Tread Carefully - A memoir by Evan Rothman

THE humidity was unbearable, especially for an autumn day. Wearing a short sleeve shirt, as everyone in KwaZulu-Natal does, armed with the tools of my trade (the day's newspaper in one hand and car keys in the other), I was ready for another day at office. This particular Tuesday, 23 May 2006, started like any other. I had to manage pressing deadlines as Motoring Editor at a daily newspaper in Pietermaritzburg.

I planned to work speedily in the morning to have a quiet afternoon. This is because I had a fast car parked outside my office, one that needed to be thrashed about and thrashed hard. (This is all in the pursuit of providing my readers with an honest opinion on a new vehicle, you see).

Being 23 years old I had the unenviable task of having to test drive a new car for a week every week, attend new vehicle launches all round South Africa in unpleasant locations such as Chapman's Peak, along the Garden Route and those twisty roads outside Nelspruit, attend various motorsport events and meet and greet with the big heads of motor companies. Oh, and I had write about it. Glamorous? Nah. Fun? Nah. It is a tough job, with almost zero perks. Pity me, please.

From as young as I can recall, I have had a deep interest in all things motoring. My Dad is a motoring fanatic and worked for one of the country's largest motor manufacturers, and so does my Mom. Besides loving fast and expensive cars, I was an active kid at school. Attending an all boys' school, sport was very much the centre of my life back then. I took part in most sports, except those that needed a stick and ball, and achieved success in the swimming pool and athletics track. I attained provincial colours on a few occasions for swimming, and loved the tussle of waterpolo. Rugby too, with its hard knocks and team spirit, as well as mountain biking and here I won a few races in my teens while competing as an adult. But I digress…

I saw a specialist neurologist before noon that day. He diagnosed me with Guillain-Barre Syndrome. I knew about as much about the illness as you do right now. Was I a little nervous, scared? Hell, yes!

Tears came when I phoned my parents with the terrible news. It felt as if time stood still, yet the world around me seemed to be racing. I went to my flat to pack a bag for what I assumed would be an overnight stay in hospital. How wrong did I turn out to be! I walked into the ICU ward of the hospital, and lay there for the next days that soon became weeks.

My story starts earlier that morning before work. I woke up with a stabbing pain in my legs and an intense pins-and-needles sensation. This problem worsened the more I walked and I was beginning to feel exhausted. At 08h30 I called my doc and we discussed my symptoms. I had x-rays taken, but these showed up nothing out of the ordinary. This ruled out a pinched nerve, but left the doc in the dark as to the cause of my discomfort. At 10-ish I could no longer battle through the day: I rang my doc again, who immediately made an appointment for me with a specialist neurologist.

Guillain-Barre Syndrome is a rare medical condition that affects any one, of any age and attacks at any time. Your peripheral nervous system (i.e. your arms and legs)

become paralysed by your own immune system. Your immune system turns nasty by attacking you in a violent, ruthless and sudden manner burning all neurons and myelin sheaths in your body. It is not known what causes this life-threatening syndrome, however scientists believe that a gastro-intestinal infection, chest infection or stress triggers the onset of this illness. This illness needs to be diagnosed quickly, treated immediately and nursed carefully. There is no cure, or any prescribed treatment, which makes this frightening experience that much more daunting for both the sufferer and the medical team. There is also no way of predicting its course or in which manner it will affect one's body. The only thing known to work is Hope.

By the end of my first night in ICU, my legs had so weakened that I wasn't able to walk. I tried with all might to move them, but to no avail; they just lay there limp on the bed. By the end of the second day, my hands and arms were losing their strength too, and by the end of the third day I wasn't able to lift a can of Coke. I was literally watching my body slowly turn into a vegetable from my feet upwards. It is an extremely terrifying feeling knowing there is nothing I could do, and even more worrying there was nothing my doctors could do to stop it.

