Denied Hepatitis C Treatment? Here is How to Fight Back

This article from the HCV Advocate offers advocacy tips for those who are denied hepatitis C treatment.

February 11, 2015 By Lucinda K. Porter, RN

Elizabeth Faraone was diagnosed with chronic hepatitis C virus (HCV) in 2001. She is 53 years old and for the past 20 years, she has been battling chronic fatigue and body aches that are increasing in severity. She couldn’t take interferon because of another chronic condition, so when Harvoni was approved by the FDA in October, she called her gastroenterologist. Elizabeth is on Medicaid. Like many patients, she was denied coverage for treatment. However, Elizabeth didn’t take “no” for an answer, and she was able to get Harvoni.

How did Elizabeth do it? First, she found a doctor who was willing to fight for her. She advises, “If a doctor tells you that your medical insurance won’t cover the cost of the medicine and he/she refuses to proceed further, tell your doctor that you can walk him/her through the process of getting the medicine. If he/she still refuses to help, find another doctor.” Elizabeth’s doctor “believes it is a medical necessity for all HCV patients to get treatment with the new safe and effective medicines.”
Elizabeth’s doctor sounds like a saint, but actually, he is following the HCV guidelines recommended by the American Association for the Study of Liver Diseases (AASLD) and the Infectious Diseases Society of America (IDSA). The guidelines state, “Successful hepatitis C treatment results in sustained virologic response (SVR), which is tantamount to virologic cure, and as such, is expected to benefit nearly all chronically infected persons. Evidence clearly supports treatment in all HCV-infected persons, except those with limited life expectancy (less than 12 months) due to non-liver-related comorbid conditions.”

The recommendations to treat HCV patients are clear. However, many insurance companies and Medicaid programs are denying HCV treatment except for those who have stage 3 or 4 fibrosis/cirrhosis of the liver. The State of Connecticut’s Medicaid program is only covering cirrhotic patients. I believe they are doing this because they have selectively chosen to follow this recommendation in the HCV guidelines: “Urgent initiation of treatment is recommended for some patients, such as those with advanced fibrosis or compensated cirrhosis.”

Can you imagine if insurers decided to withhold treatment to diabetics and wait until patients were blind or lost a few toes before they’d cover treatment? This is basically what’s happening, because waiting until someone has cirrhosis is too late to prevent cirrhosis. Cirrhosis is a serious disease, and usually not reversible. Even if the person clears HCV, the insurer now has to take care of someone who has cirrhosis.

How did Elizabeth get Harvoni? She used Gilead Sciences’ prescription assistance program, Support Path (855-769-7284 www.mysupportpath.com). If you have any questions about Harvoni or Sovaldi, start with Support Path. At the risk of sounding like an infomercial, here is what Support Path offers:

**Help with insurance issues.** If you want to know if your insurance plan will cover Harvoni or Sovaldi, call Support Path. They will verify your coverage or tell you if you can expect a denial.

**Help with denials.** If your insurance refuses to pay for your treatment, Support Path will help you with the process of trying to secure low-cost medication. They may refer you to a patient assistance program such as the Patient Access Network Foundation www.panfoundation.org, which provides:

- Assistance with co-payments, often bringing down the cost to $5 a month
- Tips and tools to help you through treatment
- Nursing support for patients

There is also help for Canadians with hepatitis C. Gilead’s Momentum Support Program provides support services for patients via their healthcare providers, along with financial assistance for eligible patients who need help paying for out-of-pocket medication costs. For Harvoni or Sovaldi you need a diagnosis, a prescription, and last year’s tax assessment to get assistance. For more information, call (855) 447-7977.
Bobby* has lived with chronic hepatitis C virus (HCV) infection for decades. In 2012, he underwent 24 weeks of triple-therapy with Incivek, peginterferon, and ribavirin. He made it through the challenging regimen, enduring debilitating side effects, but was not cured. When the new HCV medication Harvoni was approved, Bobby talked to his doctor about it. He was denied treatment because his managed care system was only treating those with stage 3 or 4 fibrosis (stage 4 is cirrhosis). Bobby fought back and won. He pointed out that his liver biopsy was three years old, and that his platelets were low. Bobby told his doctor that if he was eligible to be treated in 2012, then he should be treated now. His doctor relented.

Not everyone has a success story. Cindy* has lived with hepatitis C for at least 30 years. She was able to manage the symptoms, but two years ago, intense pain and nausea kept Cindy from sleeping. She was diagnosed with cirrhosis. Her doctor prescribed medication for the pain and nausea, but the side effects were too strong. Cindy said, “It was so strong, you could prop me up in a corner and I would drool.” Desperation drove her to self-medicate with a small amount of marijuana. She never dreamed that this choice, which seemed much more sensible than the pain medication, would interfere with her ability to get access to hepatitis C treatment. Cindy’s health insurance is through the state of Pennsylvania. She was denied treatment when marijuana turned up in the toxicology screen.

Cindy is the victim of injustice. Pennsylvania’s Medicaid program does not require drug and alcohol screening for access to medications for other diseases such as anemia, migraines, or type 2 diabetes. Why this one? There are a number of flimsy explanations:

- HCV is associated with drug use, and it is easy to target drug users (No one in power is going to come to their defense)
- This is leftover from the interferon days when there were concerns about offering a treatment that had severe neuropsychiatric side effects
- Payers are doing anything they can to restrict access so they can save money

Cindy has not fought back, and remains untreated. However, she could call Support Path and see if she could get coverage. If not, she may be forced to decide between marijuana or six months of pain in order to meet the insurance requirements.

Most of the patients who go through this process are able to get their medications. It takes patience. It can be all too easy to get angry and give up, but you end up hurting yourself. Get support, and never give up. Hold on to this truth: You are worth fighting for.

**Note:** This article went to press prior to the anticipated approval of AbbVie’s hepatitis C drugs. The intention of this article is to provide tools to overcome obstacles to hepatitis C treatment, not to promote a specific hepatitis C drug. AbbVie’s patient assistance program is [www.viekira.com/1-844-2proCeed](http://www.viekira.com/1-844-2proCeed)

*Name changed to protect identities

**Additional Resources**

[Help 4 Hep](https://www.help4hep.org) 877-HELP-4-HEP (877-435-7443)
[Hep Forum](https://hepforum.org)