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# living with HEPATITIS C

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a series of stories written  
about people living with  
hepatitis C

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## Dee



*During the summer of 2006, I was having terrible gastrointestinal problems to the point that I began losing weight. My husband finally convinced me to go to our primary care doctor to find out what was going on. I had an upper GI series and several other tests, where they found that I have a condition called Barrett's Esophagus (from long time suffering with acid reflux disease). The blood work came back with totally different (and quite shocking) results.*

My liver enzymes were extremely high so my doctor ordered a hepatitis C antibody test. When it came back, those results confirmed that I had chronic hepatitis C. When the nurse called me

to tell me the results of the blood work, you could have knocked me over with a feather! I was in shock, to say the least, and the first question I asked was: How? How did I end up with hepatitis C? I wasn't an IV drug user; I couldn't remember blood being exchanged in any manner, even with my children; and sex didn't enter into my thinking at all! Then I remembered: I almost died during my hysterectomy and had to have 5 units of blood – back in 1983. I also remembered that I had to have my blood tested for HIV/AIDS once a year for 5 years after my surgery, as that was the main concern at the time. I am thankful that I didn't contract HIV/AIDS but now I had to deal with a different monster.

I did what most computer-literate people do – I got online and started pulling up everything I could on hepatitis C. I printed out material after material, trying to find out what I was up against. I was shocked to see the statistics relat-

ing to the number of people with hepatitis C, many people having found out like me – by accident (although spiritually I don't believe it was accidental). I was overwhelmed with the information on the internet! So I went to the book store and found some reading material suggested on several of the hepatitis C sites.

The next step was to set up an appointment with a gastroenterologist, which I did. I met with her and the process began. It was important that I had a doctor who was knowledgeable and involved with hepatitis C, and that I was comfortable with her. She ordered more specific blood work, including a viral load to see how much virus was in my blood. I also had a liver biopsy, which showed the beginnings of fibrosis. When the results came back, it was determined that I would be a candidate for combination therapy of interferon and ribivirin. I will say that at this point I was quite apprehensive about the treatment because, basically what this all meant was that the treatment was going to take a relatively healthy person and make her sick. I am drug sensitive to begin with and all I could think was that I was going to react horribly to the drugs.

I would like to interject here that it was extremely important to me to have family, friends, and church support before I even began my journey. I honestly don't know what I would have done without the positive reinforcement of all who contributed. It was the most powerful and loving experience I have ever felt. My husband and Mother (80 years old who lives with us) took care of me, our children called often, and the church sent

food, cards, prayers and love. That support increased my ability to remain positive and determined – I was not going to give in to the disease! I believe that keeping a positive attitude and facing the disease head-on as I did made all the difference in the world.

The treatment began in October 2006. The first injection (that I gave myself at the doctor's office) hit me about 5 hours later – and I mean hit! I felt like I had the worst case of the flu ever. I had fever and chills for several hours, and then the headache and body aches set in. I chose to give my injections on Friday evenings after work. That gave me the weekend to chill out (literally!) and regroup before work on Monday. So every weekend from that point on was virtually lost – I had the flu every weekend for a year. By Monday, I was feeling like I could function in the office. I thought that mentally I would be able to handle the effects of the drugs but I was wrong. By week three, I had to have something for depression. (I would suggest not waiting – actually I would encourage getting on something before starting treatment.)

The second injection was the one I was dreading because all I could think was how I reacted to the first one. I just prayed that it wouldn't be like that every Friday. And it wasn't. I gave my injection at around 5:30 pm and by bed-time, I wasn't yet feeling the effects. I basically slept through the really bad stuff. Saturday was a different story. I ran anywhere from a 100 to a 102.5 degree fever, every muscle and joint ached, and my bones even ached. I kept a dull headache and thankfully was able to take 2

regular-strength Tylenol every 6 hours. That definitely helped. By Sunday, I was feeling better but not up to par. I basically just took it very easy and as the day went on, I felt a little stronger.

