A History Lesson

March 31, 2015 By Grace Campbell

"*I am the master of my fate,*
I am the captain of my soul."

- William Ernest Handley
Invictus

My journey to cirrhosis was slow and insidious.

I didn't find out I was HCV positive for quite a few years. When I did find out, I disregarded it because my liver function tests were okay.

You see, I am the sort of person who refuses to believe in illness. 10 feet tall and bulletproof. I push through, wrestle the symptoms into submission and march on. I don't much like doctors. I loathe hospitals. I tolerate nurses because they are generally the kindest of all medical professionals.

So I pushed it to the back of my mind. Every now and then it would swim to the surface, but I was experiencing no symptoms and leading a full and busy life. I drank, went out with friends, stayed up late and often burned the candle at both ends.

As I hit (and passed) 50 some symptoms started to appear. I didn't have as much energy, I had some swelling in my ankles in hot weather. I put it down to old age.

When I finally went to a new doctor for something completely unrelated (my first doctors visit in 5 years - I did tell you I didn't like them!) they took my history and ran the usual battery of blood tests. My LFTs were pretty bad. Bad enough for me to stop drinking on the spot. An ultrasound revealed early stage cirrhosis, gall stones and an enlarged spleen. All news to me. And frankly, not good news.

All of a sudden I was staring an early death in the face - and it wasn't blinking. I know death walks behind us all, but I wasn't ready for it to catch up to me.

I was anxious and depressed. I had kids, a great job, wonderful family and friends. This wasn't meant to happen.

My GI started me on interferon/ribivarin/boceprovir. And there was one of the first shocks. I had a GI. I had a GP. I had a serious health condition. A chronic, degenerative health condition.

He told me it would be tough going. In one way he was right. It took three weeks for the drugs to shred my neutrophils and platelets. I was off treatment, the only treatment available to people in in my country

at that time.

Rather than sink into the funk I had been in before, I decided to move forward. I made sure I was doing everything in my power to keep myself well. I exercised every day. I ate well. I didn't drink or smoke. I decided that every day was a gift, so I should enjoy them. This was brought into stark view when my ex husband, the father of my children, died of lung cancer just last year.

And when my symptoms started to increase (some ascites, continuing poor blood tests) I decided that it was time to be the master of my own destiny. I wasn't able to access cutting edge treatment or trials where I lived, so I reached out to people actively involved in research and treatment and found someone willing to see me.

I travel 800km return every time I need to see my specialist. But every kilometre is worth it. He managed to get special access to new DAA treatment for me. His team has made it possible for me to treated remotely. I trust him implicitly. I trust him with my life.

Here are the things I am grateful for:

My family. They rock. When it looked like my only option for treatment was going to be paying to access it overseas, my brother rang and offered me the money. I told him he wouldn't get much change out of $150,000 and he said it would be worth it.

My colleagues and friends who have rallied around me, supporting when I needed it, kicking up the butt when I needed THAT.

My employer, a very very large organisation that has provided me with sick leave, not questioned my need for it, recognised that I am honest about my leave requirements and allowed me to tailor work to suit at times.

My animals. Everyone needs someone or something that loves them without question.

The health care system where I live. It may have its flaws, but it is free, universal and accessible.

And finally, every sunrise I see. My days are a gift. I wish I had realised that years ago.

Here are the things I wish I'd done differently:

I wish I hadn't been so blasÃ© about my health.

I wish I'd tried to source treatment earlier. It might have worked. As it was, I was almost pouring petrol on a burning fire. Too little, too late.

I wish I had looked for help elsewhere earlier.

I wish, oh how I wish, I had stopped drinking earlier. I wasn't a heavy drinker, but I was a constant one.

But I'm not prepared to live with remorse or regret. I've learned from my mistakes, albeit it a harsh lesson. I hope someone out there might learn from them too.

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