There are many myths about Hepatitis C. Now it's time for the truth.
THE BEST TIME TO FIGHT BACK AGAINST HEP C IS NOW.

THE FIGHT STARTS HERE.
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MYTH: IF HEP C WAS REALLY HARMING MY HEALTH, I WOULD HAVE SYMPTOMS.

TRUTH: SYMPTOMS OF HEP C ARE OFTEN MILD OR ABSENT ALTOGETHER—80% OF PEOPLE WITH HEP C HAVE NO SIGNS OR SYMPTOMS OF THE DISEASE. BUT LIVER DAMAGE MAY OCCUR WITH OR WITHOUT HEP C SYMPTOMS.

HEPATITIS C: WHAT YOU NEED TO KNOW TO FIGHT BACK

Hepatitis C (Hep C) has been referred to as a “silent epidemic.” Millions have the condition, but many of them are not aware of it because they may not experience symptoms for decades after they are infected. That’s a big reason why Hep C testing and treatment are so important.

According to the National Institutes of Health:

▷ Approximately 1.8% of the U.S. population, or 3.9 million Americans, have been infected with the Hep C virus.
▷ About 35,000 new cases of Hep C are estimated to occur in the United States each year.
▷ Chronic Hep C is now the most common reason for liver transplantation and the leading cause in the U.S. for developing liver cancer.

While many viruses can affect the liver as they spread throughout the body, the Hep C virus infects the liver as its primary target. Hep C is the most common chronic blood-borne infection in the United States. There is no vaccine against Hep C.

WHAT ARE THE SYMPTOMS OF HEP C?

People experience Hep C in different ways. They may not have any symptoms at all. In fact, symptoms of chronic Hep C may not appear until advanced liver disease is already present. It is also possible to have symptoms but minimal liver damage. This is why tests of your liver’s health such as enzyme levels in your blood, other blood tests, a liver ultrasound, or a liver biopsy are important.

Talk to your doctor about these symptoms and what they may mean for your future health.
Symptoms that may be related to chronic Hep C include (but are not limited to):

- Fatigue
- Flu-like symptoms: fever, chills, muscle aches, joint pain, and headaches
- Nausea, aversion to certain foods, unexplained weight loss
- Psychological disorders, including depression
- Tenderness in the abdomen
- Jaundice

Remember: how you are feeling does not always match up with the severity of your condition. If you wait to experience symptoms before you start treatment, your liver may already be severely damaged.

“My doctor sent me to a specialist—a liver doctor—and I got a whole medical team assigned to me. The treatments had side effects—felt like I had the flu sometimes, especially in the beginning. But my medical team helped me to manage the symptoms. They didn’t mess too much with my life—I still played poker on Thursdays with the boys, made it to work on time, and was able to play with my daughter. I guess when you get down to it, the bottom line is I’m the kind of guy who focuses on results, plain and simple. Today HCV can’t even be detected in my blood. As far as I’m concerned, it was worth it. My liver’s healthy, my blood counts are good, and I’ve never felt more positive.”
HOW CAN HEP C AFFECT MY LIVER?

The liver is the largest organ in the body. Located in the upper right side of the abdomen, it acts as a filter to remove toxins (harmful substances) and waste products from the blood. A healthy liver filters blood at a rate of about 1.5 quarts per minute. That’s 540 gallons of blood a day!

The liver also stores nutrients, such as certain vitamins, minerals, and iron, and plays a role in making and controlling the amounts of certain chemicals and proteins in the body, such as cholesterol, hormones, and sugars. It helps the body digest food by producing a substance called bile, which is stored in the gallbladder.

The Hep C virus attacks liver cells and uses them as a host to reproduce itself. When the body attempts to fight the virus, it sends lymphocytes (a type of white blood cell) to the liver, which results in inflammation (swelling). This inflammation is a normal response to infection, but over time this process, and certain chemicals released by the lymphocytes, can damage liver cells.

When the liver cells are damaged, they cannot function well and may die. Some of these cells may grow back, but severe injury may lead to fibrosis (a buildup of scar tissue on the liver). Fibrosis slows down the liver’s ability to circulate blood and remove toxins. Treatment may help prevent further damage or reduce progression of the condition. However, the longer treatment is delayed, the more likely significant and permanent liver damage will occur.

If your liver is damaged, there are some important steps you can take to keep the undamaged cells as healthy as possible. You should talk to your doctor or nurse about your specific situation, but, in general, the following measures can help:

- Avoid alcohol.
- Eat healthy foods.

