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a series of fact sheets written  
by experts in the field of liver  
disease

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## *HCV Education & Support:*

# *Dispelling HCV Myths*

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### **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 up to 50% of people infected with HCV genotype 1 and up to 80-90% in HCV genotypes 2 and 3. However, we have a long way to go before we can completely understand hepatitis C and discover medications that can eliminate the virus in everyone with hepatitis C.

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

### *Myth – New drugs to treat hepatitis C will be on the market in the very near future*

There are many new drugs under investigation to treat hepatitis C, but the reality is that it will most likely not be until 2010-2011 before more effective medications are approved by the FDA to treat hepatitis C. It is also important to remember that pegylated interferon and ribavirin will be part of the ‘drug cocktail’ for many years to come. Newer treatments offer the promise of higher effectiveness and perhaps shorter duration of treatment. This is important to know because some people who should be treated are waiting for the magic bullet. People with hepatitis C should consult with their medical provider to decide if and when they should be treated. For some, waiting until new therapies are available is a wise decision, but for others HCV treatment is more urgent.

### *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 also many strategies to staying 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 expanded testing and care were available to everyone at risk for hepatitis C. 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***

The vast majority of people with chronic HCV will not experience serious disease progression and may never need to be treated. Hepatitis C behaves differently in different people, and as a result 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 effective 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.

The wait and see exception is people with HCV genotypes 2 and 3 since they have such a high treatment response rate (up to 80-90% sustained virological response in some studies). Most experts believe that people who are infected with genotypes 2 or 3 should be treated.

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 six months after the end of treatment) were measured in the single digits. Today we have two FDA-approved regimens of pegylated interferon plus ribavirin: Peg-Intron plus Rebetol (ribavirin), and Pegasys plus Copegus (ribavirin) which produce SVR rates up to ~50% for people with genotype 1 and up to 80-90% in people with genotypes 2 and 3. Furthermore, clinical studies have shown that, of people who have achieved an SVR, 98-99% continue to be HCV RNA (viral load) negative for 5 years post-treatment.

***Myth – Most people can not 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, 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. 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 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.

### ***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), this 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), to predict treatment response (the lower the viral load, the better chance one has of eradicating the virus), 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' levels have minimal disease progression***

ALT (alanine aminotrasferase) is an enzyme that is produced in liver cells when there is damage taking place in the 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 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, since genotypes 2 and 3 have been shown to respond more favorably to current HCV medications. People with genotypes 2 or 3 have the added benefits of a lower dose of ribavirin and a shorter duration of treatment compared to people with genotype 1.

### *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 itching, 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, 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. Unfortunately, developing an effective HCV vaccine will be very difficult because the virus constantly mutates. Research is underway, but an effective vaccine is not expected for at least 10 years.

### *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.

**For more information about hepatitis C, hepatitis B and HCV coinfections, please visit [www.hcvadvocate.org](http://www.hcvadvocate.org).**

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