On day three I was given a strong muti (after a lumbar puncture of which I remember nothing), called Polygam. This medication, at R7,000 a day, was intravenously administered to me for five days on a twelve-hour on, twelve-hour off dosage, and this I believe saved me from lapsing further into claws of this syndrome. Polygam, simply put, is a bag of white blood cells harvested from donors to replace those lost in one's body. I thank my lucky stars every night I had the medical geniuses on duty when I fell sick.

On the fourth day I woke up to find I could no longer move my fingers, hands, arms or legs. What were my thoughts back then? I can't remember, I can only remember my many tears…

For the next days in ICU I resolved not to fight the illness any longer, but rather to let it run its course. My logic, you see, was that in order for me to get better I had first to be sick. And sick did I get!

The only way of monitoring my condition was by conducting lung capacity tests every few hours. When I was first admitted to hospital my lung capacity reading was 3,5 litres. My lung capacity should have been between 5,5 to 6 litres. As the days slipped by, my lung capacity dropped to 1,0 litre, hung there for a few days, and then crashed to 0,72 litres. To put it into perspective, a can of Coke holds 330ml of liquid. That was the size of each of my lungs, meaning that that was all the air I could use to supply my entire body with oxygen. Breathing became laboured as my chest and diaphragm muscles fatigued, and I had to force myself, sometimes motivating myself using cuss words and the like, or thoughts of one day driving my dream car. But it is life, of breathing in that next (small) lungful of air that kept me going… How could I let everyone down, by not giving it 100 percent all of the time? Who was I to give up? So I never did.

A moment does not go by that I am not grateful I can breathe on my own today. After struggling to breathe, a task your body does automatically, to then have to consciously think and worry about your next breath is nothing but life-altering stuff.

The happenings in an ICU cannot be explained to you unless you yourself have lain in a bed there: it is hectically busy, what with people dying next to me (one a day on average); the noise, the bright lights; and, the constant comings and goings of doctors and nurses. It was the most frightening period of my life, and yet I found it strangely peaceful. He's going nuts, I hear you saying. Not quite, rather I let my fate rest with those with the power to fix me for I knew there was nothing I could do to alter the state of my health.

I always had a smile ready and a quick joke for those whom I felt needed a "pick-me-up", and this always surprised my room-mates' (this is what I started calling the patients around me) visitors as they were shocked I was always chirpy and smiling, yet lying looking sickly in ICU with hundreds of machines and drips wired up to my arms, chest, and legs. When they inevitably asked my nurse what was wrong with me I would pipe up I was feeling lazy and wanted to work on my tan. They always laughed, but I don't think it was because of that joke…

As my condition worsened, I felt increasingly guilty. My parents and sister live in Uitenhage in the Eastern Cape at the time, some 900km from Pietermaritzburg. When I phoned to tell them I was going into hospital, they packed their bags and drove through the night to be with me the following morning. Not only was my life uprooted in such a dramatic fashion, but theirs too. I tried to put on a brave face for them, but they saw through it.

I only slept for about two hours each night; I was terrified of not ever waking up. And with good reason: one Wednesday evening in that darned ICU bed, I felt very uncomfortable and complained to my nurse. The nurse checked my stats and all seemed okay. I closed my eyes hoping to fall asleep and dream of bikini-clad supermodels feeding me cocktails, but every time I did so the heart monitor sounded its alarm. The nurse kept a close eye on me, and it happened again and again. A little later my heartbeat dropped from around 65 beats per minute to 33 beats in a matter of seconds and then even lower into the teens and it left me gasping for air. All hell broke loose around my bed. Another nurse brought the dreaded "Crash Cart" to my bed, and switched it on. I was pretty rattled about then. The nurse phoned my neurologist, and I was then given an injection of Adrenalin into my chest, right next to my heart to boost my dropping heart rate. It then raced to 98 beats per minute for an hour. It was a chaotic moment. I later tried making a joke of it, but the nurse covered my mouth with the oxygen mask and told me to shut up! The following morning, the doctor explained to me what had happened: my heart, being a muscle, was acting up as a result of G.B.S. just the same as my other muscles had. That's great I thought, its exactly what I needed to add to my anguish.

