

Living with Chronic Illness

In January 2012, I was diagnosed with an incurable disease called Interstitial Cystitis (IC). IC attacks the bladder lining, creating internal lesions and leaving patients in chronic pain. I was 19 when I got this diagnosis, and frustration didn't even begin to cover what I was feeling. Only 3% of people have IC — I've never met another person who has it. Doctors don't know what causes it or how to cure it, and they barely know how to manage the pain.

My journey to diagnosis consisted of seeing four urologists and three women's health specialists, and taking many, many trips to the emergency room. I spent years seeing a parade of condescending doctors, taking new tests, and trying new drugs, but there's never been a cure. All anyone could tell me was that certain foods may aggravate my condition so watch my diet. That's it — the only plan to manage this non-stop pain was a diet. Leading a life of chronic pain is a lonely path; even when my mom or boyfriend attend appointments with me, I feel isolated — like I'm a burden to those I love.

I was so frustrated and felt like my body betrayed me. Some days just walking seemed strenuous. IC began to control everything — my diet, my work, my sleep schedule. The old adage, "Those who fall behind get left behind," rang so true.

I woke up between six and eight times a night, which left me constantly exhausted and frankly, often mentally unstable. Not sleeping was making me depressed and anxious; sometimes suicide seemed like the only good option.

The non-stop internal burning pain I was experiencing drove me to start drinking alcohol, and I started to drink a lot! At least enough to knock me out and keep me out for more than two hours at a time. This became my new normal, and I knew that fighting pain with alcohol was not smart, but it was the only thing that worked.

I was on a 6-month waiting list to see a doctor at the local hospital and when I finally saw her, her only advice was, "If drinking helps, keep doing that." I waited so long to see her and got my hopes up, but it ended up being a complete waste of time.

Since then, I've tried heat packs, ice packs, diets and painkillers. It's been a long road of trial and error, and I finally found that a mix of aspirin and a drug called Pyridium combats the pain best. Pyridium, however, comes with its own set of frustrations because it turns EVERYTHING orange. Sweat, urine and fingernails all become an unsightly bright orange, staining and ruining clothes and toilets. This drug can even stain the whites of eyes orange over prolonged use.

Five years after my first symptoms, I finally found a nurse practitioner who specializes in my condition. She has been proactive in creating a pain management plan for me and has been a godsend over the past year. I'm always learning new things about my condition and discovering new ways to cope. I still feel pain every day in varying degrees, and though I know some have it way worse, IC is the hardest and most painful thing I've ever had to deal with.

I have learned that although IC is a part of me, it does not define me. My new year's resolution is to have hope — hope for a cure, hope for better years ahead and enough hope to share with those who have none.

So no matter what battle you are fighting — mental or physical — never stop fighting and never give up hope.