

living with HEPATITIS C

a series of stories written
about people living with
hepatitis C

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In 1994 I was feeling the symptoms of hepatitis C – moderate to severe fatigue and other mild flu-like symptoms, but I didn't know the cause. I went through many tests over a two-year period and no one could medically explain my fatigue or the other symptoms. That was really frustrating because I thought I had this bizarre disease that no one knew about. I'll never forget the day that I had a doctor's appointment with my new primary care physician. After I explained my symptoms, he ordered blood work, including a hepatitis C antibody test. I had never heard of hepatitis C, but luckily, he had. A week or so later I received my test results – I had hepatitis C. Of course, I was devastated by the news, but in some ways, it was a relief to finally find out what was causing the severe fatigue.

About 3 months after I was diagnosed I decided to try treatment with non-pegylated interferon monotherapy (3 injections a week). I was on treatment for a year, but I did not achieve an SVR. In fact, during treatment my viral load never reached a point where it was undetectable. I also had many side effects. The first evening I had severe chills and a fever. After a while, the physical side effects such as the flu-like symptoms seemed to diminish somewhat – at least to the point where I could handle them. However, the psychological side effects (anger and depression) slowly became worse. After about three months, it was decided that I should start on anti-depressant therapy. I also started to meditate regularly and between the meditation and the antidepressants, I felt better and was able to finish treatment.

Looking back, I wished that I had been more educated about the chances for a successful treatment with monotherapy because I am not sure I would have tried it. The data about the treatment at that time showed that I only had a 9% chance

of achieving an SVR. However, even though it didn't eradicate the virus, treatment did help with the fatigue, for a while at least.

But eventually the fatigue returned so in 1999 I decided to try high daily dosing of non-pegylated interferon monotherapy. At first, there was a dramatic reduction in HCV RNA (viral load) levels, but after 10 months, the virus came back so I stopped therapy. Again, my energy level dramatically improved, but over the next couple of years the extreme fatigue as well as some of the other symptoms like brain fog, lack of concentration, difficulty with mental retention and other annoying symptoms came back. Surprisingly, the side effects of high daily dosing didn't seem that much worse than when I took interferon three times a week. I think this might be because of what I learned the first time about managing side effects. I also started on anti-depressants a couple of months before I started therapy.

In 2002, I decided that I wanted to try pegylated interferon plus ribavirin therapy. I began towards the end of 2002 and my viral load began to drop, but not as quickly as I had hoped. After about 3 months, I had a 2-log drop in HCV RNA, so I was well on my way. At about the 9-month mark, I began to do some research on treatment duration for people who had characteristics similar to me – older, genotype 1, high viral load, had HCV for a long period of time. Most data suggested that I should be treated for a longer period of time. After consulting with my doctor, it was decided to extend the treatment from 48 weeks to 72 weeks.

The side effects of pegylated interferon plus ribavirin were much less than the side effects I experienced while on the first two courses of therapy. In fact the morning after the first shot I felt so good that I wondered if I really did take the drug at all! That slowly changed

and by the third month, the side effects became worse, but I was able to manage them fairly effectively. My blood chemistries looked pretty good throughout therapy, except that eventually I developed anemia. I am VERY fortunate to have insurance to cover all of my medications including erythropoietin (EPO). Epo worked wonders for the anemia and the related fatigue, allowing me to finish treatment.

One of the strategies I put into place was to have a good support system well before I started therapy. I relied a lot on my friends and family for support. The side effects were managed aggressively with early intervention to prevent them from becoming worse. I am very fortunate that I love the work that I do for the Hepatitis C Support Project. This really helped to distract me from the side effects. Don't get me wrong – it wasn't a walk in the park, especially since I was trying to run a non-profit agency. I traveled extensively during this period and logged about 100,000 air miles. However, I made it through and it was well worth it.

It has been well over a year since I finished treatment and I am still negative for the hepatitis C virus. This was not totally unexpected, but, as most people who are treated know, it wasn't totally expected either. Ever since the news I have been thinking about what successful treatment and getting rid of the virus means for me.

First, it was fantastic news that the virus was out of my body. I only wish that everyone with hepatitis C could experience the feeling of beating HCV. It took awhile but the side effects gradually went away and I began to feel better. The hepatitis C symptoms that I had been experiencing for so long also started to get better. Slowly, my energy returned. In fact, my energy level is better than it has been in 10 years, and most of those hepatitis C flu-like symptoms

have gone away. Best of all I now feel clear-headed and I feel a general calmness that I haven't experienced in years. This is a big difference from the way I felt before treatment.

Many issues come up after successful treatment. One of the most frequent questions people ask is if they can drink alcohol again. For me, this was a no brainer. I'm in recovery so drinking again is not an option. Unfortunately, there is no data on whether someone who achieves an SVR can drink alcohol. Until there is significant data on this issue, the general recommendation is to abstain from alcohol.

Another big issue is blood. Should I cover my wounds or take precautions if blood is present? Definitely. Always be cautious where there is any blood present whether it's yours or someone else's.

Feeling infectious is probably one of the strongest emotions that almost everyone with hepatitis C feels especially after being newly diagnosed. I used to be so concerned when my blood was present that I would needlessly become almost hysterical about it. I still believe and practice safety precautions in the presence of blood. But there is a big difference between common safety precautions as opposed to knowing that you have infected blood that could potentially infect another person.

Do I feel like I will live longer without hepatitis C? I do feel that I will live a longer life, but more importantly, I feel that I will not have to suffer with the severe fatigue or the other symptoms of hepatitis C. For me, the decreased quality of life and suffering was worse than the idea that I might die from hepatitis C.

My advice to someone who is thinking about treatment is to research hepatitis C treatment medications. If you decide to start treatment,

set up personal and medical support *well in advance* of starting treatment. Another strategy that helped was finding something that I enjoyed, which distracted me from the side effects. Probably the best advice I can give is to take treatment one day at a time.

“But let us remember, we cannot wait for others to tell our stories. We must remain visible, vocal, and unified.” *Yvette Sangster and Ed Kramer*

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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