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I had had enough. I was tired of coming out of doctors' appointments dazed and confused. I was tired of feeling like the doctors were patronizing me when I had finally built up the courage to talk about my concerns. I was tired of not being given credit for knowing my own body until there was no other option but to give my "theory" a try. I was tired of trying to explain to those around me, who couldn't be in the room with me, what had happened in the appointment and getting support in figuring out what to do next. I wanted more control. I wanted to feel organized. I wanted to be an integral part of MY medical team. Sound familiar? Twenty-three years of practice as a professional patient in the medical system had not made me perfect; it had worn me out. But I wasn't defeated. I was going to rise from the ashes like the mythical Phoenix.

Three years ago, I hit rock bottom. That was the push I needed to imagine and create a new way for people like me to navigate the medical system. My goal was to have people feel that "I got this. I can be a part of the conversation and decisions about my health. It's my life, and there's no better expert on me than me!" How? *Phoenix Attitude's* Medical & Motivation, a mobile-friendly website launching October 17th, 2014.

But what did rock bottom look like?

University was a saving grace in my life. And yet, it was the scariest transition I had ever made. I moved from Toronto to Victoria, BC when I was 17, away from every safety net I had, to begin a new life. I had a rocky start, but by the end of 1st year, I was living a life I never thought possible. I was essentially failing Math like everyone else, going to parties like everyone else. I was finding *my* balance. My Spina Bifida had finally found its sweet spot, like a dog spinning round and round and *finally* getting comfortable. But there was one thing threatening to throw a wrench into my new life - UTIs (Urinary Tract Infections).

I was getting UTIs every few months, and *bad*. They were the result of my Botox procedures for my bladder, which, on top of helping with incontinence (yay), would unfortunately numb the nerves that normally would start to burn when I was coming down with an infection. The result? Not knowing I had an infection until I couldn't keep anything down for days and battling a 103-degree fever, forcing me to retreat to my vacation home - the hospital.

One time in particular, I knew another infection was looming, but there was a very important basketball game I wanted to go to. I know, it sounds stupid, but I didn't want to let my body take away another opportunity to be one of the gang. I wanted to live in blissful ignorance! But the adult portion of my brain wasn't letting that happen. I confided in a friend that I probably have a UTI, trying to assure her that I'd check it out at the end of the week after my exams. She made me promise to get it checked out the next day. You see, there was a rule of thumb amongst

my closest friends - if Jenna says she needs to go to the hospital, she should've been there three days ago.

The next day I went to the walk-in clinic and explained for the umpteenth time my medical history and that I was there for yet another UTI. The doctor was very nice and knew that I was at the end of my rope with these infections and suggested a new medicine that was stronger than the one I normally took that would knock out the little bugger quicker. Can you say "Hallelujah!"? I rushed home to take the meds, feeling stupid that I was going to put off going to the doctor in the first place.

This is where you start humming the *Jaws* theme song.

A few days into my course of antibiotics, I started having unfortunate... circumstances? Think Turbolax (any Dumb and Dumber fans out there?), i.e. the worst diarrhea you can imagine. And as much of my attention that this issue was taking, I was also worried about the scar tissue around where my cecostomy tube used to be becoming painful. Something wasn't right. Something unexplained allowed me a few hours of reprieve, and I took it and ran all the way back to the walk-in clinic to try and get some answers. I was told that diarrhea can be a very common side effect of antibiotics and that the scar tissue was probably inflamed from all the "traffic", so I should go get an Imodium equivalent and finish my antibiotics. This was a Tuesday. By Friday, the diarrhea was back and I felt like I had been hit by a truck.

That night I decided to call my friends and say I needed a ride to the dreaded "H" word. We got to the ER, where I got imaging done that only went as far as telling us that my UTI had turned into a full-blown bladder infection. You'd think I'd have been happy about getting answers, but it still didn't explain why my scar tissue was in so much pain. By 1:30 a.m. I was given Morphine, leaving my friend to believe that I wasn't going anywhere and would get a good night's sleep.

The next morning doctors came in to check on me when I, yet again, conveyed my concerns about the scar tissue, which was getting worse. They didn't seem too worried but were toying with the idea of sending a surgeon down to take a look. So, I got on the phone with my parents in Toronto and told them this *was* going to turn surgical and that one of them had to get down to Victoria.

My father landed at a relatively civilized hour and I was able to fill him in on the newest addition to the list of diagnoses – *C. difficile* – a very nasty bug. The initial diarrhea hadn't been a side effect of anything after all, but a "bacterium that can cause symptoms ranging from diarrhea to life-threatening inflammation of the colon." Oy!

I was now on IV antibiotics that I knew weren't working; my scar tissue was getting more and more inflamed. I was getting mad.

