



Hepatitis C: Why can't we be friends?

August 24, 2015 By [Grace Campbell](#)

"There is immense power when a group of people with similar interests gets together to work toward the same goals."

- Idowu Koyenkan

I read the other blogs here so that I can ~~mercilessly use their great ideas and not have to think of any of my own~~ keep up with what others in the trenches are thinking, saying and doing.

In particular, this quote from David Pieper's blog resonated with me. And while we're on the topic of David - another Australian! Yay! If it wasn't for the crappy exchange rate we'd be taking over these forums and blogs! David has given me permission to quote this section and I thank him for that.

"I am acutely aware of the absence of a similar supportive community for people living with hepatitis C. For many people, acquiring hepatitis C relates to a part of their lives they are no longer connected to. For others those connections are a painful reminder of something they need to leave behind. I hope one day we will develop a hepatitis C community to provide that invisible web of support."

I've been wrestling with what has made support, funding and attitudes towards HCV different from HIV. Both started from a point of fear, stigma and discrimination. One has moved forward faster than the other.

I think David has hit the nail on the head. There are probably hundreds of people living in your city with HCV. Ask yourself: are there support groups? Is there a visible presence? Do you see each other as a fellow traveller on the same path?

Do you know any of them? Do they know you?

Often we are disparate, we are hidden. We don't necessarily form therapeutic communities. We often live in isolation from others with the virus. And yet, it's important to reach out and touch the lives of others with hep C so they know they don't have to go through life with this virus alone. So they know they have support as they undertake treatment. So they know we care.

I believe the stigma of HCV often robs us of our capacity to bring about change. We don't want people to know about our virus. We don't want to own up to a stupid act in our youth, or a past that has included drug use. We've probably changed. A lot. We might have very responsible jobs, be in positions of power or influence. We might be grandparents who go to the movies on a Saturday night, babysit the grandkids, help out at their school. All that past is - well, in the past.

Except that it isn't.

So it stays our dirty little secret and it effectively shuts down any sort of meaningful large scale collective action. There are hundreds of thousands ... millions of us ... all around the world. Imagine how loud we could roar if we used our voices.

I'm not saying you have to disclose your HCV status, because I know how hard it is to do that. I would never encourage anyone to do it unless they were 100% ready. But if you aren't ready to take that step, perhaps you could look for something less confronting.

Send a letter to the Minister for Health explaining why access to treatment is so necessary.

Sign a petition. They help, they really do.

Join an advocacy organisation like Hepatitis NSW here in Australia, or your local equivalent. They won't expect you to march with banners and slogans if you are not ready, but perhaps there is another way you could help.

Tell someone about HCV. Someone you trust. Talk about why you need treatment and what it would mean to you.

We need a supportive and engaged community. Communities like that are powerful. They are a voice to be reckoned with. People listen. And piece by piece, bit by bit, the stigma goes. The discrimination goes. The fear goes.

All that is left is us. And people can see us as we are. Sons. Daughters. Parents. Grandparents. Secretaries. Teachers. Managers. Truck drivers. Pensioners. Retirees.

Just people.

