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# To Tell or Not To Tell People About My Hepatitis C

April 22, 2015 By Greg Jefferys

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The issue of whether or not to tell people I had Hep C was the next thing for me to consider. According to the Hep nurse most people kept their infection secret. My wife and I discussed it and initially decided that we would tell only immediate family because there was a very small chance that they might have contracted it.

However trying to keep the disease a secret seemed problematic to me simply because I regularly had a glass of wine with friends in various social situations I would have to decline the wine and that would naturally lead to an enquiry as to why. Here I could either tell a lie or tell the truth.

I decided it was much simpler just to tell the truth so the next I was with friends and the bottle of wine came around I explained that I had Hep C and could not drink. Some people knew about Hep C and some did not, so there was a period, for the next couple of weeks, when I did a lot of explaining. In the explanation section I explained that it was almost impossible for me to transmit the virus to anyone in a social situation and I also decided, when the question was asked “How did you get it?” I would simply say that I used intravenous drugs when I was 19 and 20. Really the truth is the simplest and easiest course.

Once that period of telling and explaining was over I settled down to drinking bottled water and no-one seemed to have decided to ostracize me, my social life went on as usual. The only real change was that I was always the designated driver!

In the mean time one of my sisters contacted me to tell me that a mutual friend, K, had been diagnosed with Hepatitis C a few years back. He had kept it quiet, telling only a few very close friends. My sister told me that he had managed to get onto a trial of a new anti-viral drug that had no side effects and a 98% success rate. He had affected a total cure after a three month treatment. She gave me K’s phone number and I rang him immediately.

K had moved to another city and, whilst we had been close friends for many years, we had not spoken for quite a while so after a bit of friendly banter I said, “So I hear you had a bout of Hep C.” There was a stunned silence on the other end of the line, then, “How did you know that?” He thought his infection was a very well kept secret, which I suppose it was. I explained to K that I had recently been diagnosed with Hep C and that my sister had passed on the news of his cure. After the initial shock K loosened up and was very understanding of what I was going through. He ran me through the process of his disease and cure. The new drug was called Sofosbuvir, a drug manufactured by the USA based pharmaceutical giant named Gilead. Sofosburvir had been approved for use in the USA and K had heard about trials being carried out in Sydney’s Saint Vincent’s Hospital to get it listed in Australia. He had managed to get onto the Sofosburvir trial and told me that it involved taking just one tablet each day and that he had experienced no side effects at all. K explained that the drug was available in the USA but very expensive. A treatment would cost about $90,000 and that it had not been approved by the PBS (Pharmaceutical Benefits Scheme) for a government subsidy that might make it affordable for the average person.

He suggested that I contact the doctor running the trial, Dr C. K said he had heard there was another trial coming up specifically for people with Hep C genotype 2. He told me to try to get on that but if I couldn’t then to get onto any trial that was going. He emphasized that it was hard to get on the trials because there were more than 250,000 Australians with Hep C and they all wanted to get the new drug.

K said I would need to convince the doctors that I was reliable and not going to engage in any behaviour that would re-infect me. He said that because a lot of the people with Hep C were or had been addicts there was the chance they would have a relapse and start injecting again which would screw up the results.

The big problem was that I lived in Tasmania and the trials were in Sydney.

So I Googled Hep C Sofosbuvir trials and found that some had been conducted in Melbourne. I figured I would have a better chance of getting on the Melbourne trials, being closer to where I lived.

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