good nutrition, daily exercise, stress management, avoiding alcohol and HCV treatment.

The percentage of people progressing to serious liver disease would drop even lower if more people were tested and those who are HCV positive were medically monitored and treated. But this is not to say that people with hepatitis C do not suffer and die. Conservatively, it is estimated that there are approximately ~4 million people in the United States and ~170 million people worldwide who are infected with hepatitis C; so even though a minority of people who are infected with hepatitis C develop serious complications, the large number of people who are infected with hepatitis C means that the future disease burden is going to challenge our medical system in ways we haven't seen before.

Myth – Everyone with hepatitis C should be treated with current HCV medications

Everyone with HCV should be evaluated on an individual basis. Currently, the major goals of HCV therapy are viral eradication, improvement in quality of life, and stopping or slowing disease progression. Treatment decisions should be made in partnership with a medical provider based on several considerations, including current health status, existing disease progression, likelihood of responding to current therapies, and quality of life. For example, people with minimal disease progression (little or no scarring of the liver) may want to wait until more medications are available that do not have as many undesired side effects. Conversely, someone with a decreased quality of life or serious disease progression (moderate to severe scarring of the liver) should be more aggressive in seeking medical treatment. But it is important to remember that people with minimal liver disease respond better to HCV medications, so

this needs to be factored into the decision making process. When HCV medications are developed that work for everyone and are easier to tolerate then the message will be “everyone with HCV should be treated.” However, with the use of the recently approved HCV medications and the development of even more potent medications to treat HCV, the wait and see attitude is starting to be replaced by a more aggressive approach to treating people who are good treatment candidates.

It is also important to keep in mind that hepatitis C is a public health problem so the more people who can be successfully treated translates into less transmission and eventually lower health care costs associated with more severe disease progression.

It is also important to remember that everyone who would like to be treated should have access to care, management and HCV medications and that no one should be excluded from HCV treatment. The 2002 National Institutes of Health Consensus Conference Statement states that “All patients with chronic hepatitis C are potential candidates for antiviral therapy.” In addition, from a public health standpoint, successful treatment of hepatitis C will lower the future disease burden and help to stop the spread of hepatitis C.

Myth – There are no effective medical treatments for hepatitis C

Treatments for hepatitis C have improved dramatically since the early days of interferon monotherapy, when sustained virological response rates (SVR, remaining virus-free during and 12 weeks after the end of treatment or viral cure) were measured in the single digits. Today we have medications that can cure up to 90% of people who take them. Furthermore, clinical studies have shown that, of people who have achieved an SVR, more than 99% continue to be HCV RNA (viral load) negative for 5 years post-treatment.

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Myth – Most people cannot tolerate the side effects from current HCV medications

This common myth prevents many people from seeking treatment because they have heard horror stories or worst-case scenarios experienced by some people taking the current HCV medications. Just as we have come a long way in improving treatment response rates since the early interferon monotherapy days, there have also been dramatic improvements in the way that side effects are managed. The truth is that therapy can be difficult, especially interferon-based therapies, but most people can complete the treatment regimen if they receive appropriate support from medical providers, family, friends, and others. The key to successfully managing side effects is a team approach that treats physical and psychological side effects as soon as they surface and well before they become unmanageable. Unfortunately, some people do not have access to the supportive care that is such a critical part of the treatment process. Of course, there are people who cannot tolerate HCV therapy for a variety of reasons, but they are the exception rather than the rule.

Myth – Hepatitis C is a sexually transmitted disease

HCV is transmitted in the vast majority of cases by blood-to-blood exposure. However, like many myths, this one is grounded in some truth. Hepatitis C can be transmitted sexually, but the risk is very low in most populations. It is difficult to study sexual transmission of HCV, but the majority of studies conducted to date have shown a 0-3% prevalence of HCV in the sexual partners of people in stable monogamous heterosexual relationships. In fact, the Centers for Disease Control and Prevention do not recommend barrier protection to prevent HCV transmission for heterosexual couples in exclusive relationships. However, this recommendation must be considered carefully, since there is still a 1-in-1,000 to 1-in-10,000 chance of transmitting HCV to one's sexual partner even in this setting.

Safer sex is recommended for people in so-called "high-risk" groups, usually defined as people with multiple sexual partners, men who have sex with men, women who have sex with women, prostitutes, and people seen at STD clinics. In these populations the risk of contracting HCV through unsafe sex is believed to be higher, but more studies are needed to clearly define the rate of sexual transmission.

Recently, there have been reported outbreaks of sexually transmitted cases of HCV among HIV positive gay men and men who have sex with men. For this reason it is recommended that gay men and men who have sex with men get tested for hepatitis C.

Myth – HCV viral load correlates with disease progression

It is logical to assume that if a person has more virus or a high HCV RNA (viral load), it would mean a faster disease progression, but study after study has not shown a correlation between the amount of virus and the stage or degree of liver damage. In fact, the only reasons for measuring HCV viral load are to confirm active infection (to make sure that there is replicating HCV), and during treatment to make sure HCV medications are working, and after treatment is completed to make sure the virus is still undetectable.

Myth – HCV viral load correlates with the symptoms of HCV

There have been no studies that have shown that someone with a higher viral load has more symptoms compared to someone with a lower viral load. In other words, people with a low viral load can experience as many symptoms as people with a high viral load and vice-versa.