As the weeks wore on, I was able to continue working, although I arrived a little later and went home a little earlier. I was able to go to church (where I was an active choir member) on some Sundays but after I was well into the treatment, even that was not possible. My active lifestyle of fishing and walking the beach with my husband came to a grinding halt. I just did not have the energy. I became anemic and by the end of it all, had lost 50 pounds. (I needed to lose the weight but along with that went my muscle mass as well.) I had to give up walking up stairs after fainting at church one Sunday morning. Working was very important to me. I was blessed that I could work – many people on the treatment can't. It kept my mind active and I had a lot of support at the office. But by the time I got home each night, I was on the loveseat for the rest of the evening. My bed-time changed from 10:30 to 9:00. So it was crucial that I rested on the weekends. My body needed it...my mind needed it...my soul needed it.

Eating was a problem for me. For the first few weeks, I had no taste for anything in particular, except sugar. I had to force myself to eat, which was difficult. I drank over 100 ounces of water daily and made sure I had pure juice and skim milk at least once a day. Protein was important which I mainly received from eating cheese. After well into the treatment, my appetite came back a little

but it still wasn't anywhere close to normal. I knew it was important to eat – I even tried eating small amounts during the day. It didn't work. So I continued to eat when I could and what I could.

I took vitamins daily: B-Complex, C, D, Calcium, and a Multi-vitamin. The juices I drank were immune builders, high in antioxidants, B vitamins, and vitamin C. I avoided all those things that are hard on the liver: caffeine, alcohol, greasy foods, etc. I still used skim milk, low-fat yogurt, and low-fat cottage cheese so as not to burden my liver with additional fats.

I lost a lot of my hair which I remedied by shaving my head. It was convenient and great for the summer. I had a full body rash that started in the third month and lasted for about 3.5 months. It was very uncomfortable and caused my skin to flake off on a daily basis. I already suffered from dry-eye but the meds made it worse. I had diarrhea for two days a week, each week that usually hit about 48 hours after my injection. My nails thinned and the enamel on my teeth wore away, leaving me with extremely sensitive teeth. But I was determined to continue working and was fortunate to have been able to do so. From what I have read, there are thousands of people who cannot even get out of bed.

Current: I zeroed out in April 2007 and finished my treatments in mid-October (one full year). I have remained at zero since. If there was any constructive criticism I could give the medical staff it would be this: prepare the patient for post-treatment as you

would pre-treatment. I didn't know what to expect because I wasn't told what to expect. The first 2 weeks after I stopped interferon and ribivirin, I was in a semi-euphoric state – I was so happy that I wasn't sick from the meds! I had all this energy built up but wasn't physically able to use it. I couldn't sleep at night, I was irritable during the waking hours, I was depressed, and I cried a lot. Since I was not normally like that, I became concerned. I made an appointment with my gastroenterologist and explained what was going on with me. I was told THEN that some patients go through a type of post-partum depression. In other words, the light at the end of the tunnel had gotten here...now what? We had a long talk about what to do to help get over the hump and things have gotten better.

The next viral load (May 2008) will be the clincher and I can only pray that at that time there will be no detectable virus in my blood. I have so many people to thank for getting me through this: God, my doctor and staff, my family and friends, my church family, and all of the online support sites. I reiterate that it is so important to have a line of support, and although a majority of family members and friends don't have a clue as to how it feels, just knowing that they are praying for you or sending you cards or making you laugh makes all the difference in the world!

*Dee is a self-confessed Caucasian female, 56 years old, married, with chronic hepatitis C, genotype 1-b.*



## ***Be Sure to Check Out These Other Stories***


- Alan's Story
- Brian's Story
- Carol's Story
- David'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](http://www.hcvadvocate.org/community/stories.asp)

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<p><b>Executive Director</b>  <b>Editor-in-Chief, HCSP Publications</b>          Alan Franciscus</p> <p><b>Design</b>          Paula Fener</p> <p><b>Production</b>          C.D. Mazoff, PhD</p> <p><b>Contact information:</b>          Hepatitis C Support Project          PO Box 427037          San Francisco, CA 94142-7037  <a href="mailto:alanfranciscus@hcvadvocate.org">alanfranciscus@hcvadvocate.org</a></p>	<p>The information in this fact sheet is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.</p> <p>This information is provided by the Hepatitis C Support Project • a nonprofit organization for HCV education, support and advocacy • © 2008 Hepatitis C Support Project • Reprint permission is granted and encouraged with credit to the Hepatitis C Support Project.</p>
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