31 January 2016: Where do you get your support?

If you are looking for education and support, if you are on treatment now, or if you are enjoying your new life as somebody who “used to” have hep C, I urge you to get connected to a hepatitis organisation.

January 31, 2016 By David Pieper

Fight club was one of the most controversial and talked-about films of 1999, and it achieved cult status with its DVD release. Anyone who has seen it will remember that Edward Norton becomes addicted to participating in support groups of various kinds, after visiting a support group for testicular cancer, where they assume that he too is a victim. He spontaneously weeps into the nurturing arms of another man, allowing the group to assume that he suffers what they do.

That scene was on my mind during my first interaction with other people with hep C at a support group in London. In my experience support groups are not like that at all. I didn’t expected the euphoric release that Edward Norton had, but I was certainly pleased to speak to other people who were dealing with the same thing as me.

With recent advances in hep C treatment some commentators and clinicians are questioning whether there is still a need for support groups. Treatment is now a whole lot easier, quicker and less frightening, so the need to encourage and support those on treatment has diminished. But for the newly diagnosed, the less well informed, for those dealing with multiple health issues and for those in danger of re-infection, the need for support remains.

Support groups are also a great way to find patients who may want to become advocates for their own health as well as for others who cannot speak for themselves. Support group members can be mobilised in campaigning. It is a good way to show patients how their voice matters. Showing people how to contact and engage with the office of their state or federal Member of Parliament, to help educate them on HCV is incredibly empowering and not that frightening.

Beyond treatment there are so many issues affecting people living hepatitis C, which need to be advocated for. The most powerful advocacy comes from those with lived experience, whose voice has been shown time and time again, to be the most useful tool in changing attitudes and developing understanding.

Positive voices can break down stigma and discrimination; they can argue the case for needle and syringe programs in prison; they can explain why a variety of models of care are needed; and they can paint a picture of the access problems in rural and remote areas.

If you are looking for education and support, if you are on treatment now, or if you are enjoying your new life as somebody who “used to” have hep C, I urge you to get connected to a hepatitis organisation. There are community organisations and peer organisations in many cities. There are support groups all over the world. And for those who prefer to do it online, there are dozens of Facebook groups, and forums including http://forums.hepmag.com/.

The opinions expressed above are mine alone and do not necessarily reflect those of my employer.