

Juz's story: from childhood to adult self management

I just wanted to get rid of my hep C but I was nervous about trying treatment again. I found a new specialist who was an amazing support to me. Before going on treatment, he referred me to a psychiatrist for anti-depressants to stem any possible panic attacks. Ironically, the only symptoms I didn't have were anxiety and depression!

I found an online support group – www.hepCaustralia.org – and it was an incredible experience. Before then I had been isolated and introverted with my illness. The website brought together an amazing community of people with hepatitis and gave us a forum to discuss treatment, discrimination, fears, successes, gardens, kids, dogs and anything else you can think of. These people shared my treatment journey from the first injection through the subsequent months.

Treatment was a vastly different experience this time around. I had amazing support mechanisms in place; I was much less afraid. It was a very positive experience and I am very grateful to the people who shared the journey with me.

My specialist deserves a medal for getting me through treatment. He didn't sit on the other side of the desk and dictate to me. He was a partner with me in the decisions about my health. I think partnering with medical practitioners when you have a chronic illness is a critical step in self-management. I am in my 40s now and have the confidence to drive decisions about my health. It comes from working in a career where you lead projects and use your initiative. I would like to see people with a chronic illness getting support or training in how to partner with their medical practitioners. I think the culture of medicine doesn't naturally encourage the partnership model and therefore patients need to be encouraged to actively engage in this process.

You can be emotionally volatile on treatment. It is critical that anyone going on to treatment is given information about support networks. Combination treatment requires ongoing support from a range of sources – not just the clinics or specialists. Hepatitis organisations can refer people to great

resources – from advisers on health and nutrition, to the online support network, to support groups in local and regional areas. People shouldn't have to go through it alone.

During the first six months of treatment I had significant side effects but managed well. But after six months I was shattered. I dragged myself through each day. At one point I was on over 90 tablets a week and only 35 of those were ribavirin. The rest were to manage the side effects. I had so many different side effects that I could write a manual on it. In the end, I decided with my specialist to finish early at around 40 weeks. I remember thinking that I didn't care anymore. I was just so exhausted.

There was new research suggesting people who are PCR negative at four weeks might only have to do 24 weeks of treatment instead of 48. I didn't have a PCR at four weeks but I was PCR negative at 12 weeks and everyone was confident that I was going to clear. I didn't think I was jeopardising my chances of clearing by coming off treatment at nine months.

After I stopped treatment I ached all over and felt miserable for about three weeks. Then I started to feel great. I vividly remember standing at the sink two months after I finished and saying to my husband how great I felt. I thought "if this is how other people feel, what a fantastic way to live your life". We both thought I was going to clear.

About two weeks later, we went into Federation Square for the day. I had noticed a stitch in my side in the morning. It wasn't until an hour or two later that I realised that the pain was in my liver. I went and got a test the next day. My ALTs were up. It was all over red rover. I'd relapsed.

I wasn't mentally prepared for a relapse. Everybody thought I was going to clear. At first I was terrified. What did this mean for my future and the future of my family? Then I was furious at everyone. I was angry at my specialist even though he had done nothing to deserve it. I was angry with everyone who had flippantly said that I would clear. It was a terrible shock which took me many months to recover from.

self medication

my story



Image © by Stephan Ceyer, via www.flickr.com

Before you do treatment all you can think about is starting. When you're on treatment, all you think of is finishing. But when you relapse, and you are looking at a future with ill health, it is like being reinfected over again.

In the www.hepcaustralasia.org online support group the only people who understood my relapse were the people who had relapsed themselves. People on treatment understandably don't want to know – it is frightening to them. People who haven't been on treatment still have the hope that future treatment will clear them.

I got fantastic support from the website whilst I was on treatment, but once I had relapsed I turned away from the site for many months. It is easy to discuss being on treatment and hep C when you might get rid of it. But I couldn't face being reminded of my hepatitis after my relapse. I wanted to ignore it and get on with my life.

Recently, people have asked me if I would do treatment again. I would do treatment again in a blink of an eye. It is a relatively short time in your life and absolutely worth the effort if there is a chance of clearing. But could I go through a relapse again? That's a different story. The hardest thing about the relapse was the loss of hope.

Like all relapsers and non-responders, my sight is on the new treatment regimes with the protease inhibitors and polymerase. My specialist will keep me informed about the trials, but I don't have the same hopefulness. There is

a lot to lose if the next round of treatment fails. I am now cautiously interested in treatment rather than naively optimistic.

After the relapse, I am more interested in self-management: good diet, exercise, rest, relaxation, focusing on the day instead of the future, etc. I am forcing myself to slow down and I resent it – not being able to work more hours, sit on committees, travel, study at night, bushwalk. I want to feel a part of things and I hate feeling different. On the other hand, hep C makes me look at what is valuable in my life.

It'd be easy to say if I didn't have my hep C that my life would be perfect, but I'm sure this wouldn't be the case. Hep C is like a dysfunctional family member that you have to make peace with when you would rather run screaming for the hills. I hate my hep C but it is part of me – for better or worse.

I was thinking recently about whether I would stop being a "hepper" (that's what we call ourselves) if I cleared. And I knew I wouldn't. Hepatitis came from some fundamentally defining moments in my life and continues to take me in unexpected directions. It has shaped me as a person. I will always be a hepper because of everything it has brought to my life – both good and bad.

- **Juz, VIC.**

Part three of three. See previous two editions for our abridgment of Juz's story. Alternatively, see Juz's full story on www.hepatitisaustralia.com/about_hepatitis/personalstories.html#Justine