Stigma and Hepatitis C

September 13, 2016 By Carleen McGuffey

My particular disease has a unique set of problems as most people carrying this virus were or are IV drug users. Most. Not all. So there is that. And hep C is contagious. Communicable. Infectious. Catching. Virulent. Deadly. Need I say more? Just writing those words out made my shoulders tense. So I try to understand when I feel the energy of a conversation change after I share my disease, but its hard. Doable but hard. What I never have been able to shrug off is when people behave differently around my children. My kids are my Achilles Heel.

This disease has been very difficult. The hardest part wasn't the fatigue, or joint pain. It wasn't having to wean my baby because I was too sick to care for him. It wasn't even the complications of Hepatitis that caused me to spend a Month in the Hospital and a year in bed on oxygen fighting for my life. The hardest part by far was and is the relationships. The stigma; the poor behavior of my friends, family, strangers, even Drs. in relation to hep C Then there's the shame I heap on myself for contracting this virus.

When I shared my status with my parents my Dad changed the subject…something about losing his car keys. I remember, because it hurt me deeply to have him disregard something that took me years to work up the nerve to disclose. Even though I was on the phone with my Mom I could see her nose turn up as she said Hmmmm. Just Hmmm. That was it. Never once did either one of them bring it back up to me. Ever. My Christian friends talk about orphanages in Africa but whisper about my kids being infected behind my back, this despite the fact that none of my kids or husband have hep C. It hurts. Strangers are mostly silent, which clicks on my default position of insecurity.

I hear people say things like *It doesn't matter how you got it* and I understand, and appreciate the sentiment but it's not true. It DOES matter if I got it from IV drug use or a Blood Transfusion. I had both high risk factors and it mattered enough that I only shared the latter possibility until very recently.

I hear people advise others to share their status *because it doesn't really matter* and again I appreciate the motive some people shouldn't share. For instance, if you expect everyone to support you and say just the right thing don't share. In fact, if you are hoping for much support at all then perhaps reconsider sharing. Truth is, often times people don't behave well so sharing is something to consider carefully and with low expectations.

I know this post is negative. Can't help it. Stigma is hard, and hurtful and negative. Yet it is real and happens to people with hep C all the time. The best way to behave around people with Hepatitis is simple. Use good manners. That’s it. Just be polite. Imagine how you would behave if our disease was trendy like Breast Cancer and do that.

If you are alone and made to feel ashamed by others poor behavior, please find a good Hep-C forum or support group to join for support and love from people who know how hurtful this disease can be.

Also consider being a friend to someone else that is also alone and ashamed. God can and often does turn our own captivity when we relieve the suffering of others.

http://beta.docker.hepmag.com/blog/hepatitis-c-stigma