

Bitter Medicine

Growing up, I had highly mixed feelings about most of the fiction I read. Don't get me wrong, I've always loved a good story, but the heroes were always so ... uncertain, so convinced they couldn't possibly be the champion of any tale. Not me. I've always known I was meant to be a hero. Not the real-world kind you read about in the news, like firefighters who rescue families and their puppies or philanthropists who build schools and hospitals. Me, I was meant to be the kind of hero you read about in children's books and ancient epics. The problem is that my body doesn't seem to agree. You see, while my heart and soul are those of a mighty warrior, my body is that of a homebody — preferably one perpetually cocooned in bubble wrap.

As far back as I can remember, I've known there was something not quite right with me. I got hurt more than the other kids and had the same aches and pains as my grandparents before I even started high school. At the time, I wrote it off as clumsiness or low pain tolerance, and the adults around me assumed I was just a little precious and wanted to skip gym class. It was easy enough because we all wanted to believe I was normal. But deep down, I always knew something was *off*.

By the end of high school, people had started asking questions. I mostly deflected them with humour, which is my usual response to hard things anyway, so it didn't attract much attention. All the while, I insisted to myself that no matter how much evidence was piling up, I

had to be fine. I had to be fine because heroes were strong, fast, and inhumanly adept, not clumsy, fragile, and constantly exhausted. They certainly didn't struggle to stay upright long enough to do the dishes without pre-emptive painkillers.

I was in high school when I went on my first date. We were having a picnic and he asked me why I kept fidgeting. When I responded that my back hurt, he asked what had happened to it. Nothing had *happened*, I explained. It was just a bad day. His baffled response made me realize for the first time in my life that some people — most people — didn't feel pain on a regular basis. I didn't understand what that would be like, but I covered up my confusion and distress with a flirtatious smile and a well-placed hand on his arm.

When I started college, I decided the time had come for me to face the facts. All heroes have mysteries to solve and this would be my first. I could almost taste my triumph: I would either fix the broken thing inside me or come to the dramatic realization that it had been my secret power all along. I researched optimal diets, habits, and exercise regimens. I pushed through injuries and the kind of exhaustion I had never imagined possible. Still, things got worse, not better, and I was finally forced to:

One - Admit something was wrong.

Two - Seek out someone in a white coat to help me figure out what that something was.

Not long after, I started filling out what I affectionately nicknamed my “Medical Specialist Bingo Card.” My friends and family thought it was a funny name and most were glad for the comical diversion from a topic they didn’t really want to talk about. Strangely, though, nobody ever asked what the prize for a BINGO would be, which is a real shame because I’m sure there’s a nugget of comedic genius somewhere in the witty answers I’ve had years to brainstorm. I can’t say I enjoyed the hours spent in pristine waiting rooms, but if this was the path I had to travel in order to live the life I know I was meant to live, so be it. As far as trials go, my uncomfortable chairs and elevator music seemed a lot better than Heracles’ divine cattle excrement, so I figured I could manage.

For years, I hunted for answers. I fought my way through a jungle of paperwork, trained myself in the art of “medical speak”, and vanquished the monster whose insatiable hunger I was certain was responsible for the many documents lost in transit. To be fair, I didn’t so much vanquish it as build a protective personal stash of records to use when it reared its ugly head. However, I had made sure it no longer had any way to hinder my quest, so I called it a victory. I named my binder Aegis after Athena’s famous shield. Every hero needs a mythical weapon and for now, getting answers was my battle and well-catalogued records were my shield. The name had the added benefit of getting a laugh out of those doctors who knew their classics.

It was a Friday when I would finally be able to give my mystery condition a name. Hopefully. I'd been down this road a few times before, only to realize I'd found a big, fat, red herring, but I had hope for this particular appointment. I picked up a tattered notebook from where it sat on my lap and flipped through the pages. For the last few years, it had housed the notes from every medical appointment I had attended. The first third was filled with the myriad conditions that had been ruled out. Essentially, I wasn't dying – at least not any faster than anyone else – and whatever was wrong with me didn't seem to be degenerative, which was a relief even if it wasn't an answer. However, my status quo also meant I wasn't a priority, so the appointment dates got further and further apart in the second third of the notebook. The density of question marks, on the other hand, grew with each passing page.

The assistant called my name before I had a chance to peruse the part of the notebook featuring the various professionals who first told me that everyone I had previously talked to had been horrifically wrong in their analysis (but not to worry because they, *my saviour*, would have it sorted in two ticks) but then without fail found a way to hand me off to someone else just a few weeks later. During those years, I felt less like a hero of legend and more like I was living in a Shakespearean comedy of errors. As my footsteps echoed in the empty beige hallway that led to Room 106, I desperately hoped that today would not be another installment of that play. Fragile as I was, I'd rather have fought a dragon than faked one more understanding smile while being sent on yet another wild goose chase.