My condition began to improve. My weakened muscles regained some sensation and the pain subsided to more manageable levels. My physiotherapy sessions changed from chatting about exercise to sweaty workouts. Even though my movement was very limited, the smallest exertion was draining. I did, however, feel stronger and stronger as time rolled past. I felt I could get out of bed and walk out of the hospital, but I was of course only being optimistic and most probably still under the effects of the medicines.

After my L-O-N-G stay in the ICU, I was transferred to the Medical Ward of the hospital. I was on my way to recovery, the doctors all told me. After a short stay, in what was easily the most boring period of that hospital stint, I pleaded, nagged and whined for my doctors to discharge me. They spoke to my folks a while and swapped cell phone numbers in case of an emergency, and I went home that day the happiest man alive!

At that stage, I was not yet able to walk - I was totally reliant on a wheelchair for mobility. I could feel my legs and move them ever so slightly, but they would not support my weight. My physiotherapist, who saw me twice a day during my stay in the hospital, worked me hard to get my muscles in working order. She gave me a gift: it was shiny, aluminium, an engineering marvel, and rather desirable in certain circles… A Walking Frame. I had just turned 85 years old in a matter of minutes. After the initial exuberance of finally having a Walking Frame of my own, it became my goal to walk using it, then progress to crutches and then to my own two good(?) stumps. It sounds easy, doesn't it? The old adage is very true: it is easier say it than to do it…

I left for Uitenhage (where my folks lived) early a week or so after being discharged after spending time in my flat recuperating and adjusting to life outside of a hospital. Once again, I packed only the bare minimum expecting to need only a maximum of two weeks recovery, and then head back to Pietermaritzburg to work. Boy, am I over-optimistic or what? Surely I deserve an A-Plus for that?

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Some weeks into my convalescence at home, my chest started burning and with that my hands and arms began feeling heavy and painful. I thought nothing of it at first. I went out with the family one afternoon for some fun in the sun. I returned home dog-tired. Of course, I was still in a wheelchair and pretty much useless (and some would argue that nothing has changed). The following day I was battling to breathe. Ever the optimist I didn't immediately assume the worst (a relapse case of G.B.S.), but believed I was headed for flu or some such illness and called to see a local doctor for a quick fix. I was a local celebrity with the medical types. The doctors were a little nervous to treat me as they'd never seen or heard of G.B.S. That calmed my nerves some.

My GP seemed reluctant to prescribe me any meds and decided to rather phone my specialist neurologist in Pietermaritzburg. They were convinced I was headed for a relapse, and told me to head to hospital to await its full onset. Of course, I refused to go to hospital until I was convinced it was on the rebound. This took only two days…

My worst nightmare, the one that kept me from sleeping most nights, was coming true. All I could think of was that I had to once again endure the pain and suffering. All my hard work exercising and moving in a wheelchair (for I still couldn't walk) were for nought. It was a sickening feeling.

G.B.S. is so rare that statistics compiled about the syndrome state that less than a tenth of one percent (0.1%) of 100 000 people suffer from it. And of that tenth of a percentage, only three percent suffer a relapse and four percent of those die from it.

The odds of me suffering a relapse were so minimal, but luck was not on my side.

In ICU in the hospital in Uitenhage, I was once again attached to those machines, my companions I became familiar with in Pietermaritzburg. By this time I knew everything about my condition and knew what to expect. The majority of these ICU nurses never even knew my condition existed and were frantically reading up on the subject in their medical journals and reference books. If I told you I wasn't feeling nervous lying in that bed, I'd be telling a BIG lie.

It was even more terrifying watching my fragile body succumb to the Guillain-Barre Syndrome a second time. I felt with the first G.B.S. attack I had learned lessons I needed to become a better person, to not take my body and life for granted, so why had I fallen ill with it again? I was angry, furious and very frustrated. My jaw locked up, making talking difficult, just to make matters that bit more challenging. Frankly, I was petrified. My poor parents and friends had to relive the whole ordeal again. It was a punishment none of us deserved or expected. The doctors pumped me full of painkillers and sedatives, putting me on a "high" for days on end. In this stupor, I lost track of time, my surroundings and - best of all - what was happening to me. I can't remember a solitary thing while I was in that hospital. In hindsight, it was a blessing.

