



## *A LIFE IN TRANSITION*

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ON*

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My GBS story begins Saturday morning, August 22, 2015. It was day two of an annual cottage weekend that was a highlight in what had already been a pretty spectacular summer. In June, after three years of sweat and sacrifice, I received my Master's degree. The first two weeks of August brought us to France for a wedding and reunion with my husband's family, which except for my unfortunate bout of food poisoning at the end, was rather fantastic. And just a couple of hours prior to leaving for the cottage, I had met with my business coach to begin building my new consulting practice. Now, to top it off, here I was spending quality time with some of my fabulous girlfriends. Life was pretty sweet.

As I climbed the stairs from my bunk to the main house that morning, I stretched out my strangely stiff calves. I couldn't remember doing anything strenuous that would make them feel so tight, but I shrugged off the oddness and looked forward to another day of delicious food, wine, conversation, and some serious dock time. Sitting in my Muskoka chair a little later, I reached over to flick an ant from my arm, but my fingers barely nudged it. So weird. I looked at my hands, opened and closed them, and stretched out my fingers. They felt slow and a bit weak when I made fists. What was going on? I tested my hands by grabbing a can from the ice bucket and popping the cap. I grinned... Well, at least I could still open a beer! I'm not much of an alarmist when it comes to health matters, and tend to have an "if it's bad it will get worse" approach. Unfortunately, things were about to get far worse.

By dinnertime I was having difficulty lifting my feet when I walked, and needed help cutting my steak. The next morning, I was marching rather than walking. When I went to the washroom my right leg buckled underneath me. My shin bones were buzzing, my calves felt like I had just run a marathon, and I couldn't even move my toes. When we left the cottage that afternoon I couldn't walk on my own and had to leave my car at the marina.

My friends delivered me to a very shocked and worried husband at about 7:30 pm. I insisted on waiting to see our family doctor the next morning, but when the next morning came it was obvious that I needed a hospital, so we called for an ambulance. A couple of hours later I heard "Guillain-Barre Syndrome" for the first time and was admitted to hospital soon after.

By Tuesday morning my limbs were almost completely paralyzed and it began to feel as though hot barbed wire was being pulled through my hips. But Tuesday also brought me a wonderful senior resident neurologist who was my kind of doctor. He performed a lumbar puncture and pushed for an urgent CT scan and MRI. Where others had been vague about what to expect, he answered my questions and gave it to me straight. He explained how my body's immune response was overreacting to my little bout of food poisoning and attacking my nerves. He laid out his prognosis, which wasn't pretty. Because my symptom onset was so swift and severe, he expected I would get

far worse before I got better. He described how IVIG treatment would help slow the attack, but advised me to prepare for “the long haul”.

After some prodding and googling I learned what “the long haul” was. Two to four weeks of decline into full body paralysis, reliance on a respirator and feeding tube, six to twelve months in a rehab hospital, months of outpatient rehab, crippling fatigue and nerve pain for who knows how long, with the potential for residual symptoms for the rest of my life. Now, how exactly does one prepare for that?

Well, here I am 15 months later, and I have learned a few things.

One, a prognosis is only a best guess. It is not a certainty. After two intensive nights of high-dose IVIG treatment, my decline halted and my body began to improve. No respirator. No feeding tube. On day eight I was transferred to a rehab hospital. In total I spent six weeks in hospital, not six months. Take that, long haul!

Two, psychological care is essential. Within three days I had gone from completely healthy to completely dependent -- it was sudden and it was scary. With GBS, decline is quick, recovery slow, and transitions tough. I needed help processing everything that was happening to me. In my opinion, the lack of psychological care as a fundamental, automatic part of GBS treatment is a huge gap.

Three, outpatient therapy must be scheduled before going home. During inpatient rehab I worked my butt off and made huge progress. As soon as I could use a walker and climb a flight of stairs, I was transferred home with the expectation that outpatient therapy would continue the following week. However, my therapy was delayed for six weeks during which time I declined physically and psychologically. Make no mistake: this was the worst experience of my whole GBS journey.

Four, we can't always choose our circumstances, but we can choose how we respond to them. GBS sucks and recovery is tough, but crap happens to everyone, and I'm a part of everyone. I personally do not believe that “everything happens for a reason,” but I do believe there is value in every circumstance. This experience will change you for better or for worse; the choice is yours.

My fight with GBS is not over and I continue to face some challenges. The financial impact has been tough. After investing so much in my degree, I am not able to work, and for various reasons I seem to fall through the cracks of all government assistance programs. Fatigue is another challenge, and is a symptom that is hard to understand. People want to visit and you can't. You want to do more, and you can't. As mobility improves, expectations begin to return (from others and yourself) that you just can't live up to. But my biggest challenge is staying motivated with physical therapy. Physiotherapy was really helpful, but after my allotted healthcare sessions were used, I was left on my own. And we can't afford private physiotherapy.

But I'm not complaining: mine is a life in transition. I may or may not be able to return to my career, but I can move forward from where I am. With the help of Make A Change Canada's Business Abilities program, I am creating RehabForBeginners.com where I aim to help others by addressing some of the gaps I experienced in my rehab and recovery. Stay tuned!