I stopped learning doctors' names sometime between the first and second thirds of the notebook. Instead, I gave them mnemonic nicknames like Dr. You're-Probably-Dying, Dr. Have-

You-Tried-Yoga, and Dr. Somehow-Never-Late, who was a personal favourite. That Friday, I was seeing Dr. End-Of-The-Line. The nickname was perhaps overly optimistic, but I'd been told earlier that week that what I called realism was verging on pessimism and that simply wouldn't do. She was a middle-aged woman with big, knowing eyes, tight curls that bounced when she laughed, and the kind of demeanour that made you think she ran on problem-solving instead of food and water like the rest of us. When I met her, my first thought was that in another life she would have made either a very scary or a very inspirational politician, depending on whether or not you sat on her side of the aisle.

I was sitting in the tent that had been set up in the middle of campus for graduation. It was hot and muggy and the chairs were uncomfortable. I'd let my parents talk me into coming even though all my friends had graduated long before. They told me that getting a university degree was something to be proud of, but instead, I was ashamed. I had limped my way to the end, not yet diagnosed but not well enough to take a full course load or do well in my classes. Not even in the ones I loved. A few of my friends had offered to come watch me cross the stage, but I had told them it wasn't worth the money; they could watch the live stream instead. That arrangement suited me just fine, because I couldn't bear the thought of watching them clap for something I didn't feel was worthy of their pride. When I had dreamt of my friends and family applauding me, it had been for doing something amazing and heroic, not barely succeeding at something no one ever doubted I would do.

The door to Room 106 was ajar. It was, I was sure, meant to make the sterile room seem more inviting. To me, it just meant I wouldn't get that last moment to steel myself before walking in, which was annoying at the best of times but was particularly unfortunate before an appointment that could change my life. Of course, many appointments were supposed to have changed my life — some of them even had — but this time felt different. That feeling was good, I thought, because it meant I was turning back into an optimist. I'd learned long ago that doctors like it when you come in smiling, so I used that happiness to plaster a reasonably convincing smile on my face and knocked.

“You can put that binder down, I've got all your files right here,” was the first thing she said to me when I walked in the door.

The last time I had been there, Aegis had come in handy since the records monster had struck somewhere between the last specialist's receptionist and hers. I clutched Aegis defensively, but her good-natured smile convinced me that she meant to be reassuring, not confrontational. Another day, I might have changed her nickname to Dr. Surprisingly-Reassuring-About-Useful-Things. Not that day. That day, I was choosing to have hope.

Dr. End-Of-The-Line asked me how I had been since I last saw her (no different than usual), how the trip to the clinic had been (fine) and how tests she had ordered had gone (smoothly). Then, she picked up the file jacket with my name on it, tapped it twice on the desk and opened it. My heart started racing – and not in the way the cardiologist said could be fixed by getting more electrolytes. I noticed that my legs were bouncing so much the desk had started to shake. I tried to still them; I wasn't going to wait on my answers any longer than I had to just because I was too anxious to hide my nervous habits.

I was sitting in the therapist's plush blue chair and my legs were bouncing up and down at an alarming pace. I hadn't yet learned how to affect calmness and composure, so my frayed nerves were written all over my face and body language. I had been resistant to the idea of what my friends and family euphemistically called '*talking to someone*', but I had finally given in. Officially, it was because my schedule had opened up: a dislocated shoulder and a sprained ankle – resulting from an unfortunate encounter with an uneven sidewalk – had ruined my recent attempt at resistance training. Realistically, I was engaging in some good old-fashioned escapism by rereading a favourite series of mine where the main character got himself into a whole lot of trouble because he was too proud to ask for help. The irony vis-a-vis my current situation wasn't lost on me.

I wanted to be invested in the process, but I was nervous and distracted. If I was honest with myself, my mental health had been suffering ever since my physical health had gotten really bad and I probably needed the help. But all I could think about was the fact that if I had seen the man across from me in a film, I would have thought he was laughably stereotyped as the obvious therapist whose job is their entire identity. On the other hand, if his ability to embody his profession was any indication of his competence, maybe I was in extraordinary hands.

In response to my nervous fidgeting, he proposed a meditation exercise which he called a body scan. I laughed. Surely, he didn't expect me to focus all of my attention on how my body felt after I had just told him about how my pain had been getting in the way of my living anything approximating a normal life. Surely, he understood that I was constantly focused on

ignoring the cacophony of nerve signals screaming at my brain that I was in agony and that actually *focusing* on my body would be counterproductive at best and catastrophic to my near future productivity at worst. Surely, he must have been joking; he had picked up on my dark humour and was mirroring it. I would like that, I thought. It would be novel. Unfortunately, the quizzical look on his face informed me that I had been gravely mistaken.

In an effort to mitigate the damage my laughter had done to our fledgling relationship, I agreed to do the body scan. It took what can only be described as a herculean amount of self-control not to crack under the mountain of pain I was finally confronting head on. I knew I had already taken my maximum daily allotment of ibuprofen but by the time I got home, I had stopped caring what the label stated. The increased blood pressure and associated jitters kept me up all night but the medication had allowed me to make dinner instead of collapsing into a useless heap. All things considered, I can't bring myself to believe it was the wrong decision.