MYTH: IF I HAD HEP C, I WOULD KNOW HOW I GOT IT. ONLY PEOPLE WHO HAVE A HISTORY OF RISKY BEHAVIOR NEED TO BE TESTED.
TRUTH: 30% OF PEOPLE WITH HEP C DON’T KNOW HOW THEY GOT IT. AND EVERYONE WHO WANTS TESTING AND INFORMATION SHOULD HAVE THE OPPORTUNITY TO GET IT.

▶ Drink plenty of water.
▶ Reduce salt in your diet.
▶ Get vaccinations against Hepatitis A and Hepatitis B.

Although Hepatitis C can lead to scarring and inflammation of the liver, treatment may help. Even if Hep C therapy does not rid your body of the virus completely, it may help reduce inflammation and improve the overall health of your liver.

HOW DO PEOPLE GET HEP C?

The Hep C virus (HCV) is spread through contact with infected blood. Common routes of infection include illicit injection drugs (eg, sharing needles), blood transfusions (before 1992), needlestick accidents among healthcare workers, and any other blood-to-blood contact, such as may occur during sexual activity. Because Hep C is often not detected for many years after infection, it may be difficult to pinpoint the exact event that caused your infection.

If you don’t know how you got Hep C, you’re not alone. About 30% of people with chronic hepatitis do not know how they contracted the virus. In many ways, it simply does not matter how you contracted Hep C:

▶ Your body’s experience of the disease will not be different if it was transmitted through “risky” behavior rather than via blood transfusion or a workplace accident.
▶ There is no “judgment” made by the disease itself. The only messages are ones you may already know: Any risky behaviors should be avoided, and unsterile needles should be handled and disposed of as safely as possible.
▶ The goal for your healthcare team is to help you get better. Their focus is not on your past but on your treatment and how to optimize your future health.
MYTH:
ONLY PEOPLE WHO USE DRUGS ON A LONG-TERM BASIS ARE AT HIGH RISK FOR HEP C.

TRUTH:
IV DRUG USE, EVEN ONCE OR A FEW TIMES MANY YEARS AGO, IS A MAJOR RISK FACTOR FOR HEP C.

WAYS HEP C CAN BE TRANSMITTED

- Blood and Blood Product Transfusions
- Needlestick Accidents Among Healthcare Workers
- Illicit Injection Drug Use
- Other Blood-to-Blood Contact:
  - Acupuncture
  - Tattooing
  - Sharing certain personal care items (eg, razors, toothbrushes, nail clippers, or nail files)
  - Healthcare workers’ or other professionals’ occupational accidents
  - Transmission from a mother to her unborn child
  - Transmission during hemodialysis treatment
  - Blood-to-blood contact during sexual activity
  - Intranasal cocaine use through the sharing of straws or other instruments
ones to get tested and find out about all of your treatment options.

**WHY SHOULD YOU GET TESTED?**

The Centers for Disease Control and Prevention have told your doctor that: “Anyone who wishes to know or is concerned regarding their HCV [Hepatitis C] infection status should be provided the opportunity for counseling, testing, and appropriate follow-up.”

- **If you want the test, you should be able to get it just by asking—you don’t need to give a reason.**
- **If you want information before testing, you should be able to get it.**
- **After your test results are in, they should be explained to you along with a plan for your future health.**

An important reason to get tested is that patients treated earlier for Hep C may respond to treatment better.

There’s also the risk to those close to you if you have Hep C and don’t know it. There are many ways to spread Hep C, including through personal care items (such as a razor or toothbrush) or a household accident that brings anyone into contact with your blood. You owe it to yourself and your loved

**WHAT DOES TESTING FOR HEP C INVOLVE?**

- **Blood Tests** A simple blood test looks for the presence of the Hep C virus, or viral load, in your blood. If the virus is detected, it means you have Hep C.

  To check how your liver is functioning, your doctor may also conduct another blood test called a liver function test (LFT). This test looks for chemicals in the body that are produced when the liver does its various jobs.

- **Liver Biopsy** Though more expensive and invasive, a liver biopsy is the best way to measure the extent of liver damage. This is a procedure in which a tiny sample of tissue from the liver is removed and examined in a laboratory. Liver biopsies are also important in ruling out any other forms of liver disease. To track the progression of the disease, your doctor may perform a liver biopsy every few years. A liver biopsy is an essential tool in monitoring chronic Hep C infection.

