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living with HEPATITIS C

a series of stories written
about people living with
hepatitis C

..... Jake

Prior to my diagnosis with HCV in January of 2005 I was a vital, active 45-year old gay man. I worked hard and played hard – my hours were always filled with some type of activity. I was generally happy, motivated, outgoing and well-adjusted. It appeared to everyone on the outside that I “had it together.” I had been diagnosed with HIV in 1986 and fortunately my body was able to fight the virus on its own. I did not require HIV medicine until 2002. Although I was HIV+ for almost two decades – internally I felt somewhat invincible in that I had never had to medically “deal” with my disease. This all came crashing down in 2005.

During my last relationship my partner and I started occasionally using Methamphetamine (meth) and practiced group sex while occasionally often blowing caution to the wind. After the relationship ended I continued to use meth recreationally. I worked long challenging hours in a growing company and the sex and drugs were my release – at least so I thought. One-weekend things got out of control and I injected meth with a shared needle. I had done this once before a few years earlier and had made a commitment to myself that I would never do this again.

A few days later I got quite frightened and went to my MD for a blood test. Soon thereafter my worst fears were realized in that I found out I had hepatitis C. The diagnosis took months however to “set-in” and my body soon began manifesting trademark side effects. I was already on a mild antidepressant

and had been for 3 years. I began to get occasional headaches in my occipital ridge – these arose out of nowhere and lasted for days. Additionally I started losing energy, gaining weight and becoming ornery. My liver enzymes started to rise and my MD had me take a Fibrosure test – it simulates a biopsy (with often highly inaccurate results). The results of the test were not good – it stated that I was in Stage 3 of fibrosis. My MD referred me to a local gastroenterologist who had a good history with co-infected patients.

I saw the new doctor and immediately stopped drinking all alcohol – by that time my consumption was significantly less and this proved not to be too much of a hardship. The gastro MD said he would do a biopsy after the 6 months off drinking. When June came around the gastro MD performed the biopsy – he was not that skilled with the needle and had to poke me twice, which was quite uncomfortable. When the results came back they showed I was somewhere in between Stage 1 and 2 of cirrhosis. The gastro MD felt that because I was relatively young and that my HIV was under control I should start HCV treatment. My regular MD disagreed and felt that I should wait the year or two for antiretroviral drugs to be approved by the FDA.

This created a conundrum for me – one doctor said to wait and the other said to proceed. I found out later that this is representative of all things with HCV. You will have symptoms, take tests and receive medical advice.

The health care professionals and support personnel you speak with will all read the tea leaves differently. Ultimately you must take control of your own health, learn the facts and determine the best way for you to proceed. You need to make a decision you can live with afterward. Easier said than done by the way.

I decided to consult a specialist here in the SF Bay Area on HIV/HCV coinfection. He gave me many more tests, analyzed my biopsy results and came up with the same results. I was somewhere in the middle of two options: Go on treatment or wait for the new drugs. After much deliberation I decided to move ahead with the pegylated interferon treatment along with ribavirin. My Doctor was participating in a clinical trial of these two therapies used for coinfecting patients – they were seeking to determine what level of ribavirin was appropriate for HIV+ patients. The treatment ended up being the most difficult thing I have done in my life.

Incidentally, the gastro MD and my hepatologist both felt that I had been infected with HCV for 20+ years. It probably happened sometime around my infection with HIV although I am not sure how. I have rationalized that it doesn't matter how it happened but that it did and I needed to act appropriately and responsibly.

I decided to start treatment at the end of the summer in 2006. My plan was to work through the treatment and take my injection on Friday afternoon. I also was advised to

bump up the dose of my antidepressant, as the strong medicines would most likely upset my current regimen of Celexa. At about 3 months my Doctor added a 2nd antidepressant - Welbutrin. I am happy to say that while on the 48 weeks of therapy I never was that depressed. I attribute this to great emotional support from my family, friends, the community and the staff at my hepatologist. In regard to work – my plans required adjustment – the treatment caused me to be extremely tired and not able to deal with the typical day-to-day issues of a growing company. After 1 month on treatment I determined that I would go on disability.

As someone who never had to question my ability to do things, being on treatment was a major psychological adjustment. From everything I have heard, read and researched each person's journey on treatment is personal and will differ from others. I, fortunately, was spared side effects such as flu symptoms, loss of appetite, loss of hair and major depression. I did however win the jackpot in my loss of stamina, fatigue, dry skin and the omnipresent headache in my occipital ridge. What caused me the most grief however was my inability to concentrate and articulate my thoughts. What a paradox – I had all this time to read yet I couldn't concentrate on anything longer than a USA Today style newspaper story. Often would lose my train of thought when trying to express my thoughts with others. Losing these characteristics and gaining over 20 pounds all contributed to me losing a big chunk of my self-confidence.

After about 90 days on the treatment the interferon and ribavirin were decimating my white and red blood cells. My hepatologist had me add Procrit and Neupogen to the treatments, which helped to manage the problem, yet they required biweekly injections and caused some new side effects of their own.

The 48 weeks went by slowly at first and then moved into an eventual rhythm. I worked to ensure that I got out of the house at least every other day and forced myself to interact with others even though I didn't feel like it. I found also that certain friends and family were unable to deal with the person I was on treatment and avoided me. Others were superstars and did everything they could to help me feel love and acceptance.

I went to a weekly support group and this helped immensely to hear and speak with others in the same condition. It gave me hope to hear their stories and how they coped with their illness. I also got the opportunity to take care of others emotionally – at times just by listening and sometime through sharing my own experiences. Through my group I found out about acupuncture and massage which were invaluable in helping me deal with the treatment side effects, especially the headaches. I also began to meditate each morning – this helped to accept my circumstances and face each day with some level of hope and joy.

After 8 weeks on treatment I had a two-log drop in my detectable viral load and was vi-

rus free by the 12th week. I am quite thankful this was persistent throughout the entire 48-week treatment. It has now been 6+ months for me off the treatment and my viral load remains undetectable. A few weeks ago I had a liver biopsy and my liver is somewhere between stages 0 and 1. I am grateful that I have had a SVR and each day feel like a little more of my brain gets turned back on. I plan on starting work again as soon as I get a new job.

I am no longer on any form of antidepressant and my headaches are completely gone. I have been exercising rigorously almost daily and have lost most of the weight I put on during the treatment. Although the treatment for HCV was the hardest thing I have ever had to go through; I feel that it changed me in a positive way and that I am a much better individual than I was at the onset.

During those 11 months I often looked out my front window and saw people riding their bikes and enjoying life. I am happy to report that I have joined these people and am now out on my bike and enjoying the fresh air and sunshine.



Be Sure to Check Out These Other Stories

- Alan's Story
- Brian's Story
- Carol's Story
- David's Story
- Dee's Story
- Gerald Moreno's Story
- Kathleen's Story
- Leslie's Story
- Martha's Story
- Mike's Story: Part 1
- Rosa's Story
- Twila's Story

www.hcvadvocate.org/community/stories.asp

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• *hcspFACTsheet* •

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