“I have good news and bad news, but I'll start with the good: we have a diagnosis.”

My entire body went slack. I half expected the skies to open up and reveal a chorus of angels breaking into song. Scratch that, I fully expected the floor to open up and reveal Hell suffering its first snowstorm. The corner of Dr. End-Of-The-Line's lips tugged up into the beginnings of a smile but she was kind enough to frame her amusement at my reaction as empathetic happiness.

“You must be so relieved and I'm so pleased for you. I know you've been waiting for this for a long time,” she continued.

That was an understatement. The bad news – which is to say the actual diagnosis – followed. I did my best to write everything down in my notebook, but the rest of the appointment was something of a blur. There were words like ‘genetic disorder’ and a polite suggestion that I encourage my family to get checked out. There was a discussion of how it was incurable (the main source of the aforementioned bad aspect of the news), but not degenerative (which I already knew). She reassured me that with the proper screening (*sigh*) my life expectancy would be no shorter than it would have otherwise been (which was encouraging). We went over different options for pain management. I was to research and consider them over the next week at which point we would meet again to make a decision. She gently told me that I might have to adapt my life to the special needs the condition engendered, but enthusiastically assured me that there was no reason why I couldn’t lead a very fulfilling life.

She was thorough, but I felt like I was missing something. What I really wanted to know was when I would get to start living this fulfilling life. I had never been able to shake the idea that there was some grand exciting adventure waiting for me out there away from the waiting rooms, testing centers and offices. But for that, I needed to have a functional body with which to pursue it. It only occurred to me after I opened my mouth to ask her about it that I had never considered the practicalities of this grand adventure and had no way to ask that question without sounding completely insane.

I wish I could say that in that moment, I started the process of reframing my life in a more realistic way. Unfortunately, while adaptability may be a virtue, it certainly isn’t one I could ever claim to possess. Instead, I asked some inane question about when I could expect to be sufficiently improved to start working full time and get back to regular exercise which was the

closest approximation to the real question I could think of on the fly. Dr. End-Of-The-Line's next words echoed in my head for months.

I was standing in the kitchen at the family reunion. In order to avoid any more questions, I was doing my best to look busy. It was the first time I had seen most of my extended family since things had gotten really bad and I had had a bad spell earlier that day. I wanted to be understanding because it was only natural for them to have questions. That said, I couldn't decide which I hated more: the conspicuous silences or the incessant questions. After explaining for what felt like the thousandth time that *no*, I didn't have a full-time job; *no*, I wasn't looking for one at the moment; *yes*, it was because of my mystery illness and *no*, I wasn't diagnosed — let alone cured — yet, I decided that the questions were definitely worse. I briefly considered convening a family meeting and climbing onto the antique soapbox to read out the definitions of the words 'chronic' and 'undiagnosed', but if nothing else, the image of that felt a little heavy-handed. Instead, I took out my frustration on the potatoes I was mashing because when it came down to it, they meant well and didn't know how much it hurt to have to repeat those answers over and over. They couldn't know that every smile I forced, every self-deprecating joke I made, every silver lining I came up with and every cheeky retelling of the ordeals I'd undergone to get a follow-up appointment at such-and-such clinic were slowly killing me inside. Certainly, they didn't realize that the pleasantries I added at the end of every answer about how I had hope that I would soon have a plan to manage my symptoms and would be back to my regular brand of trouble making were the only thing keeping me together. How could they know when I didn't?

In the end, maybe I was the person who needed to have the definition of ‘chronic’ read out to me.

Years at best, but that might never be my reality.

Many stories taught me how to become a hero. But I was at a loss when it came to accepting that I was one of the helpless villagers, left behind when the hero leaves for their epic journey. I hadn’t ever really believed that I wouldn’t have the life I had imagined until Dr. End-Of-The-Line had said those words. I didn’t have a clue how to begin wrapping my head around it.

I probably should have cried or broken something, maybe called a friend to take me out drinking or to bring me ice cream and a box of tissues. I had moved past denial, so I should have been sad or angry. At least that’s what it said in the leaflet Dr. End-Of-The-Line had slipped into the pile of papers she had given me. The cover read: “Chronic Illness and the Stages of Grief: Coming to Terms with a New Diagnosis”. Predictably, I didn’t do or feel any of those things. All I felt was the profound need for a new life plan.

My office is decorated with an ancient Greek theme. It may not be original but, if you ask me, no one does epic heroes like the Greeks. The shield behind my chair is a replica of Aegis as described by Virgil: a private joke just for me. I may not be the hero I imagined I would be, but I like helping people navigate the diagnosis process. I like it even more because working for a

non-profit means I don't have to charge for my help. My door is always closed so people can collect themselves privately before I greet them and I send them home with files neatly organized into binders with the names of famous weapons and armour surreptitiously printed on the inside cover. I don't know if anyone else gives the people they encounter silly mnemonic nicknames like I did but in case they do, I try my best to be Ms. A-Little-Bit-Quirky-But-Surprisingly-Helpful. In time, I hope that will become enough to keep me happy.