I woke up in a daze in a Port Elizabeth hospital's High-Care Unit. My parents and docs transferred me there as its head neurologist was confident of making me better. It was a thirty-minute drive in the back of an ambulance (I had always wanted to drive in an ambulance, and here was my big chance, but I was so drugged up I would have put hardened stoners to shame), and I have no recollection of it. I wanted some sort of fun time, but no such joy for the wicked.

My symptoms this time round were: my legs, arms, neck and jaw were useless, my left ear went deaf and I had major problems with my eyesight. Nevertheless, I was still smiling. The first time I fell ill, the syndrome worked its way up from my feet to my chest. This time, it went from my head down to my feet. And, it was a lot more violent than the first attack. Fortunately, it was over rather quickly (well, it took a few weeks, but the civil war in my body came to rest as quickly as it had struck me).

After another stint in a hospital. With much the same experience as with my first stay in hospital with this illness, I was always chipper and charming. But, I was reliving a hell I was unable to relate to anyone. I was later transferred from the High-Care Unit to the Medical Ward where I stayed for a week or so. My condition, and attitude, was improving somewhat. The neurologist recommended I stay at a physical rehabilitation centre to undergo specialised care. I was not exactly overjoyed at the prospect of laying up in yet another hospital bed, but thought if that is what it would take to get back on my feet (literally), then that's what I'd do.

I was transferred to this new facility, one I had never known existed even after living in the city for all my life. On entering the physical rehab centre, it brought home the severity of my situation. I was surrounded by disabled people, making me to realise I was now one too even if it was only temporary. Tough like you cannot imagine.

A physiotherapist and an occupational therapist saw me twice each day and I also underwent hydrotherapy and speech therapy every other day. All my hard physical

and mental work paid off because after L-O-N-G weeks of intensive therapy, I was able to stand and take a few steps while in the Parallel Bars. Learning to walk, for what was essentially the third time, was no easy task. It takes heaps of patience and a will as strong as Russian vodka to persevere. The whole process is a battle between mind and body, with my mind willing my legs to coordinate their movements into a semblance of a stride.

I was able to forego my wheelchair for that shiny Walking Frame after proving to my caregivers I was no longer confined full-time to my wheelchair. It was a great achievement in my recovery. Those first steps were mind-blowingly awesome! (Walking now has become my absolute favourite past time; I still wake up every morning grateful that I'm able to walk under my own steam). For longer distances of more than, say 20 meters, I had to be carted about in my wheelchair, but for anything less you had to force me to not walk with my Walker.

I have what the medical world terms propioreception and sensory denigration. Basically it means I have to watch my feet when walking so that I know my foot is on the ground and that the other is in the air and moving in the right direction. I still hve these residual effects from my G.B.S., but it is more mild-mannered now. It took many hours and bucket loads of sweat to learn to walk in this way. For instance, I used the mirror to look at what my feet were doing.

My propioreception problems do not only make walking that bit more of a challenge, but also everyday tasks. Have you ever tried to eat crisps out of a bag when you can't feel what your hands are doing? And eating popcorn at the movies? These are simple tasks that cause me great frustration. Obviously, I have adapted to it, and now eat crisps out of a bowl and I don't eat popcorn at the movies all too often. Easy. Other areas are a bit more tricky though. After you've been to the loo for a number two everyone knows where to wipe once the fax has been sent, right? I've had to scrub my hands clean many times…

The physical rehab taught me life lessons I will forever treasure, and I am the better for having had that experience. In fact, it was the watershed in my recovery. My outlook and perspective of my illness and life in general terms changed dramatically as a consequence of being there: I was fortunate enough to be surrounded by positive nurses and therapists who only showed me love and understanding, and as a result I've forged deep friendships with those I met there. I arrived there depressed, angry at myself and at the world, and in a wheelchair. I left walking on my own two feet, with a smile stretching ear-to-ear.

