
a series of stories written
about people living with
hepatitis C

• • • • • **Martha** • • • • •

Like a lot of people, I walked around with hepatitis C for about 30 years before treatment became an option. In 1981, my doctor told me I had “non-A non-B hepatitis” – something a lot of folks began hearing in the 80s. The advice was just to get liver function tests occasionally and to avoid alcohol. For years I thought I was just a person who needed a lot of sleep. I tired easily and slept 10 hours a night. Other than that, I didn’t have a lot of symptoms. Oh, occasionally my limbs would itch like mad for a few days for no reason; that drove me crazy, but I never suspected it had anything to do with liver disease.

In about 1997, my doctor suggested that I get tested for HCV, so I did – or at least I thought I did. A phone call from the medical office let me know my test

was negative. A year later the doc asked me why I never got tested for HCV. Well, it turned out the lab misread the original order and tested me for HIV by mistake. The negative test, it turned out, was for HIV! Another test, of course, turned out to be positive and my odyssey into the world of hepatitis C began in earnest.

In 1998, liver biopsy wasn’t as much a standard of diagnosis as it is today. The GI specialist I saw said my viral load was low, so he didn’t recommend treatment. During my work-up, it turned out I had gall stones, so my doctor decided I should get a liver biopsy during the gall bladder surgery. Lucky me! I slept through my biopsy. As it turned out, the biopsy showed I was at a stage 2.5 – 3, and treatment was recommended after all.

As a genotype 1, I needed the full 48 weeks of interferon shots and ribavirin pills. That was before the pegylated interferon was approved by the FDA, so I did the shots 3 times a week. What was

treatment like? Well, I can't pretend it was fun. No, actually, it was pretty awful. I had the typical side effects: headache, nausea, brain fog, major depression.... I lost some hair, and what I didn't lose turned straight as a stick. Having had really curly hair all of my life, that might have been the most bazaar side effect; every morning I would get up and look in the mirror to see if my hair was still straight (luckily it grew back in curly after treatment ended). I lost about 30 pounds, which I admit, made me very happy. I got to wear size 6 clothes for about a year....and I did a lot of shopping therapy. I found that the side effects were up and down. About every three months I would get very down for a few weeks.

I was very lucky in so many ways. First, I had insurance. Second, I had a wonderful support system in place. My husband, David, was there for me the entire time, as was my Welsh corgi, Dotty. It was also helpful that I was able to greatly reduce my workload because I am self-employed. I was also working on my master's thesis, which did suffer greatly because of my brain fog. At that time, there weren't a lot of support groups around, so I was doubly blessed to have good friends who saw me through the treatment. I used to take Dotty to the dog park every day, and during that year and I became very close to a group of women with whom I am still friends, "the dog park ladies." I also had a friend in another city who was a couple of months ahead of me on the treatment. It was incredibly helpful to talk on the phone every couple of weeks to compare our progress and whine.

Three months into the treatment, I learned that the virus was undetectable. That really kept me motivated to keep on the meds! I knew there would be light at the end of the

tunnel. But even with all of the support and the good news, I think depression was the worst side effect. I used to hide in the shower to cry, so I wouldn't upset David. If the news was so good, why did I feel so bad?

By the time I decided I really had to get on anti-depressants, treatment was almost over.

One of the things that really stays in my mind, even years later, is New Year's Eve 1999. I had two months to go. I was undetectable, and determined to stay that way. I remember as a little girl thinking that I would be an old lady when the century turned. Here I was, 48 and feeling pretty old. I kept thinking, "This is a special night, something special should be happening." At midnight, I took Dotty into the street to watch the fireworks, but she didn't like the noise so I sat on the porch and wondered what would come in the New Year. At that moment, I determined that I would find a way to be an advocate for HCV care. I visualized myself supporting other patients, but I had no idea where this would take me. I just knew that this hellish year had to mean something.

When I finished treatment, it took about a month for the year's worth of meds to get out of my system. I remember one day suddenly realizing that I felt great! I had so much energy. It wasn't just because I wasn't feeling the effect of the interferon anymore; I truly felt better than I had in years. It was amazing to realize that I was healthier than I had been in 30 years.

I began volunteering for the Sonoma County HCV Task Force. I was able use my experience as a strategic planning consultant to help the task force set its direction. Soon I had hatched a project idea with my col-

leagues at the Center for Health Improvement in Sacramento. In 2003 we applied for a grant to help other counties increase their capacity around HCV prevention, education and care. Along the way, I met incredible people who shared stories very much like mine and who were doing amazing work. Today, I am still working in HCV prevention and policy. Again, I am blessed to be able to do work that I feel completely fulfills me. What continues to touch me is that for as many sustained responders I meet, I meet people who did not respond to treatment but are still able to find the energy to work for this cause.

As a six + year sustained responder to Hepatitis C treatment, I am often asked for my advice about treatment. Even though my experience was positive, I always preface anything I say with, "It's is an important and personal decision and I would never tell you that you should do the treatment." However, I also talk about the important positive things people can do to increase their chances of successful treatment and to improve their health, regardless of treatment. These include eliminating alcohol, eating a good diet, not smoking and losing weight if needed. I also add that it is my understanding that treatment can have beneficial effects on the liver, even if the virus is not eliminated. Hep C isn't an emergency situation; there is plenty of time to consider all of the things that might get in the way of treatment and to take care of them before starting on a treatment regimen. It is important to get your support system in place, assess your work situation and decide if you can take time off or let your co-workers know you may not be quite yourself for a while. Talk to your doctor about getting on anti-depressants before starting the meds. I wish I had.

I remember the first time I heard Alan Francisus, of the Hepatitis C Support Project say "Having Hepatitis C is the best thing that ever happened to me." Was he crazy? No, he knew that without HCV, he would not have had the opportunity to meet people all over the world who have been touched by this disease. He would not have found work about which he was so passionate. I'm with Alan. We are in a growing fraternity of folks who understand this issue from the inside out and are determined to make positive changes. If publishing my story to the world-wide-web helps even one person who is struggling with the news that he or she has HCV, it was worthwhile for me to write it.

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For more information about hepatitis C, hepatitis B and HCV coinfections, please visit www.hcvadvocate.org.

• *Living with Hepatitis C* •
 A publication of the Hepatitis C Support Project

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