
a series of stories written
about people living with
hepatitis C

• • • • • *David* • • • • •

In 1994 I was in pretty rough shape and getting worse and nobody knew why. Well of course I was under a lot of stress—just finishing a PhD, writing a book, going through a divorce, alternating between smoking a pack a day and drinking quite a bit, and going to the gym to try to work it off.

But that didn't explain why all of a sudden I started getting lost in the city I grew up in; or why all of a sudden I would get very pale and woozy and lose my balance, or why sometimes I just felt like curling up in a ball on the sidewalk and going to sleep.

What made it worse was that when I told my doctor this, she thought I was under too much stress and that maybe I should take a valium. Of course I was under a lot of stress, but not any more than what I'd been under for quite some time, and being the neurotic East Coast Jewish intellectual type that I am, I thrived on stress!! Well that and bagels and a good smoked meat sandwich on rye with real crunchy pickles and some chopped liver on the side!

I insisted that I didn't need any drugs – that in fact I thought that a health program would be better, and my doctor, herself having run a few marathons, agreed. So I started cleaning up my life and swimming more and drinking and smoking less....but still I was zonking out

and really getting scared.

Six months later my doctor ran some blood tests. A few days later she called me and told me that she had some bad news for me: "You have tested positive for hepatitis C." Boy was I ever relieved. I didn't know what hepatitis C was, but at least I knew I was not crazy.

Then the tests began, and what with the PhD finally finished, I earned the right to collapse and I did. I went downhill so fast that if not for some very good friends I don't know how I would have survived. There went my savings, I was overdrawn, my lease was up, I couldn't work, I didn't know what to do. I was really tired, confused and I cried a lot.

I had to sell everything I owned to stay alive, and I almost wound up on the street!! But as luck would have it, social services in my municipality stepped in to help. I got a real social worker who helped coordinate all my appointments and my application for disability (that took about 3 years, and is a whole other story!).

Having been in the university environment for a long time, I began to do some research on hepatitis C, and was appalled at the lack of current information then available. I tried turning to a local liver support organisation but they were not into patient empowerment and didn't know much about HCV either.

Luckily I had a computer and internet access and I found the HEPV-L list. As soon as I began to read the stories of other people with Hep C, I heard my own inner words that I was using trying to explain my situation to others, as I tried to explain how I felt about these strange symptoms I was having.

Anyways: the long and the short of it is that I got so sick that I couldn't do much of anything at all except sit on the park bench with people 30 years older than me. What a life. Eventually, I did get my disability pension and some friends encourage me to move to the West Coast of Canada where the weather was friendlier than in Montreal, where I lived. I was broke, so my friends who had moved to Vancouver Island (God bless them) paid for the move, and took me in, and helped coordinate everything for me. Basically, I was on a full disability; I couldn't walk much, spent most of my time zonked out, I couldn't read, and I couldn't drive. What a life!

Between 1997 and 2003 I was able to get on treatment 3 times. The first time with just regular standard interferon 3 times a week, I had viral breakthrough so they pulled me off. The second time I got into a clinical trial for Genotype 1 patients. I went on standard interferon and ribavirin for 48 weeks. I was a non-responder. Finally, I was put in a clinical trial of pegylated interferon and ribavirin for 48 weeks, and for the first time since I was diagnosed my alt's became normal. But I did not clear the virus.

However, since the last round of treatment, I have been able to walk, and sometimes swim; I can also drive a car again and I can read and actually remember what I'm reading. It hasn't been all at once, but it has definitely been the result of treatment. In fact I have regained enough health to come off a complete disability and go back to work; this has helped me greatly, giving my life purpose and direction as well as helping me fight the depression that being chronically ill causes. I still feel lousy a lot of the time; but being able to work at something I like helps me ignore it.

Anyways, it took a long time for me to clear the drugs from my system. I do NOT like treatment. It made me a wreck. I did take antidepressants to help (and believe me they helped); but to quote me

on this: "this stuff makes you crazy!"

I still have the virus, and I have my life back (to a large extent); I do not want to take interferon again, but I don't want to die soon either. So, I am encouraged by the breakthroughs in new treatment options, and will wait a bit longer to consider what to do.

In the meantime: I haven't had a cigarette or a drink of alcohol in 10 years. I eat mostly organic and lots of fresh veggies and fruit. I spend a lot of time walking in nature or playing music, and these are really good for my soul. However, I still get very tired and have to sleep a lot; I also have developed Hep C-related fibromyalgia and I have some pretty achy days, and attacks of brain fog...but these seem to be less and less.

Last: since the beginning of my fight with Hep C I have been involved in the Hep C movement, and it has really helped me keep my perspective. I am really thankful for those out there who give of themselves for others, and saddened by the loss of a lot of friends to this disease.

Thanks for listening

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

• *Living with Hepatitis C* •

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