I returned to work, and my life, in Pietermaritzburg in 2007. All was going splendidly well; my boss was glad to have me back at work and I was once again engorged in the daily grind of a "normal" life. To me is was a major coup: I had proved to myself that the illness had not robbed me of my life, entirely. Sure, there are many limitations and heaps of compromises and sacrifices I've had to make, but on the whole I was happy to be once again leading a "normal" life.

Life with this illness, which has left my body but has forced upon my body these unwanted residual effects, has not always gone smoothly. My first hospital visit after my return to work in Pietermaritzburg happened on a Sunday morning. I woke up

early and felt out of sorts. I thought nothing of it and went about my routine of showering, shaving and got dressing. After breakfast, I started having difficulty breathing. It was not the usual breathlessness that disappeared after a short rest, but a hunger for air in my lungs. I was feeling faint and decided to rush to hospital. On the way, I phoned a friend to meet me at my favourite place. Upon arrival there my legs were feeling weak and I collapsed. I woke up a few minutes later in a bed with nurses feverishly attending to me. At this time my friend had arrived and informed the nurses of my medical history. I was placed on oxygen, and my specialist neurologist and specialist physician were promptly contacted. You can imagine the stressed voices making those calls.

I was immediately admitted to ICU. I was given painkillers and sedatives that fortunately knocked me out for the rest of the day. My parents once again drove through the night to Pietermaritzburg and I was pleased and relieved to see them again, but not under these miserable circumstances.

My specialist neurologist ran a few tests on me, I went for x-rays and MRI scans, but still no reason as to my sudden fainting could be found. I couldn't sit up in bed, couldn't walk and was constantly gasping for breath. My heartbeat was more erratic than usual, and the neurologist arranged for a cardiologist to attend to my heart matters. Blood tests showed my blood was thicker than it should be. And I am not talking a little darker, deeper in colour, but actually thick like mud. The nurse had a tricky time drawing blood from my now needle-marked arm. I was diagnosed with Polycythemia; it was found to be the cause of my low heart rate and the reason my heart was so fatigued all this time, it seemed. This problem could be solved by having blood drawn every so often for the rest of my life and take pills to thin my blood. It's easy enough to follow and seems to be treatable, but remains another incurable ailment. Yay!

Then a figurative bomb exploded that afternoon. My neurologist told me he didn't think I was suffering from Guillain-Barre Syndrome at all, but from Myasthenia Gravis. Myasthenia Gravis is also a neurological condition very similar to G.B.S., but is a chronic form of the syundrome whereas G.B.S. is supposed to be a once-off attack. It was nearly a year of battling with my body, and now the doctors are second-guessing themselves. I was angry, and very frustrated.

To treat my suspected Myasthenia Gravis, the neurologist injected me with medication specific to Myasthenia Gravis. After 15 minutes, I was gasping for air, I was unable to swallow my spit and unable to focus my eyes. Of course I started to panic, compounding the problem. My breaths became more and more shallow. The doc also started panicking, and injected me with more medication and still my condition didn't improve. I was near to passing out from the lack of oxygen, and I saw sweat form quickly on the doc's brow. The medical team tried various tricks and different medicines, and I thankfully came right after an hour of toying with my mortality.

Between you and me, I was certain I'd die that night. I tried my utmost to breathe and fight for air, but it was not working. There was nothing I could do but lie on the bed. I resigned myself to the fact that I was not going to see the sun rise the following morning. Gladly, the neurologist performed his magic and I was lucky to wake up

from it all. That following morning he came to check up on me and told me I was the luckiest guy in the world to be alive that morning. Whoa! Not the sort thing I pay near on a R1 000 a visit to hear…

I was sent for x-rays, CT scans, MRIs and even ultra-sound scans to look for possible causes to my condition. As suspected, the results showed up no new issues. The doctors were still somewhat in the dark as to why I was in agony, yet seemed determined to get to the bottom of it. I was in no mood to entertain their curiosity, and only had one thing on my mind: to climb into my own bed and get plenty rest. It was not to be. My overnight stay had turned into one of weeks, and I was very glad to once again see the outside world. I was able to walk after all this, albeit even more slowly than before and battled with severe nausea and headaches, but those symptoms were no problem: I was out of hospital!

