

Mark's Story

Infection

I was sharing injecting paraphernalia with an ex on a disastrous relapse bender. It is ironic that trying to stop using can be the most dangerous time in a junkie's life, things get chaotic. I used a clean needle but shared water and a spoon. I remember getting horribly ill for about two weeks after that, I don't think everyone feels that bad when first infected but I definitely did!

I was diagnosed by a lovely GU clinic doctor. She was attached to the local drug advisory service in Colchester and she tested everyone who wanted it for HIV and Hep C and also vaccinated against Hep B. I was tested on one visit and given the bad news on the next a fortnight later.

I was about 25 or 26 years old at the time so this was early 1990s. She was fantastic and helped me to understand what the diagnosis meant and gave me some basic pointers on how to look after myself, she had a way of being supportive without enabling. I have spoken of her as being like the iron fist in a velvet glove. Sadly, I was deep into my addiction at this point so I found it difficult to care much about myself. There wasn't much known about Hep C and I felt like I'd dodged a bullet by not getting HIV. It was even considered as a kind of badge of honour amongst some of us, a sign that you were one of the gang. Dumb really.

Sometimes I would worry about the disease and I would try and make positive changes but usually it would just be an excuse to use more drugs. When I thought about having Hep C I felt dirty, like a stereotypical scumbag junkie.

Symptoms

Whilst I was still using there were every more epic hangovers to deal with and constant low grade sickness. Once I got clean and my physiology normalized I actually felt pretty good for nearly a decade. I would get occasional bouts of tiredness and odd days of brain fog but nothing that bad.

Eventually though I started to get the classic symptoms of fatigue and general malaise. Brain fog became the norm rather than the exception. Brain fog doesn't sound bad but it's a horrible feeling, it feels like you've got a size 10 brain in a size 9 head, concentration and focus gets more difficult and I would be irritable and, at times, obnoxious. The best description I've heard is that it feels like the water in your brain needs changing like a dirty fish tank.

I didn't think that I suffered too badly from depression but with hindsight I can see that I suffered pretty much constant low mood and a listless apathy. I had a terrible episode of depression after my initial treatment with Interferon and Ribavirin failed. That was a deep hole.

Treatment

I have had treatment, I had a 48-week treatment of Peg Interferon and Ribavirin which didn't work but a recent treatment with Zepatier has given me SVR+12 and I'm confident that my re-test at one year will show SVR too.

Broadley, I am happy with the care I have received. GPs were (and still are in many cases) totally clueless and don't seem to take it seriously. I was told as recently as five years ago that there are no symptoms associated with Hep C. I'm generally amazed at how little is known about Hep C by the general public, it's like nobody really cares. No information

campaigns, no TV adverts and only a couple of charities against the hundreds of those advocating for HIV.

The specialist centre at Addenbrookes has been great and I'm grateful to them for my care and treatment, it's just a shame that they're 45 miles from where I live. I'm lucky to have the resources to get there, many don't

I was disgusted at the way that the new treatments were deliberately delayed. I wonder how many died whilst the bureaucracy ground through the many obstacles placed in its way?

The ODN system now seems to be doing a fantastic job though, I think that NHS England will get the job done and prevent a lot more suffering.

The future

First off, it feels amazing to even have a future. I feel like I've got my vitality back so now it's all about enjoying life and being able to live a life without the shadow of Hep C coloring everything.

If I were to share advice with someone newly diagnosed I would say don't panic! You have time to treat the disease and the treatments are effective.

- Talk to the Hep C Trust and arm yourself with all the information you need to look after yourself and then hassle your GP until you get referred to your local ODN. Most of them will be actively looking for people to treat by now or in the near future.
- Look after yourself, don't take drugs or alcohol and find out what a healthy diet means to you.

Getting and staying clean has been the best thing I have done. Achieving SVR is up there though, and managing to live a good life despite having a chronic illness. I've helped to fight against the stigma of having Hep C by speaking out.

The stigma is a real thing and something I still fight against even though I'm clear now.

Ultimately, Hep C was one of the biggest consequences of my using that made me turn my life around and get into recovery but it could equally have been one of the biggest reasons not to bother...