“My doctor warned me that treatments could make me feel under the weather. The bad news is he was right—there were times I felt just awful—down and defeated. But the good news is I had a whole team helping me, not just my doctor, and they helped me to manage the side effects. They’re better now, and I’ve learned a thing or two about managing them myself.

The best news of all is, after 6 months, my viral count is as low as it’s ever been, and my liver is functioning well. The doctor thinks I have a real shot at beating this thing, and I’m excited. It has been a long tough road, but I can see the light at the end of the tunnel.”

Michael
test, ask to be referred to a gastroenterologist (GI) or hepatologist (liver expert). GIs and hepatologists specialize in taking care of people with liver diseases. They will evaluate the disease and discuss treatment options available to you.

Because Hep C management can be complex, you will also have the support of several healthcare professionals on your team. In addition to your primary care doctor and a liver specialist, different types of nurses, a pharmacist and, in some cases, a mental health professional and specialists in fields such as diet and exercise may be part of your treatment team. Sometimes you may feel that it’s too complicated with so many people involved, but remember that all of your treatment team members want what’s best for your health.

You’ll never be stronger than you are right now—today.

**WHAT ARE MY PRESCRIPTION TREATMENT OPTIONS?**

The standard treatment for Hep C is pegylated interferon plus ribavirin. It is the most advanced, most successful course of action that medical science has yet found for fighting Hep C. For a significant percentage of patients, pegylated interferon works—clearing the virus from their blood and/or making a real difference in their liver health.

Combination therapy using pegylated interferon and ribavirin can get rid of the virus in up to
5 out of 10 persons with genotype 1 and in up to 8 out of 10 persons with genotypes 2 and 3.

**Sustained virologic response rates in patients with Hep C (pegylated interferon and ribavirin)**

| Genotype 1 | 41%–51% |
| Genotype 2 | 70%–82% |
| Genotype 3 | 70%–82% |

What we call “interferon” is a protein, and it’s no stranger to the human body. In fact, your body naturally produces interferon and makes even more when it tries to fight off an intruder, such as a virus. You’ve experienced this if you’ve ever had the flu. When you have the flu, your body makes extra interferon to defeat the virus that’s causing the illness. It’s this extra interferon that also causes symptoms like fever, nausea, and fatigue.

People with chronic Hep C may inject extra interferon into their bodies to help fight the virus. While the interferon that’s used for injection may be slightly different from the kind your body makes, it helps the body defeat the virus in 3 ways:

- **First**, interferon attaches to healthy cells and helps them defend themselves against the virus.
- **Second**, the medication helps the immune system stop the virus from multiplying.
- **Third**, interferon also helps the body get rid of infected cells while preventing healthy cells from being infected.

**TRUTH:** WATCHING YOUR DIET, EXERCISING AND TAKING SUPPLEMENTS ARE HELPFUL, BUT THEY ARE NOT ENOUGH TO TREAT HEP C.
Generally, you will obtain your medication monthly and refrigerate doses until you are ready to use them. The details of how to obtain, store, prepare, and inject medication will accompany the medication itself. Online information and phone support are also available.

Though the course of treatment can be difficult for many patients, there has never been a better time for Hep C treatment, and there has never been as much information and support available for those who choose treatment.

WHAT ARE THE SIDE EFFECTS OF TREATMENT?

Side effects are common with Hep C treatment, and consideration of side effects must be part of your decision-making process. But you also must think about the long-term effects of untreated Hep C, including possible liver failure. All of medicine is a comparison of risks and benefits. For a broader perspective, ask your doctor about how he or she makes decisions about Hep C treatment.

MYTH: THE SIDE EFFECTS OF PRESCRIPTION TREATMENT ARE ALWAYS WORSE THAN THE DISEASE ITSELF.

Pegylation is the process of attaching 1 or more chains of a substance called polyethylene glycol (also known as PEG) to a protein molecule such as interferon. Since the body does not react to PEG, it helps provide a protective barrier around an attached protein so it can survive in the body longer.

When used with medications, this barrier may help provide benefits over molecules that are not pegylated. In the case of pegylated interferon, it stays in the bloodstream longer and is cleared by the body more slowly. That’s what makes once-a-week treatment possible. It also may account for the higher rates of response seen in patients whose chronic Hep C infections were treated with this pegylated interferon compared to nonpegylated interferon.

WHAT IS THE COURSE OF TREATMENT?

