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Hepatitis C: A sharing network

September 26, 2015 By Grace Campbell

There’s only one thing more exciting that writing a blog post you are proud of - having someone read it.

Or perhaps having someone share it.

When I was asked if I would blog this crazy trip I’ve been on, I couldn’t understand what I might have to offer. I was a relative newbie and the drugs I was on had been available in the US way before I was given access to them here in Australia. I really didn’t know much about hepatitis C, and I still don’t! I even discovered I’d been pronouncing protease* wrong all this time. How embarrassing.

I was thrilled if anyone read a post of mine, although amazed might be a better word. Compared with everyone else here, I really didn’t have much to offer, save an education in English literature and a penchant for quoting old dead Roman and Greek guys. So very useful for a blog about hepatitis C.

Lucinda, bless her heart, is a fully fledged expert, with published BOOKS no less. Rick has more lived experience of HCV treatment that anyone should have and yet is positive and intelligently challenges preconceptions. Matt is amazing in his capacity to delve deep into the human soul and investigate his own feelings, emotions and motivations. Kim makes a difference every day with her foundation. Connie is passionate in her belief that we can get through this. David is insightful, self-aware and a source of wisdom regarding many issues surrounding blood-borne viruses. Greg is determined to change the way access to hepatitis C drugs plays out round the world. Karen is amazing in her capacity to march onwards whatever life throws in her way.

And then there’s me. The dilettante. The scatterbrain. The inappropriate sense of humour. The continued scattering of “u” throughout words Lucinda is sure should not have them.

All I wanted to do with this blog was to leave a trail of breadcrumbs: little snippets of information about my treatment for others to read or not, as it suited them. I thought of it as a flashlight illuminating some of the less travelled roads and the dusty corners of treatment. Not the bright and shining areas where everyone passes, the wide corridors, the meeting places.

Because frankly, I had nothing to add to the general traffic. I live in Australia. We have less access to the new drugs than many other countries. Those that are accessing the new treatments, like me, are generally doing so because we are very sick and have been allowed compassionate access. The others are on trials.

So with this in mind, imagine my excitement when people did read this blog (thank you, all three of you, much appreciated - yes, you too Mum). The sense of excitement when someone liked something I’d written was tangible.

And then not long ago, I saw one of my blog posts on Facebook. It had been shared. And then in a comment under the share someone else had written “stealing!”. the original sharer wrote back “that’s okay I stole it too”.

My blog post had been “stolen” and I was so excited that they did it. Everything I write I hope people take something from. If it meant enough that two people thought it was worth sharing then I had doubled my anticipated outcome.

That’s how the hep C community works best. We share. We share good news. We share bad news. We share tips for side effects, we share commiserations. We share our knowledge of treatment, our compassion, our empathy. We share news and updates. We share our lives.

I don’t have any idea what most of the people I speak to on the forums every day look like. It doesn’t matter. I know what they are like. I know how they speak from their heart. I know how much they care about everyone’s victories and I know how much their hearts break when there is a loss.

Sharing builds communities, and our community needs to be strong. We need to fight for the right to treatment, for the right to be treated as worthwhile people deserving of equitable treatment. We need to keep fighting, even if we personally have what we need. We need to fight for the people that haven’t.

Let’s continue to share; to develop strong, proactive communities; resilience in the face of adversity; and most importantly HEALTHY people.

*I pronounced it like pro-tractor - pro-tease.
