Stigma and Hepatitis C

March 21, 2016 By Lucinda K. Porter RN

Recently I asked someone who is active in the hep C community to submit a story to HEP Stories. The advocate wrote, “I’ve thought about this and my reluctance to submit a story. It really relates to the shame and stigma I felt being HCV positive. I never told anyone about my Hep status and, even though I’m cured, I guess I’m still feeling stigmatized, wondering if people will treat me different if they read my story.”

Sadly, I understood all too well. Stigma is the part of hepatitis C that I hate the most. Like hepatitis C, stigma brings a sense of powerlessness. However, feeling powerless because a virus is consuming your liver is completely different than stigma, which is powerlessness over other people’s ignorance, judgmentalism, and sometimes cruelty.

Hepatitis C is preventable and curable. So is stigma, but it is a tougher problem to fix. I think we fix it by telling our stories. But speaking up about having hepatitis C is a risky, radical act. And once you tell your truth, you can’t put it back in the box. It’s out there.

Holocaust survivor, Elie Wiesel said, “Whoever survives a test, whatever it may be, must tell the story. That is his duty.” Perhaps Wiesel was right. However, having hep C is different than being a Holocaust survivor. We can see that Holocaust survivors were victims of a horror beyond all horrors, whereas in the case of hep C, society blames those who have it. We shoot our wounded rather than help them heal.

Despite this, I decided from the beginning to be open about having hep C rather than living in its shadows. Perhaps this was easier for me because I didn’t have a history of injection drug use, I am white, and I am a nurse. Stigma didn’t land on me as readily. But there were plenty of times that people shied away from me, concerned that the virus would leap off my body onto theirs. Regardless, living with hep C was easier than carrying a secret was.

I didn’t try to persuade my advocate friend to defy stigma by submitting a story. The decision is far too personal. However, my friend is considering it and wrote, “It might just be the last step in my cure.” Yes, wouldn’t it be wonderful if in addition to hep C, we also cured stigma.

For more about stigma, the new Acting Director of the Office of HIV/AIDS and Infectious Diseases, Richard Wolitski has written a couple of posts about stigma. Here’s a link to another post about stigma.

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