Sharing My Deepest Secrets

September 1, 2017 By Carleen McGuffey

I recently shared publicly that I was an IV drug user years ago, the response I received from my friends and even family warms my heart and gives me much hope for the vulnerable Americans who still struggle with addiction.

Like most people with Hepatitis-C I didn’t learn my status until decades after I had contracted the virus. By the time I was diagnosed I had changed my life so thoroughly that during the very few times I would even think about my wild years it would literally feel like I was considering a whole other person. I had gone from hitchhiking across the country with 10 dollars in dimes, while drinking Bloody Marys, to teaching Sunday School and homeschooling my children.

I made a commitment to never share my past unless it was to help someone. So when I found out I had hepatitis C and needed to disclose to a Dr. or eventually the world when my husband started his non-profit to serve the hepatitis C community it was a relief to share I likely got hepatitis- C through a blood transfusion just prior to when America started checking our blood supplies for the virus.

I did have a blood transfusion in 1988. I did mushrooms and shot up meth one night and lost my baby girl at 6 months, I also lost enough blood to need a transfusion. My baby only lived a few hours. I'll never forget the doctor who came into my room and smoothed my hair while I cried. He kept asking if I wanted him to call anyone. I didn't. I bummed money from some of the nurses for bus fare back to Lower Westheimer in Houston where we were living.

I really mean that I only share this to help and so I want to stop here and help someone.

These memories are very hard to recall and yet as I do I am struck by how many of these memories are of the kind people I met only in passing. That doctor that showed compassion despite my bruised arms and lost baby girl, he knew how I lost my baby. The nurses, that one in particular who scurried around to the other nurses to make sure I had the right change for the bus. The man who would buy Mark and I food and hand it to us through the window of his car, wanting nothing in return? We were so suspicious, insisting he tell us what he wanted? Nothing at all, "I just want to make sure you two are fed".

Those people made an impact on me, and now 30 years later I can see their faces and continue to feel the impact of the kind gestures. They are the part of the story that I remember most about those years.

To understand that while we can't cure every one of hep C today, or instantly deliver an addict out of bondage, we can add to the healing of those who suffer. Perhaps with just a seemingly small gesture. Healing almost never happens instantaneously. You may be just a small part of the 3 year slow release regimen God has for the healing of a lost soul. Don't doubt the power of love, its medicine. Don't feel like a small effort doesn't help so "why try?" Indeed small efforts from many people over the course of days, months or years is the only way to help.

Want to make significant changes in the world? Love on someone who doesn't deserve it.

I love my friend Susanna's tag line on her email signature. "A smile is a ministry." It really is! And so is bus fare or a moment of kindness towards a passing stranger who is down and out. Sure the recipient of our kindness is ministered to but the biggest winner is us. When we share we win. It contributes to goodness that may end up in a blog post 30 years from now, printed to inspire until who knows when?

James saw a lack of resources in the Hep-C community and decided to change that on my behalf? Yes that is a question mark….who does that?

As I have been sharing here with all of you, I have been sharing with my children, my older ones in particular. Kelsey got tears in her eyes today when I told her that American Airlines gave me an 89.00 bereavement round trip ticket to be with Mark while he died from HIV, and they put me in first class. First and last time I stretched my legs and smiled at the pitiful souls who sat in the back. That was 20 years ago and my daughter got choked up hearing about it today. Don't underestimate the power of love, compassion, and mercy. It ~~may~~…it must propagate for generations to come.

Back to my mode of transmission. So I had that blood transfusion and was an IV drug user as well. Neither one noble, or glamorous. But I have mostly shared the one that was easiest for me. And when James created his hepatitis C blog he wrote that I had contracted hepatitis C from a blood transfusion. You know what's sweet? I shared all of my past with James and he has not only told my story with complete respect and regard for me but he has also loved and hugged me for 26 years, perhaps even tighter despite my story.

Our Mentor and example of passion in this fight against Hep-C, Pam Ford with my hunny James who has never one time been ashamed or embarrassed about my status. In fact started a Non Profit campaign to save me and others like me.

I appreciate my friends who share with their hepatitis C status with everyone. Like Pam Ford of HEALS of the south who wears a different hep C t-shirt every day, has asked me about hepatitis magnets on her car and even carries a purse that shares the message. I wish I was more like Pam.

I’m not. I worry about people being mean to my kids…again. I’m insecure and embarrassed. Still. I am rolling my eyes at myself. Still. I am embarrassed.

The fearless Pam Ford who considers human suffering more important than her own ego. T-shirt and all….

To disclose or not to disclose? So I don’t think one way or the other is right or wrong. Stigma is real, people are cruel and we can only take so much. I tell my clients who just got diagnosed to considering waiting a bit to post on Facebook or share with the world. Consider the response and set your expectations low in case people behave…well….like people. I asked one positive client if he had someone to share with and he told me about his dog.why can’t we adults just learn from our dogs and children!?

We can learn from our kids.

One thing I hope we advocates, and fellow patients will do is to allow hepatitis C patients to behave differently or opposite than ourselves or our convictions. I don’t think there is a right or wrong way to handle disclosure, if you do have a passionate belief regarding disclosure, perhaps your belief isn’t as important as the soul of a person who doesn’t see it just like you. Be thoughtful, set your expectations low, and move slow.

I share as much or as little as I want to. That changes with the day. Perhaps today I will feel like sharing I was an IV drug user, but tomorrow I will share that I had a blood transfusion prior to 1992, still the next day I may share nothing at all.

http://beta.docker.hepmag.com/blog/sharing-deepest-secrets