The Final Chapter of My Hepatitis C Story

July 29, 2019 By Lucinda K. Porter RN

“Hold those things that tell your history and protect them.” ~ Maya Angelou

In 1988, a blood transfusion saved my life and gave me a virus that would send me on an amazing trajectory. It is the beginning of this story.

At the time, the virus was called, non-A, non-B hepatitis. A year later, I read the headlines announcing the discovery of the hepatitis C virus (HCV). I knew that was what I had, but it would be a few years before a lab test confirmed it.

> “Those who do not have power over the story that dominates their lives, the power to retell it, rethink it, deconstruct it, joke about it, and change it as times change, truly are powerless, because they cannot think new thoughts.” —Salman Rushdie

Living with hepatitis C was an opportunity. I could:

a. Feel sorry for myself,
b. Ignore it,
c. Plunge myself in bad behavior (drugs, alcohol, compulsive shopping, whatever…),
d. Let it galvanize me.

Jean Houston wrote, “If you keep telling the same sad small story, you will keep living the same sad small life.” I chose ‘d,’ and went to nursing school. My first semester of nursing school, I was assigned to a patient who was dying from hepatitis C. I had never met anyone else with this disease. She was 35, a mother and an alcoholic. The day I met her, she was quite vital. A week later, she was gone. It scared me, and further galvanized me.

In 1996, there was a nursing job shortage, so I volunteered at an underground syringe exchange site. Everyone had hepatitis C. It broke my heart wide open. I wanted to make a difference, but didn’t know how to. I began by listening to people’s stories. We cried together. Hugs were exchanged along with needles, syringes and other drug-related utensils.

“Without stories we would go mad. Life would lose it’s moorings or orientation….Stories can conquer fear, you know. They can make the heart larger,” said Ben Okri. My heart grew larger. I joined forces with others in the San Francisco Bay area. We formed coalitions, classes, and a presented a conference. We spoke up, wrote to our newspapers, and found others like us on the internet.

Along the way, I met Alan Franciscus, founder of the Hepatitis C Support Project (HCSP) and its newsletter, the HCV Advocate. (Click here to read Alan's Hep Story from 2015.) Meeting him was a life-changing event, one that I deeply cherish. Alan's work offered a platform for me from which to write.

Eventually, I was hired to work in the Liver Diseases department at Stanford Medical School. Emmet Keeffe, MD would become my mentor. He and his colleagues shaped me, giving me a solid background in liver disease. Dr. Keeffe's death left a huge hole in the world. A tribute to him was jointly published by the American Journal of Gastroenterology, Gastroenterology, Gastrointestinal Endoscopy, Hepatology, and Liver Transplantation.

During this time, HCV treatment was in its dark ages. I endured two unsuccessful rounds of old-style interferon treatment (one with peginterferon and ribavirin). My Hep Story from 2014 is available here; it gives more details about my treatment experiences than I will in this blog.

All of this leads me to this final chapter. I discovered Hepmag.com on the internet around 2012-ish. My first contact was via Hep's Forums, where a kind, supportive man named Jack Berlin extended the hand of hope. In 2014, I began working with Hep more formally. These five years rounded out my years of speaking up for everyone affected by viral hepatitis.

The folks at Hepmag.com and its print magazine Hep, share my values. Yes, they have advertising, and sometimes the advertising comes from corporations that have done things I didn't particularly like. However, Hep and the people behind it have integrity. They never censored anyone. I was free to write whatever I wanted, and no one ever said anything.

The relationship was pure pleasure and quite frankly, I love everything and everyone I do. All this makes it very hard to say this next part. I am taking a break from this work. Some call it retiring. I prefer Dr. Ruth Westheimer's word, "rewiring."

My decision to rewire came shortly after the death of my father, two years ago. While cleaning his office, I discovered an unfinished manuscript. He had already written one book, which was not published. Although I have published two books, I too have an unfinished manuscript. I want to see it to the finish line.

When I say, "I am leaving Hepmag.com," I am not sure what that means. I am joining their advisory board and I may pop up on this blog from time to time. I can't really say goodbye to this work or the people I've met as a result. But, I am rewiring, so I am not sure what shape my life will take. I will continue to blog on www.LucindaPorterRN.com, but the material won't be liver-focused. When my liver needs to vent, you'll find me here at Hep, albeit irregularly.

It takes a thousand voices to tell a single story. ~ Native American saying

Here is the hardest part of my story – the part that says thank you to the hepatitis community.

Your stories are my story. Keep speaking up, please. You can share your story on Hep Story. I just took a quick glance at the people who shared their stories, and between them and those participating in the Hep Forum, we have a lot of shared history.

I carry your stories with me, our stories.

Thank you, all of you.