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living with HEPATITIS C

a series of stories written
about people living with
hepatitis C

• • • • • *Brian* • • • • •

My experience begins in 1996. I was diagnosed first with HIV. That was devastating enough. When I got over the shock a month later, I finally started treatment. The “cocktail” of drugs for HIV treatment had just been approved for use. This included a protease inhibitor. A month after starting that, my liver enzymes went sky high and I turned bright yellow. I was having a hepatotoxic reaction to the protease inhibitor but one more dramatic than the doctors had usually seen. After some tests, there it was – hepatitis C. I didn’t know much about it and I still don’t know how I got it for sure or for how long I have had it.

So I got a double blow, HIV and HCV. At that time the doctors were unsure

of how to treat me or which disease to tackle first. This is very different from today when doctors are more familiar with treatment of co-infected patients like me.

After my first liver biopsy (and yes I was scared of the biopsy needle, but it was all over pretty fast) it was discovered that I had stage 2 fibrosis and inflammation. It was time for action. I started on standard interferon injections 3 times a week. That was all that was available at the time. I did get very fatigued and had the usual flu-like symptoms, but the worst was the depression. No one told me that could happen on interferon! The depression was severe, but after consulting with my doctor about an antidepressant, I found one that worked very well for me at a very low dose.

Treating a co-infected patient can be tricky because the interferon made my T cell count go down, that’s a measure

of my immune system function. While the depression was now well controlled, the fatigue and insomnia grew as well as my inability to concentrate. After 8 months we saw only a slight dip in my HCV viral load and then it rose again while still on treatment. So I barely responded to it and we decided to stop.

It was frustrating, but the one piece of good news was that on a later liver biopsy my fibrosis and inflammation had improved to stage 1. So I was happy that the treatment had at least bought me time.

When ribavirin became available in 1998 for use in combination with standard interferon, I asked my doctor to try that. But instead of using the interferon 3 times a week I insisted we try harder and use the interferon daily. Well this all lasted only 2 months. I got so sick on that high a dose that I could not even keep water down. And I developed hemolytic anemia from the ribavirin.

Unfortunately with my coinfection of HIV with the HCV, my liver steadily worsened to stage 3 by 2002 and my liver enzymes sky rocketed with my ALT hitting 1600!! My liver was going downhill fast.

It was time for action and I was determined to fight this. By this time pegylated interferon had been approved for use as monotherapy and in combination with ribavirin.

I opted for the combo even though it had not yet been approved for use in coinfecting patients like me. It would mean a year of treatment. For the first time at the 12 week mark I did have an undetectable viral load which was a great sign of the treatment working. I had sort of become a treatment “expert” by this time, so I knew enough to start an antidepressant a few weeks before I started the HCV treatment. That way my mood remained very stable throughout the treatment.

“Every situation is different and I am not a doctor, but my experience told me that it was better to take the medications to treat each side effect and try to keep on as full a dose of HCV treatments as possible to get maximum benefit.”

I kept drinking my water to flush my system and pushed myself to just do some walking and light exercise each day that actually helped keep the flu-like symptoms

and body aches down. I have to say that these symptoms were a bit milder with the pegylated interferon as opposed to the older standard interferon.

I was never able to tolerate a full dose of ribavirin. Even with the lower dose it was working but I developed hemolytic anemia again – you really feel tired and out of breath like altitude sickness with that. Fortunately I had a good doctor who prescribed erythropoietin, an injectable drug to counteract this type of red cell anemia. Unfortunately I also became neutropenic, (type of white cell count drop) and I was more open to other infections. So my doctor started filgrastim, yet another injectable drug to fight that. It worked but gave me a

lot of internal bone pain. Eight months into treatment I developed acid reflux disease due to the ribavirin and had to start medication for that. So I was on tons of pills each day and several injections of medications every week.

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Sounds bad, but it was finally worth it all. I achieved a Sustained Viral Response (SVR) 72 weeks after starting treatment. No more hepatitis C six months after stopping treatment. It was hard to believe that I was no longer a person with HCV. It had become part of my identity! But I was happy because for me that was one disease down and only one to go. I have a future and can work on my HIV treatment now with fewer complications.

My liver has normalized as have my liver enzymes. I am more energetic and have better concentration than in years. I have even taken up playing bridge! I had forgotten what it was like to have a clear head again! It was a dramatic difference just a few months after finishing treatment.

I guess my advice to folks going through this is that you CAN get through it. You have to want to stick to it and want to get rid of it. If you do not respond to initial treatment or you have a relapse, remember that your liver health has still probably improved. YOU did not fail treatment, you still got some benefit. You have to stay on top of every side effect of the treatment and be in charge of knowing your options for

treating them. Some doctors lower the dose of HCV medication rather than treat the symptom. Every situation is different and I am not a doctor, but my experience told me that it was better to take the medications to treat each side effect and try to keep on as full a dose of HCV treatments as possible to get maximum benefit.

Yes we still need much better treatments, but they are still years away. Don't delay treatment. Being on it is not fun and can be disruptive to your life. But if you are proactive, plan and have the support of loving friends and family YOU CAN GET THROUGH IT. And you will likely feel and be so much better for it. Hopefully with an SVR.

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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