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living with HEPATITIS C

a series of stories written
about people living with
hepatitis C

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I am not sure when my life with hepatitis C began in my body. Not having any high-risk factors such as blood transfusion or illicit drug use, my source of acquisition remains a mystery.

It was January of 1995 that I went to my primary care physician complaining of fatigue. I had been diagnosed with an underactive thyroid a couple of years ago, so my thoughts were that I needed my medication adjusted again. I had also been told 20 years before that my liver enzymes were abnormal and that I had non-A, non-B hepatitis – a totally benign condition as far as they knew in 1975. My physician, knowing how very busy I am – “burning my wicks at both ends” as he called it – told me that I was probably just tired from the holidays with the children and I should come back in a couple of months if my energy was not restored.

As I was leaving the doctor’s office, the physician approached me at the counter and indicated that he had recently read about hepatitis C. “I don’t suspect that you would have such a disease, but we could run a blood test to check.” So, back into the exam room I went and blood was drawn for this special test.

On the third day, my diagnosis came – *you do test positive for hepatitis C and you should see a specialist immediately!* Wow – what a shock. The specialist, a gastroenterologist, was very knowledgeable at that time, and ordered a liver biopsy. I was very afraid of this procedure but knew it was the right thing to do if I was to understand this disease and its course in my body. Actually, the procedure was not a big deal and the information was very helpful. The verdict in March of 1995 – Stage 1, Grade 2. This meant that I had little fibrosis or scarring of the liver but that I did have some moderate inflammation of the tissue.

What goes through one's mind when they are told they have a potentially life-threatening disease??? Well, my mind had me dying at any moment and I was overwhelmed with feelings that my life had been cut very short. I later learned about the grief process and that this is one of the stages. No one is exempt from the process so understand it and allow yourself to go through the phases. It is supposed to be important that we do.

I decided to seek a second opinion from another gastroenterologist. He was very positive about treatment, unlike the other physician. Although the chance of curing the illness was only about 5% at that time with my genotype 1b, he indicated that I could be one of the 5% and that he and his office would support my side effects along the way. He also suggested that we partner with a well-known hepatologist in Los Angeles, Dr. Karen Lindsay, so that we all could stay within recommendations that she would make for me. I was impressed with his thoughts and care for me.

In December 1995, I began treatment. Afraid to give myself injections, I actually drove to my doctor's office three times a week to have the nurse give me my shot. Later my daughter gave me the injections as she was a medical assistant and lived at home making it much more convenient for all.

My Alt's were about normal within the first 2 weeks, and at that time there was not much information available about how frequently to check for the virus. Anyway, I became virus undetectable within a short amount of time and felt that the cure was mine to behold. Tears of joy rolled down my face when the gastroenterologist called me to tell me that the virus appeared to be gone, for now. I finished treatment with minimal side effects and

was elated that my viral load was still undetectable 4 weeks later.

What were my side effects? I had the emotional issues, feeling teary-eyed about many things, which necessitated a prescription for a mild antidepressant. I must confess that it was my husband who insisted that I see the doctor, remembering that the doctor had really emphasized with him that he should be called or that I should have a visit for any change in personality or mood. I had justified my sadness with the fact that *I had the hepatitis C* and that *I was taking shots that made me not feel well* – the whole martyr thing. I tell you this so that you understand that it is important to have someone close to you interested in your wellness and perhaps attending at least that one pretreatment doctor's visit with you.

I also had periods of feeling weak, versus being tired, and recognized that I was not eating enough, sometimes a side effect too. Once I started eating frequent and smaller portions, the weakness diminished, but never went away all together. I lost about 15 pounds during treatment and responded to reactions from coworkers that I was just eating less. I had made a decision that my workplace did not need to know about my condition or my treatment. These are things that everyone must think about and make decisions that work best for each individual.

I always had the body aches which I called flu-like symptoms following the injections. Since the shots were three times a week at that time, I frequently became achy – almost as if I had a mild temperature. This was doable and I worked full-time throughout treatment without missing a day because of the interferon. I actually think work and its distraction was helpful.

You may recall that earlier in this story I was virus undetectable 4 weeks after completing therapy. Well, one month after that I had virus detected and it rocked back and forth from detectable to non-detectable for many, many months until it finally decided to soar and stay DETECTABLE at almost my baseline number – 4 million copies.

It is now 10 years later and I am still alive and well unlike my fears at diagnosis a long time ago. I had a repeat biopsy in 2005 to see the impact of hepatitis C for a decade and the good news is that there is little change at all in the fibrosis, although the inflammation is ever present. My ALT's bounce around from 50-75 and my platelets, another marker of liver disease, remain well into the 300,000s with no change in 10 years. My liver is normal in size and so is my spleen. I feel great and have definitely moved on in my life and away from my fears, although ever cognizant that I must take care of myself and regularly see the specialist.

I now see a hepatologist as my monitoring physician about 3 times per year. He is strongly recommending that I be treated with the newer therapies – pegylated interferon and ribavirin. I am encouraged with his comments that, since I responded so well to the earlier treatment, I may have the cure in hand with 48 weeks of these new drugs. Although my disease has been very stable, his rationale is a good one – I am getting older and may not tolerate the treatments as well once I get beyond age 60, and with age I run a greater risk of other illnesses that may prevent me from being retreated or that would make it much more difficult to complete. I know he is right about retreatment. The medications have gone from the 5% chance I had 10 years ago to almost a 50% chance today. Isn't this a no-brainer?

I have had a prescription in hand for about two months now. Still thinking, still watching the pipeline of new drugs. I know what I should do now but seem to be missing that little voice that says – *do it, it is the right thing*. I will keep you posted.

Fondly, Carol

Be Sure to Check Out These Other Stories

- Brian's Story
- Gerald Moreno's Story
- Leslie's Story
- Martha's Story
- Mike's Story: Part 1
- Twila's Story
- Alan's Story

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