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living with HEPATITIS C

a series of stories written
about people living with
hepatitis C

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Part 1

In the spring of 1991 I made a decision that was to alter the course of the rest of my life. I'd been married to my present wife, Janice for several years. Her two girls, Jennifer and Danielle were on their way to being grown. Our own daughter, Stephanie, was still our little girl but she too was growing up. I'd tried and failed at running my own roofing business and was working for another contractor. My decision? I thought it might be wise to get some life insurance, just in case. Know what I mean? The process required a small sample of blood to be sent in and analyzed. I wasn't worried, in my mind I was the picture of health. In my early 40's, working at a physically demanding job and in good physical shape I figured I'd be getting that policy back in no time and it would be another step on the long road back.

Back from a life of alcoholism and addiction. Back from a life of failed marriages and broken promises, to friends and loved ones. Back from a life of jails, institutions and death. Quitting drugs and alcohol gave me a little breathing room. Treatment for my alcoholism was a start, I learned that I wasn't necessarily crazy, just a drunk. I was still desperately lonely and unsure of myself but at least I wasn't drinking. Up until then I'd been mostly just marking time, trying to make it through another day, some better than others. One good thing about that time was picking up a trade, roofing. I seemed to have a talent for it and many days it was the only thing I did that I felt good about. About a year after I sobered up I met Jan and suddenly I found something I wanted. Wanted more than anything I'd wanted for a long, long time. If I could convince her to marry me I'd be a regular person, like everyone around me who I thought had figured life out. Of course it wasn't at all like I'd imagined, it was better! I settled

into my newfound routine and began living the American dream. I started a business, did my best to be husband and father, and more or less enjoyed life. Except for the anger that would spill out for no apparent reason from time to time. Except for the occasional use of drugs. We bought our present home, settled into horses, school and work, and did the best we could.

I vaguely remember getting a letter back from the insurance company declining to offer coverage and suggesting I contact my doctor for an explanation. I did and he said something about hepatitis, maybe he said hepatitis C, and suggested I go to the health department and get tested. I don't recall much being made of it, the hep C. It took me a while to get around to following his advice but eventually I did get tested and I suppose I was informed. I'm unclear about it because at the time it meant absolutely nothing to me. As I said, I was in good health and I considered it a minor inconvenience, so I couldn't have life insurance, I was going to live forever. So far, so good, so what?

Aside from some cellulitis which would show up around where I'd lost my big toe I don't recall being very sick. I didn't get the flu or colds, had quit smoking and aside from shortness of breath on exertion I can't recall feeling unwell. All that began to change around the spring of 93. At one point, while I was tearing off a roof my boss noticed I was pretty puffy and thought I should go see a doctor. That was when the hep C became important. I was still unaware, I really had no idea what lay ahead. Because I'd been denied life insurance coverage twice I became eligible for medical coverage under the Oregon High Risk insurance pool. Great good fortune! Dr. Wiltse sent me to see Dr. Engstrom, a GI in Roseburg and he began

treating me. I don't think I really had any idea at the time that I was gravely ill. Certainly no one told me that. The following is what Dr. Engstrom had to say about me in May of 93:

The patient is a forty-seven year old male with a variety of medical complaints. He describes an eight year history of tendency blah, blah medical talk. . . , no known history of liver disease, more blah blah. The family history is remarkable for lung carcinoma for his father and mother having had a history of breast cancer, but dying of pneumonia. Surgical history includes loss of right great toe with motorcycle accident in 1971. He had another motor vehicle accident in 1976, which included laparotomy for splenectomy, as well as repair of left hand injuries. He is employed as a roofer. He discontinued tobacco 2 years ago. He discontinued history of alcohol abuse thirteen years ago and discontinued use of street drugs (including needle sharing) thirteen years ago. Transfusion was apparently part of the treatment for the 1976 motor vehicle accident.

Physical examination reveals an alert, well-nourished, well-developed male in no apparent distress. By the end of June the assessment was: Abnormal liver testings and hepatitis C serology. At that time Dr. Engstrom decided he wanted to biopsy my liver (ultrasound guided) and see exactly where I stood. The next 14 months were a blur of more testing and diagnosis, increasing difficulty holding my own as a roofer along with increasing anger and irritability. The anger and irritability part were sort of just under the surface and not really focused. So it often came out directed toward my wife and daughters. I even got a little abusive to our pets. Nothing serious enough to cause bells to go off but I was tormented inside

and unaware of the fact. In March of 94 my employer had enough of my unpredictability and he kindly showed me the door. He continued paying my insurance premium for several months and eventually tired of that and I was left with no job, no one paying my insurance and the previously mentioned unrest.

That summer was pretty rough, I can tell you. Dr. Engstrom started me on interferon monotherapy 3 mu 3x per week, no appreciable sides but no success, The girls were teenagers (Stephanie was just getting there) and luckily involved in 4H with their horses. I've always been pretty self-centered, something every alcoholic reading this will be able to relate to, and was emotionally unavailable to my family. Bless them forever, they stood by me. Maybe in part because they were still teenagers and in school, I like to think it is because they have good hearts. We stayed together because the glue of our family is my wife, Jan. It started to look pretty bleak but somehow through all of this I remained optimistic. The village idiot, that's me.

In September Dr. Engstrom called me in to his office to tell me that the Interferon hadn't worked and that we could try it again; but he was doubtful of a positive outcome. He wanted to refer me to Oregon Health Sciences University in Portland. I asked why and he told me I needed a liver transplant. I'm sure that news shocked me but I don't really recall being scared. In fact, I'm pretty sure that my thought was "No thanks". I'm thinking I'm in pretty good health, all things considered. The picture I have of transplants revolve around the guy in Utah with the artificial heart, the Jarvis heart. He's walking around the hospital towing this mechanical contraption behind him and

it's making these pumping sounds. Now I'm going to let you in on another secret about me, I'm pretty conceited. That trait coupled with my self-centered nature made it easy for me to imagine that somehow I'd not need a transplant. I really don't know what I thought at the time but I went home and waited for my September appointment with the hepatologists at OHSU to roll around.

In thinking about how I was going to tell my story I decided that it was too long to do in a single piece and so I'm going to leave you readers here. When next we meet you can expect to hear about the evaluation and the wait. Until then

Peace,
Prankster

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