Surviving Life with Hepatitis C, Telling Our Stories

January 26, 2015 By Lucinda K. Porter RN

Recently I heard one of the most inspiring talks in my life. Although it didn't have anything to do with hepatitis C, it had everything to do with it.

The speaker was Diana Nyad, the first person to swim from Cuba to the U.S. without the use of a shark cage. She attempted this feat five times. Nyad was 63 when she successfully completed her fifth try, after having emerged from a thirty-year retirement from swimming. She was 63 when she successfully completed the 103-mile swim that took just under 53 hours. Nyad is my hero.

I have other heroes, hep C heroes who keep trying treatment despite relapse or lack of response. I try not to call these treatment failures, since the word "failure" should not be uttered in the same sentence about someone who tried treatment. I know people who have endured five or more hepatitis C treatments; some of them used interferon each time. I know people who had many hepatitis C treatments, finally cleared, only to suffer liver failure or cancer. Hep C heroes endure a lot.

I had three treatments, the last one resulting in a cure. It is tempting to compare myself to others, to say, "I only did three treatments." Or, "I never had to endure telaprevir or boceprevir." And, "It was easier on me because I did not have cirrhosis." However, comparison diminishes the miracle.

We should never compare our stories; comparison just weakens the miracle. Our stories are gifts that we can let shine. When saying our experiences are "less than," aren't we chipping away at the amazing fact that we are alive? "Less than" doesn't help anyone; a frank admission of your own truth helps everyone.

Our stories can unlock something deep inside of another person, something waiting to be unleashed. Tell your story and you may be the key bearer. Your story may lead someone to places they were too afraid to go. It may unlock fear. You may save a life.

A good way to share your story is via Hep Stories. Perhaps your story isn't about swimming to Cuba, but it is about swimming in hepatitis C, which is like swimming with sharks without a shark cage.

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