Myth – People with 'normal' ALT levels have minimal disease progression

ALT (alanine aminotransferase) is an enzyme that is produced in liver cells and released into the bloodstream when there is damage taking place in the

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liver. Most people with hepatitis C and 'normal' ALT levels have minimal liver disease progression, but some people (about 20%) with 'normal' ALT levels have moderate to severe HCV disease progression. For this reason, many experts believe that the only way to really tell if an HCV positive person has liver damage is by a liver biopsy or non-invasive tests rather than through the measurement of ALT levels. Studies have found that people with 'normal' ALT levels can be successfully treated with current HCV medications.

Myth – People with HCV should not take Tylenol

This myth grows out of the liver-related problems that people have when taking large amounts of acetaminophen (brand name Tylenol) or paracetamol especially when consuming alcohol. Medical providers often recommend acetaminophen to relieve symptoms associated with hepatitis C infection and treatment-related side effects. But it is very important that people follow the recommended acetaminophen dose and duration of use prescribed by their healthcare provider and read the product label of any medications they are taking since acetaminophen is often a common ingredient in many over-the-counter and prescribed medications. It should also be noted that people with advanced liver disease should avoid acetaminophen.

Myth – Genotype 1 is the 'worst' genotype

This myth is the result of earlier studies that reported a faster rate of disease progression in people infected with HCV genotype 1. Like many reports in the early years of HCV research, this has been debunked by more recent research which has not shown a correlation between genotype 1 and more rapid disease progression. In regards to the other genotypes, genotype 3 causes steatosis which could potentially increase the rate of HCV disease progression and lower treatment response, but more studies are needed of steatosis in people with

genotype 3 to completely understand this. The exact way that hepatitis C causes steatosis is unknown.

Genotype information is important, though, for people seeking treatment because genotype will dictate how long to be treated, which medications to use, and the dose of ribavirin that is given.

Myth – HCV is an asymptomatic disease

This is another myth that is grounded in some truth, but has led to a misunderstanding of the symptoms from which people with HCV suffer. It is well-documented that people with decompensated cirrhosis may have severe or even life-threatening conditions such as, ascites (accumulation of fluid in the abdomen), uncontrolled bleeding, and encephalopathy (brain disease). However, people with HCV may experience many debilitating symptoms even if they have mild disease. This is because HCV is not only a liver disease but affects other parts of the body through various mechanisms – most notably those involving autoimmune processes. The more common symptoms reported by people with HCV include fatigue (mild to severe), muscle pain, joint pain, headaches, itching, depression, anxiety, "brain fog," abdominal pain and other extrahepatic manifestations (diseases outside of the liver). Many patients report that their symptoms are not acknowledged or taken seriously by their medical providers, especially if the providers are not well versed in hepatitis C.

Myth – There is a vaccine to protect against hepatitis C

This myth results from people confusing hepatitis A or hepatitis B – both preventable with vaccines – with hepatitis C. At this time there is NO vaccine to protect against getting hepatitis C although recent breakthroughs in HCV vaccine development are encouraging. Unfortunately, developing an effective HCV vaccine will be very difficult because the virus constantly mutates.

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Myth – Sharing household items such as razors and toothbrushes poses a very high risk for transmitting HCV

There is a potential risk of transmitting HCV by sharing personal items, but experts believe that the risk is very low. Here's what would have to happen to transmit hepatitis C in a household setting: the blood of an HCV-infected person would have to get into the blood of another household member. To prevent HCV transmission in a household setting, do not share personal items, such as toothbrushes or razorblades, and cover items that could infect another person. And it is a good idea to keep any personal items (razors, toothbrushes, etc.) in a separate area so that people will not mistakenly use them. The good news is that we know hepatitis C is not spread by sneezing, hugging, sharing eating utensils or drinking glasses, preparing food, or any other kind of casual contact.

Myth – I am feeling worse than usual so my liver is becoming more damaged.

The general mild flu-like symptoms that people experience from hepatitis C are believed to be the result of the immune system fighting the virus and not necessarily the virus damaging the liver. People also report that the symptoms come in cycles. Sometimes they feel ok or mildly sick and other times feel like they can't get out of bed. Since some of these flu-like symptoms are from the immune system fighting the virus it does not necessarily mean that the liver is becoming more damaged. Of course, anyone who feels that they are getting more symptoms or that their symptoms are getting worse should be evaluated by a medical provider, but it does not necessarily mean that the liver disease progression is getting worse.

Check out the following publications:

- **Stigma and Hepatitis C**
www.hcvadvocate.org/hepatitis/factsheets_pdf/Stigma_Guide.pdf
- **A Guide to Hepatitis C Disclosure**
www.hcvadvocate.org/hepatitis/factsheets_pdf/Disclosure_Guide.pdf
- **A Guide to Understanding HCV**
www.hcvadvocate.org/hepatitis/factsheets_pdf/HCV_Guide.pdf

For more information

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| <ul style="list-style-type: none"> • Centers for Disease Control and Prevention
www.cdc.gov/Hepatitis • Mayo Clinic:
http://www.mayoclinic.com/health/hepatitis-c/DS00097 | <ul style="list-style-type: none"> • MedlinePlus:
www.nlm.nih.gov/medlineplus/ • National Digestive Diseases Information Clearinghouse (NDDIC)
http://digestive.niddk.nih.gov/ddiseases/pubs/hepc_ez/index.aspx |
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