The Hepatitis C Stigma

January 11, 2021 By Greg Jefferys

For reasons that still elude me, people with Hepatitis C are terribly stigmatized in many countries. For some reason, people with Hep C are made to feel ashamed of having this disease, as if they had committed some terrible sin.

Such attitudes are really bizarre given that Hep C is not a sexually transmitted disease and a large proportion of people with Hep C have become infected with the virus as the result of faulty medical or dental practices, through absolutely no fault of their own.

Because of this stigma associated with Hep C many people keep their Hep C infection hidden, which greatly reduces their chances of getting assistance.

The social outcasting that occurs in many societies when it becomes known that a person has Hep C is truly terrible because the person has to deal with the double trauma of learning that they have a potentially fatal disease as well as the trauma of being ostracized by family and friends.

If this happens in a low income situation, where the chance of being able to access treatment to cure the Hep C is almost zero the situation for the patient is even worse because they can see no light at the end of the tunnel. All they see is continued social isolation and a gradual deterioration of their health until eventual death.

In this post, I share some of the often devastating experiences people with Hep C have had as a result of the stigma associated with Hep C.

The Philippines

Help me sir..i cannot afford to undergo the treatment or the testings.

As of now sir i have no medicines to maintain health, I can not afford even vitamins..cus I am the only one who support my mother and brother.

Sir Greg, thank you for all your help. I’m sorry if I had to ask you about my medication for my illness. You see, when they knew that I have hepa C, all of my relatives rejected me. They loathe me. And I cannot afford all medication needed because I only work in the construction company.

Hep C Stigma USA

BH

I stupidly told someone i thought was a friend at work that i have hep c. Within 2 days of me telling her she called our corporate office to try and get me fired for being a health hazard as she put it. I didnt get fired and she quit that day. That was thw worst time.

DZL

I’m sure I got hepatitis C in 1982 when I was hospitalized after a horrific car accident. I was given three pints of blood while in surgery. I immediately started having digestive issues but since nothing was known about hepatitis C and there was nothing like it diagnosed I just thought my body is changing because of the car accident and the time I had spent in the hospital. In 1985 I got horribly ill. Couldn’t figure out what was wrong with me and when they did blood work they told me I had mono because my liver enzymes were elevated. I know now it was hepatitis C which in 1985 did not have a name. For years I suffered with many illnesses. In 1990 half of my thyroid was removed because my thyroid was giving me issues and they took half of it. I now realize it was the hepatitis C. I was finally diagnosed in 1999 but I told no one because there was a stigma attached to hepatitis C people thought you were a drug addict if you got it. Over the years I may have told a total of 10 people that I had hep c. I finally did treatment with Mavyret in July August of this year. I am undetected. The end of November it would have been 12 weeks since I finished treatment and still undetected. And another week I get tested again per Doctors orders and I should still be undetected. I still even now that I’m cured have a hard time telling people that I had hepatitis C. I did not do drugs I did have a blood transfusion that was to save my life but it ended up almost taking my life. I want to educate people with what I have learned over the years. Doesn’t matter how you get it but please get treatment. I have cirrhosis and I will have to deal with that the rest of my life. I’m 66. But I will not die from hepatitis C. I now have hope

SHB

This seems to be what several people in the medical industry I’ve talked to want to know, and they seem to want me to “confess” to some drug or alcohol problem since they keep asking! Not all of them by any means, but a few (three to be exact) have really kinda grilled me over it. I’m retired now, but I was a cop for a decade and touched probably hundreds, literally, of bleeding people even though I was always careful and used gloves, scenes could be dirty and chaotic. I also have a few piercings and a couple of tattoos, so those were also potential exposures, and several medical incidents where blood was “shed” or I was poked with needles and scalpels, including my last dentist who seemed a little shady and who has since retired! If I knew where I got it, I’d tell them, but there’s just no way for me to ever, ever know. However, I do know damn sure where I didn’t get it but, sadly, that doesn’t seem to be the answer they are fishing for!

Hep C Stigma in China

Greg, I read that you are asking everyone to share their experience so you can include in the blog about the stigma associated with Hep C.

My sister lives in China and does not know exactly how she contracted Hep C. She never uses drugs.

She had two C-sections in the mid-80s and one surgery in the early 90s. It’s unclear if she contracted the virus because the surgical tools weren’t properly sterilized or had a blood transfusion (not sure if she did) during surgery.

When people in her society learned she had Hepatitis C she was generally shunned and made to feel ashamed.

Now she was cured for four years ago, thanks to you for introducing me to Parag in India, but her liver remains cirrhotic.

Her hepatologist conducts an ultrasound every three months. I also know another woman living in the same town as my sister, who also gave birth via c-section in the mid-80s. She, too, contracted Hep C. Unfortunately, she developed liver cancer and passed away before the oral medicine was available. Other than the c-section, the woman had no other surgery, so it was clear that she contracted the virus from surgical tools.

Like my sister this woman was made to feel shame of having Hep C even though it was not from any fault of hers. She died carrying this shame.

Thank you, Greg, for your continual services to the Hep C community. My sister and I have been and will forever indebted to you.

S. Han.

Visit Greg’s blog to read more stories of stigma from around the world.

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