

my story

Juz's story: from childhood to adult self health management

I went onto treatment for the first time in 2000. It was three injections a week of interferon and daily ribavirin pills. I didn't go through a clinic because I saw my specialist privately, but I was referred to a nurse at one of the hospitals for the initial injection. I remember crying because I was so afraid of putting drugs into my body with a needle. The nurse was very frustrated and terse with me and I was sent home with no support.

After 10 days I woke up in the night on a Saturday morning and started vomiting. I started shaking so badly I couldn't sit down and I spent the next 48 hours pacing the house. On

Monday, I rang the specialist. He was away but his colleague instructed me to come off treatment immediately. I was left feeling confused and afraid. I felt that I'd failed somehow. My experience was put down to a reaction to interferon but I believe I had a severe panic attack brought on by a lack of support. After I stopped treatment, I was told that there was no cause for worry and that I would live with hep C for the rest of my life.

Around this time, I met my husband. It was a lovely period in my life. My health was good. We went to the specialist to ask about having



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children. We were advised that the risk of transmission was low and that there was no reason not to have kids. I got pregnant and had a very easy pregnancy. My ALTs were very low during the pregnancy. I naively hoped that my hep C had cleared. My birth experience was wonderful. The staff at the hospital knew I had hep C. My obstetrician was very reassuring and careful with the birth. The midwives encouraged me to breastfeed. I was optimistic about the future.

After my son was born, I had a severe flare up of the hep C. My ALTs went up to the 400s and 500s. Nobody could tell me why it was happening. I felt incredibly fatigued. I remember going to the supermarket and thinking that the pram was the only thing holding me up. My viral load rocketed up. My specialist started mentioning transmission risks to my son. Before your child is born the possibility of passing hep C is theoretical and statistical. Once they are born, and you are waiting out the testing window period, the prospect of transmission becomes horrific. Health issues with a child are bad enough, but a health issue that you've created from irresponsible, risk-taking behaviour is almost beyond bearing.

I went and saw a paediatrician. He gave my son a PCR test. I still remember the overwhelming sense of relief when my husband called me to say that my son was negative. Things started to calm down and my flare-up settled down after 18 months.

Looking back, before Thomas's birth I didn't think about hep C much. I could sometimes go months without giving it much thought. After the birth and the subsequent flare-up, I now think about it every day. I hate it. I wish I could go back to just forgetting it was there. But I can't.

I have told very few people about my hep C. Only my very close friends know anything about what I have been through. I have managed to develop a very rewarding career. One of my core values at work is professionalism. Bearing this in mind, to some degree I think that health is a

private issue. Even if I had a different health issue, I wouldn't tell work colleagues, but it is even more so with hep C. There is little understanding around drug use and I think that people are naturally quite afraid of it. If my workplace knew of my hepatitis, I really believe it would affect my career negatively. I also don't want to be judged by my behaviour of 26 years ago.

Do I fear discrimination? Absolutely. I think it is natural for people to judge and make assumptions about you. If work thought I had a serious illness that might affect my performance, I believe it would restrict my opportunities. I have a child to support and a mortgage. I'm trying to balance looking after my health in the present with ensuring that my career is protected so we don't live below the poverty line in the future. That's my major concern at the moment.

Unlike some people with hep C, I get an amazing amount of support from my partner. He is an exceptional person. Without the hep C I think I would have married a completely different person; I chose someone who was so accepting. There are pluses to everything.

Once the flare after my son's birth had settled, I just wanted to get rid of hep C. I'd had a gutful of it but was nervous about trying treatment again.

[More about Juz's treatment re-run in the next edition.]

- **Juz, VIC.**

Part one of Juz's story can be found in Edition 65, *The Hep C Review*. The final installment, part 3 will be published in our next edition.

Abridged from www.hepatitisaustralia.com/about_hepatitis/personalstories.html#Justine