Treatment with pegylated interferon can take 24 or 48 weeks of once-weekly injections. Pegylated interferon is usually taken with an oral medication—ribavirin—which is taken twice a day. Fine-gauge needles and prefilled syringes are available.

Generally, you will obtain your medication monthly and refrigerate doses until you are ready to use them. The details of how to obtain, store, prepare, and inject medication will accompany the medication itself. Online information and phone support are also available.

Though the course of treatment can be difficult for many patients, there has never been a better time for Hep C treatment, and there has never been as much information and support available for those who choose treatment.
The following are some of the most common, but often manageable, side effects associated with treatment:

- Flu-like symptoms, including fever, chills, and muscle aches
- Fatigue
- Upset stomach, nausea/vomiting
- Loss of appetite
- Difficulty in controlling blood sugar levels (which may lead to diabetes)
- Skin reactions (such as rash, dry or itchy skin, temporary hair loss, or redness and swelling at the site of injection)

- Temporary hair thinning
- Trouble sleeping

Possible serious side effects, which your doctor or nurse can talk to you about, include mental health problems, such as depression, blood problems, infections, and problems with your lungs, eyes, immune system, and heart. Your healthcare team may treat these side effects, change the amount of medication you take, or stop treatment.

TRUTH: THOUGH SIDE EFFECTS OF TREATMENT CAN BE HARSH, MANY PATIENTS FIND THEM MANAGEABLE. ALSO, SERIOUS SIDE EFFECTS DO NOT OCCUR IN EVERYBODY.
Understanding the Risks of Not Treating

Something to keep in mind: NOT getting treatment for Hep C is an important decision that may have long-term consequences for your health. It’s not simply giving yourself more time to think about it or looking for the right time to do something about it. You are choosing a course of action—making a conscious, active decision. The short-term benefits of not getting treatment are obvious. The long-term effects of this decision may not be so apparent.

Here’s what you risk:

► **Scarring of your liver (fibrosis), which may have been slowed, prevented, or even reversed by treatment**

► **Cirrhosis: severe liver damage that may lead to liver failure**

► **The development of liver cancer**

► **Need for a liver transplant**

More than half of people who opt for treatment have a sustained virologic response, meaning that the virus is undetectable in their blood 6 months or more after they complete Hep C therapy. This may vary based on individual factors.

But what about those who don’t clear the virus from their blood? Have they all wasted valuable time and significant effort for nothing? For many of them, the answer may be no. Tests of your liver’s health are also a significant part of your doctor’s assessment of your overall health. Even if you do not get rid of the virus, you may benefit from treatment.

In the end, not treating your Hep C is an option that is open to you. But remember that this is a real decision that you are making, not merely procrastination or deferring your choice. There is no “pause” button for your liver’s health.

Remember, even if you don’t feel its symptoms, the virus could still be doing damage to your liver.

You’ll never be stronger than you are today to treat Hep C.
WHAT IS SUCCESSFUL TREATMENT?

You and your doctor will be looking to achieve these main goals through your treatment: virologic response and histologic response.

- **Virologic response** is the more common way to look at Hep C treatment success. To measure virologic response, doctors use a blood test to measure how much Hep C virus is in the blood (this is also known as your “viral load”). The best virologic response would be a “sustained virologic response,” which simply means that the virus remains undetectable in your blood 6 months or more after you complete Hep C therapy. Such a result is very good news: In studies that followed patients for 2 to 3 years after their sustained virologic response, very few relapsed (had a recurrence of infection) after this point.

- **Histologic response**, another way to evaluate Hep C therapy, looks to see if liver inflammation has gone down. Therapy may help your liver by reducing inflammation.

  Patients may have both of these responses or may have a histologic response even if they continue to carry the virus in their blood.

“My doctor knew how committed I had been and told me that those changes in my lifestyle may make a real difference for me. She said that though treatment didn’t work, I could improve my overall health—and even my liver’s health—in many other ways.

So am I disappointed? Sure. But committing to treatment helped me change my view of my Hep C. Now I know that I’ve taken it on and am doing everything I can. I tried treatment and don’t need to think about it anymore. And I know all the things I need to do to have the healthiest future I can.”

**Carolyn**
Your doctor or nurse may tell you that the way you feel during treatment is “normal” or that the benefit of taking the medication should outweigh the side effects you are experiencing. But you are the one who will make the choice and commitment to continue your treatment. Make sure you have all the facts to help you get through it.