At 4 a.m. on Monday morning, I officially lost my mind. I started screaming that I was tired of the party line “Let’s just give the IV meds time to work,” that I needed imaging for my scar tissue which had now turned brown, and that I wanted the surgeon to come in - now. I certainly got my point across, but I also knew that just as easily I could be arrested, so I called my lawyer-father at his hotel and told him he might want to come to the hospital.

It was soon established that I was septic. This made sense from the new imaging that explained my colon had ruptured. The *one* time I didn’t want to be right. I was moved up to ICU and waited for the surgeon. I was finally feeling tired, knowing that I had gotten to the root of the problem and there was nothing more I could do. Or at least that’s what I thought was causing my eerie calmness.

This is where you tell me not to go into the light, which by the way looks so pretty.

Ultimately, they had to do emergency surgery *in my ICU room and* deal with a sneaky little abscess. No big deal.

I spent 10 days in the hospital and months after that recovering. I was given my last diagnosis a few weeks after being discharged from the hospital - PTSD (Post Traumatic Stress Disorder). After all the time I spent trying to get people to listen to me, staff members constantly ignoring my obvious signs that made it clear I was allergic to Latex, chemical burns, and more than a few IV mix ups had all but defeated me - body and spirit.

I took the next term off of school (even though I was *so* close to graduating) and thought there must be a better way to navigate the medical system. Nobody else should ever have to go through what I did.

Phoenix Attitude Medical & Motivation mobile-friendly website is my dream tool - accessible on your phone, tablet and computer! With it, I feel calmer. It keeps my medications, doctors, past surgeries and procedures, symptoms and vital information about me organized and at my fingertips. This is great for those scheduled appointments as well as those surprise visits to the ER which just happen at midnight when I’m tired/in pain/anxious/distracted and basically not at my best.

With *Phoenix Attitude* Medical & Motivation mobile-friendly website, I can make sure I have the information I need when scheduling and preparing for appointments. It helps to highlight what might seem like common sense points when I get to my appointment. There’s nothing like being surprised with a cystoscopy because you didn’t know that was part of the appointment!

One of the greatest features of the *Phoenix Attitude* Medical & Motivation mobile-friendly website is the ability to upload voice recordings of my appointments with my practitioners,

and it stays in one convenient location - in the appointment file! Every phone I've seen can record. I always ask my practitioners first, but I've learned that they see the value in it. They see that:

- 1) I can stay in the moment so that I can ask relevant questions, instead of being focused on writing down important details in notes. I know my practitioners are anticipating the inevitable phone call to go over information we've just discussed, having not remembered it in any really meaningful way. Efficient for either of us? I think not.
- 2) If I come to my appointment alone (my family lives on the other side of the country), I may eventually want to get their support to help me sort through and pick out the information that is going to make the most impact to my life. Well, with *Phoenix Attitude Medical & Motivation* mobile-friendly website, I can send the information about my appointments to anyone else (we're still working on the most efficient way). This way, anyone I choose can hear a firsthand account of what happened during the appointment, and support me more effectively so that I feel more comfortable with the next steps I may have to take.
- 3) For me, there are some appointments that I get so nervous about, it is hard to stay present for them. My emotions can take over and leave me with a completely different impression of what was said. So, I take advantage of being able to listen to appointment-specific recordings as often as I want - usually, when I feel calmer and am in my happy place. It shocks me every time how my perspective changes and how I can see things more clearly with every new listen. More often than not, I feel more competent in making the best decision for me when I have a well-rounded understanding of the situation at hand.

I believe that physical health and mental health are interconnected, and that you can feel better when you nurture both (it must be the Social Worker in me). To give *Phoenix Attitude Medical & Motivation* mobile-friendly website a little more personality than it already has, I designed it to give you easy access to content that motivates you whenever you need it (ER visit, surgery, doctor's waiting room, dealing with test results, laid up in bed etc.); to cheer you up when you're feeling like you might never crack a smile again; the opportunity to let you see how others are coping with what you are; and the ability to pick up some tips or tricks to help make daily life easier. Whether you have Spina Bifida, know someone who does, or know someone dealing with other chronic or congenital conditions - the collection of content becomes more expansive every day.

All of this has been a labour of love. I am glad that I have found a way to learn from my experiences and give them purpose by hopefully making you feel a little more confident, a little more in control, a little more organized around your medical needs. In doing so, I hope you can go out and make an amazing mark in the world - turning adversity into opportunity. You can do it!

For more information on Phoenix Attitude Inc., and its newest dream tool - Medical & Motivation visit us at www.phoenixattitude.com on October 17th, or on Twitter before then @Phoenix-Attitude