Hepatitis C: The benefit of a group

June 28, 2016 By Grace Campbell

I’ve heard people say hepatitis C is one of the most lonely conditions to live with. Many people keep it a secret, not even sharing the news that they have it with family or friends It might not feel like a hard burden to carry alone when people are younger or when the virus hasn’t had a chance to cause much damage, but as people age and the effects of HCV can become more pronounced, keeping the secret of HCV can become a burden.

I’ve always thought that the silence engendered by stigma and discrimination is one of the most harmful parts of the virus. People are often reticent to say they have been affected by the virus. It can affect work relationships, friendships and families. That’s why people often keep it a secret.

This secrecy harms us all. It harms those of us who have lived with hepatitis C because we often don’t get the care, support and treatment we need. It also harms those who haven’t got hepatitis C - those people never know that some of their friends and work mates are affected by the virus. They’ll never know how sick some of their companions might become. They lose the chance to make a difference to someone else’s life. They don’t have the opportunity to have their preconceptions challenged.

That’s why it can be great to spend time with others who have walked down the same road. The discussion can range widely around diagnosis, health care, treatment and side effects. It can veer into the highways and byways of hepatitis C without any fear of stigma, discrimination or judgement. Support can be offered to people starting treatment, those who have finished can compare results. Jokes can be made, connections forged and relationships enhanced and strengthened.

I spent the weekend in Sydney with other people from Hepatitis NSW’s advocacy arm. We are all people with lived experience of HCV. We are at varying stages of treatment, recovery from treatment or enjoying life after treatment. It was a pleasure and an honour to be with so many people who have worked so hard to gain access to treatment for Australians living with HCV.

We all need support. Sometimes it can be hard to find, especially with something like hepatitis C, which can be so isolating. But it’s worth looking for. You could try your state organisation such as Hepatitis NSW, or a forum like Hep forums. Wherever you find it, make the time to take advantage of it.