Another incident that sticks out in my memory bank, is when one Friday afternoon I was on the way home from work when I had to make a sudden detour to my bed at the hospital. In my car, I phoned my neurologist to tell him of my symptoms and he insisted I see him immediately. I walked into the Casualty Ward, and was promptly directed to the ICU: they were all expecting me. How nice, I thought. The neurologist was once again baffled by the sudden downturn in my condition and was unsure of how to treat me. My tongue felt thick and heavy, making talking very difficult. My legs were weak and wobbly, as were my arms. I was feeling very disoriented and dizzy, which only fuelled my frustration, anger and depression (those three emotions keep popping up you see, if you are paying attention). The first night was a challenge, as breathing once more seemed an issue to great for my body to handle, but after the few days in ICU I was already feeling fit and was looking to go home. These two incidents are notable to me for they broke m rhythm, my confidence in myself and my health.

As I've already stated, my Pietermaritzburg neurologist wasn't too sure as to whether my condition was Myasthenia Gravis-related or Guillain-Barre Syndrome once again rearing its hideous head in ways that the medical fraternity in South Africa had never before seen. On that basis he made an appointment for me to see one of South Africa's leading neurologists, fortunately based in Durban. It was a nerve-wracking experience as I had pinned all my hopes on this medical genius to immediately sort me out. From that sentence you can tell it was not the case. After a lengthy meeting and consult, the professor said I was a "diagnostic dilemma". And a lovely day to you too, I thought.

He was convinced I had a very rare form of Guillain-Barre Syndrome and that it was "highly problematic and highly intriguing." Sure, sure, but can you heal me? No, was his curt reply. There is nothing that can be done. Great news, I thought. My hopes were completely shattered, like an insect on a Bugatti Veyron's windscreen after it had smashed the World Land Speed Record on its way to the nearest shopping mall.

Anyhow, life must go on. I returned to work the following week and hobbled about as usual. Under advisement from my doctors, I was placed on sick leave once more the week after that though (and other short visit to Hell), but this time with a view to being temporarily medically boarded. I was to undergo extensive testing (as a guinea pig) for various medications to help me get better. Unfortunately, the powers that be

thought I was not ill enough to warrant a six month absence from work. I ended up taking three months unpaid leave, as my company was unwilling to budge on the matter.

No surprise to me, my heart started playing up some months later. It was also another memory worth sharing here. Not wanting to play around with such matters I saw my cardiologist. I gave him a sweet to eat, hoping he would give me good news. It didn't work: he'd prefer a black M5, but my cash flow was a little tight. I underwent a Coronary Angiogram (which is quite a scary experience, while also being really cool watching your heart beat from the inside!). I heard my favourite three letters spoken after the Angiogram: NAD - No Abnormalities Discovered. Phew!

I was, however, admitted to Inkosi Albert Luthuli Central Hospital in Durban for extensive and invasive testing for G.B.S. This was a public/governement hospital, but I was told it was of the best in South Africa. In the neurological unit, where all the loonies are kept under lock and key, the brilliant neurologist I mentioned ealier and his gaggle of over-enthusiastic neurologists and student doctors couldn't make heads or tails of my condition. I sat through hours of nerve conduction studies, blood tests and other examinations I had only seen in horror movies, yet the team of neurologists could not explain why I had repeated "episodes" nor why I had a loss of sensation, or had heart and blood problems. According to them, "it does not fit the profile of GBS, or Myasthenia Gravis." It was another dead-end for me, but the good news is that all those neurologists believe I am going to recover and recover completely, rendering my times with G.B.S. a memory. I did leave that hospital with a re-daignosis of G.B.S.

