My Complex Relationship with Hep C

April 22, 2016 By Philip Christopher Baldwin

It was early September 2013. I walked through the gloomy lower level of the Mile End Hospital. My shoes squeaked against the green linoleum floor. I reached a central staircase. I could hear the pitter-patter of rain drops colliding with the large skylight. The Hepatitis clinic was located on the first floor. The receptionist said the doctor would be able to see me shortly and gave me a glass of water. I was there for a liver test to ascertain the health of my liver, the first since my diagnosis three years earlier. I was nervous.

I am really excited to be blogging for Hep Magazine. Over the last five years I've had a difficult journey with Hep C. Since 2010, when I was diagnosed, first with HIV and then a week later with Hep C, there have been amazing advances in the Hep C treatments offered by the NHS. The landscape has been completely transformed, interferon now replaced by the new drug sofosbuvir. My doctor had always advised that I shouldn't start an interferon-based treatment. I will be commencing sofosbuvir this summer. I am going to write a series of blogs describing my experience around Hep C and the treatment.

Stigma is a topic I've explored in the past. With my Hep C treatment commencing soon, I've been reflecting more on Hep C and its impact on me. In my late teens and early twenties, I worked hard to be an out and proud gay man. My HIV and Hep C diagnoses, at the age of 24, were hard to deal with. At the time of my diagnosis, I was beginning my career as a lawyer. I had just started working at the international law firm White & Case. I found that stigma impacted me in a number of ways.

I was petrified about telling White & Case that I was HIV and Hep C positive. I had friends who worked in these sectors who were HIV positive, but none dared to disclose their status in the workplace. I told everyone about my HIV, except for my colleagues at work. I found it hard not to tell my employer about my HIV and what was going on in my life. I hated being furtive about my HIV in the workplace, but I thought I had to be. Having to conceal my HIV impeded the process of coming to terms with my HIV. The silence enforced a sense of shame around my HIV. The air felt heavy with stigma and I was struggling to breath. I knew that I had nothing to be ashamed about. I had done nothing wrong. I was still proud of the person I had become. I told White & Case that I was HIV positive at the end of 2012. This was triggered by my CD4 count dropping, at which point I started HIV medication. My employer was supportive. I confronted the stigma head on and the acceptance I received was empowering.

My relationship with my Hep C was even more complex. Whereas I was open about my HIV status, except in the workplace, I hid my Hep C from many people. I found there to be a lot of stigma around Hep C within the gay community. I felt isolated from HIV negative gay men on account of my HIV and isolated from HIV positive gay men on account of my Hep C. This was a toxic combination of stigma. It felt like a wedge had been driven between myself and other gay men. My Hep C made me feel less sexually desirable. I was frightened about telling other HIV positive men that I was Hep C positive. No one ever asked if I had Hep C. I did not reveal my secret. As a consequence, I felt distanced from the gay men whose intimacy I cherished so much.

My anxiety was such that, when a good friend told me he had Hep C, I felt I could not open up to him about my own Hep C. Another friend knew about my Hep C and I became paranoid. I thought he was talking about me behind my back. From 2013, I changed the way I behaved. Telling my work about my HIV had been a positive experience and I longed for similar acceptance around my Hep C. I confronted my fears and told everyone around me. I was very direct about this. A number of gay men, face-to-face and online, told me that they were co-infected as well, but were experiencing similar stigma. They too had been afraid of telling me. It was empowering to chat to other men in a similar situation. I was relieved to share my secret. It felt like the burden of the stigma had been lifted. In some ways it will be strange to be Hep C free. By confronting the stigma head on and broadly disclosing my Hep C status, I was starting to incorporate my Hep C into my identity. I wish I had felt able to discuss my Hep C broadly amongst my gay peers sooner.

When the results of my September 2013 liver test came back, I found out that my liver was in great shape. For a while, I was worried that the stigma of Hep C would permanently scar me. The scars of Hep C were more psychological than physical for me. We must build stronger communities. We must confront our fears. Most importantly, we must continue to challenge stigma.

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