Here is the part that takes courage: You have to choose to continue on a course of treatment that may be causing you to feel “sick” in order to fight a virus that may not have been making you feel sick. In a sense, your treatment plan is like an investment in your health. Short-term costs can be unpleasant, but may lead to long-term gains. There are no guarantees or easy answers, but Hep C can cause serious complications, especially if left untreated. Remember that the most serious effect of Hep C is on your liver—and damage to the liver can take time (even decades) to emerge.

**WHY IS STAYING ON TREATMENT IMPORTANT?**

Taking Hep C therapy requires your active participation and a strong commitment to finish what you’ve started. By following your doctor’s exact instructions and taking your medication as directed, you are giving yourself the best chance of reducing the virus to a level where it cannot be seen in your blood (a virologic response). You may also be able to help improve the condition of your liver (a histologic response) by decreasing inflammation.

Of course, treatment may not always be easy. People will experience varying degrees of side effects that make taking medication difficult. Should you have any questions or concerns about side effects or your medication, be sure to talk with your doctor immediately—and don’t make any changes to your therapy without talking to your healthcare team first.

**MORE OF THE TRUTH**

**MYTH:** Since Hep C is a long-term condition, treatment will be just as effective if I wait until later to start.

**TRUTH:** Patients treated earlier may respond better to Hep C treatment.

**MYTH:** I feel fine, so I don’t need to be treated. I’ll wait to get treated once I have symptoms.

**TRUTH:** If you put off treatment until you notice symptoms, the damage done to your liver may be less reversible.

**MYTH:** My liver enzymes are normal, I don’t need to worry about the virus.

**TRUTH:** Even though your liver enzymes are normal, your disease may still be progressing.

**MYTH:** Only about 40% of people have a positive response to treatment.

**TRUTH:** Response rates are affected by many factors and may be significantly higher for some types of patients. And even if therapy does not rid your body of the virus completely, it may help reduce inflammation and may improve the overall health of your liver.

**MYTH:** Treatment does not work for patients of African American descent.

**TRUTH:** New treatments have shown encouraging response rates in patients of African American descent.

**MYTH:** If the level of the Hep C virus in my blood is low, my disease is not so bad.

**TRUTH:** Viral load alone does not give a clear picture of the progression of the disease and the health of your liver.
**TRUTH:** HCV now infects more than 4 times as many Americans as HIV.

**IS TREATMENT RIGHT FOR YOU?**

The decision to get treatment for Hep C is one of the most significant ones you will ever make. Use this tool to prepare a list of questions and concerns you may have and to evaluate the benefits of treatment.

**Use numbers to indicate how these benefits are important to you:**
1—most important, 2—very important, 3—somewhat important….

**Benefits of Treatment**

- Getting rid of the virus
- Staying strong
- Avoiding further liver damage
- Getting on with my life
- Feeling better
- Acting for my long-term health
- Possibly reversing liver damage
- Meeting this challenge
- Taking back control
- Best treatments now available
- Putting my Hep C behind me
- Earlier treatment may mean better results

**My Main Concerns About Treatment**

- Self-injection/needles
- Side effects
- Obtaining/storing/managing medication
- Treatment not working
- Not being able to finish
- Cost
- Need for support
- Questions during treatment
- Impact on my life
- Not a good time for me to start
RESOURCES

American Liver Foundation
Phone: (800) GO-LIVER (465-4837)
E-mail: webmail@liverfoundation.org
Internet: http://www.liverfoundation.org

Centers for Disease Control and Prevention (CDC)
Phone: (888) 4-HEP-CDC (443-7232)
Internet: http://www.cdc.gov/hepatitis

Hepatitis C Association
Phone: (866) 437-4377
Internet: http://www.hepcassoc.org

Hepatitis C Support Project
E-mail: AlanFranciscus@hcvadvocate.org
Internet: http://www.hcvadvocate.org

Hepatitis Foundation International
Phone: (800) 891-0707 or (301) 622-4200
E-mail: hepfi@hepfi.org
Internet: http://www.hepfi.org

Hep C Connection
Phone: (800) 522-HEPC (4372) or (303) 860-0800
Internet: http://www.hepc-connection.org

Latino Organization for Liver Awareness
Phone: (888) 367-LOLA (5652)
Internet: http://www.lola-national.org

National AIDS Treatment Advocacy Project (NATAP)
Phone: (888) 26-NATAP (62827) or (212) 219-0106
Internet: http://www.natap.org
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