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I returned to work as usual and tried my utmost to impress my bosses. I went about writing cracking articles, driving fast cars and having a good time. A hospital-free future was looking promising, and I was feeling confident that my G.B.S. had well and truly lapsed into remission. The G.B.S. had all but disappeared from my nervous system, but an "ordinary" life was still proving rather taxing. Working a full day, attempting to have a social life, and do the things I enjoy doing (walking, exercising, reading, watching movies, braai-ing with the mates) was too much for my tired body to manage. I was beginning to doubt my own strengths, and sought medical advice from my favourite neurologist. We chatted at length about my future life with G.B.S. and how it might all turn out. Meetings were held with various other doctors, and I also included my physios and occupational therapists in Port Elizabeth in the discussions. A seed was planted in my head, and I slowly began to think more and more about my future.

It was during yet another hospitalisation that I woke up early one morning with a clear vision, a clear direction as to what my future entailed. I phoned my father early that morning with a nurse' cell phone and told him I was going to resign from my current employer, the newspaper, and move home for a few months to regroup my life and then take the next step with no pressure of having to return to work or whatever else. He agreed that it was a great idea. It had been just this that my folks and friends and medical team had actually been nagging me to do for months. On my own I made the decision. I called my boss and we had a meeting at the hospital, and I turned in my

resignation to him right there. I immediately felt a huge weight lifting from my shoulders. I was Evan, but a new Evan. A relaxed Evan. I like that Evan.

Well, living back in my home city has proved to be a sensible move. I feel more at ease, less stressed about life and have easier days to meander through. I am not racing from deadline to deadline anymore, from editorial to printing meetings, from airport to hotel to car launch to airport to desk, but I have embarked on my own little mission wherein I have put my heart and soul. It is more me, more the new Evan that I like.

G.B.S. has not left my life completely yet, despite it being a little over five years since my initial attack. During my most recent stint in hospital, my neurologist popped in to see me a few times and phoned twice daily for updates from the nurses instead of seeing me personally. My growing concern for my heart condition has not been unfounded: I was diagnoses recently with Hypertrophic Obstructive Cardiomyopathy. Yes, another mouthful.

It came about after yet another heart "episode" as the medical professionals so love to call them, when my heart beat shot from a leisurely 60 beats per minute to 240 in a few seconds and remained there for several agonizing minutes. Scary, scary, scary… It returned to normal after an injection to two, but I was totally drained. It was then that they did another ultra-sound exam of my heart and found it to be thicker than it should be. One of my heart's chambers is now smaller as a result and pumps out less oxygenated blood to my body. This makes me sluggish and lazy. Not lazy per se, but less energetic. Coupled with the G.B.S. residual side effects and the Polycythemia, I guess I could call myself lazy. But, not on my terms it must be noted!

G.B.S., in layman's terms, works like a safe-breaker. The virus (a safe-breaker) unlocks the code to the safe, and it opens and the virus then has free-rein to do as it pleases with my nervous system. All the G.B.S. virus, which is still in my body but is inactive, needs is for another virus to enter my body with the same "coding", and then all hell breaks loose again. It works the same as cancer cells, in principle.

The scope and magnitude of this syndrome cannot be explained in a story such as this. It is simply too far-reaching for my tiny brain to grasp, let alone for me to attempt to explain it all. Guillain-Barre Syndrome is unwittingly the centre of my life, and I detest the syndrome for this. It is like another person inside me, and he is an evil fucker.

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Guillain-Barre Syndrome is no walk in the park. I have learnt a great deal about life and myself. Along the way, I have made friends, and strengthened friendships, of which I would not have managed to cope without during the last five years. My parents and sister have been unbelievably supportive. There is no way in which I can thank them enough for their love, understanding and unwavering support. I can only attempt to show them this by dedicating this story to them. Thank you!

The many doctors, specialists, neurologists and nurses carried me through these stormy months, and have equipped me with the tools to tackle life head-on. If it were not for the physiotherapists, speech therapists, occupational therapists and nurses, I

would not be in the fortunate position I find myself in today.

I am looking at the positive side of my situation. I WILL one day be able to run and jump like a five year old. I WILL one day be able to feel my own skin, or the floor beneath me. One day. What does my future hold? I cannot say. Will I get better? I KNOW I will.