

Steve's Story

By mid December 2012, I felt fairly certain that, within a year, I would be dead. My breathing had become so strained that I could not even utter more than two words without become breathless. I became breathless just moving from a lying to a sitting position. This had been constant for some weeks without relief. The three year long sensation of pressure at the bottom of my left rib cage worsened to such a point that it eventually yielded to a folding sensation that I can only describe as feeling akin to a collapsing lung. I had to sleep upright as I would wake several times a night gasping for breath. Results of breathing tests at this time were 'uninterpretable'.

My health originally became bad in the spring of 2007. Previously a young, active and very fit twenty-five year old, I developed a vague sensation of physical fatigue following an Epstein Barr infection in September 2006. Continuing my daily running and training exercise program became increasingly difficult, until, in April the following year, I found myself so physically weak that I was unable to walk or hold a cup. I was diagnosed with chronic fatigue syndrome six months later.

The diagnosis of chronic fatigue syndrome itself was a case in point. When I first reported to my doctor with symptoms of fatigue it so happened that he didn't see me enter the consulting room because he came in via reception. By the time he saw me, I was already sitting down. I told him I had been feeling very tired. He told me to go home and rest for a few days. When I got up to the leave the room he seemed quite surprised and said 'but what's wrong with your legs?'. I said I'd told him I was tired. It seemed perhaps that I had somewhat understated my symptoms.

Improvement over the ensuing eighteen months saw me back to about 90% of my previous fitness level. Having followed a strict graded exercise program and taken a year out from work, I was able to go hill walking on a weekly basis as I had previously always enjoyed, as well as resuming my career path. Still having to monitor some restraint over exercise levels, I had a few small minor relapses during 2008-2009 lasting a period of about six weeks in which the feeling of heaviness and fatigue in my legs returned. This feeling of fatigue can be described as the sensation of wading through treacle with a sack of coal on one's back. It was as if I had walked 1,000 miles without rest or anything to eat.

At the end of 2009, I developed a high fever with flu-like symptoms. During this time of elevated body temperature I experienced an acute attack of breathing difficulties accompanied by a short-lived but sudden heightening in fever. In the following days a nerve impingement in my lower back became severely exacerbated leading to subsequent numbness in my left leg, a numbness that was to remain for the next four months. During these difficult days I attempted a fifteen minute walk to the emergency department. I found it very difficult to sit upright in the waiting room due to the pain from my back injury. My speech became slurred. I was immediately dismissive of it and even joked with my friend that it must be due to the coffee we had drunk on the way there. On standing, my legs gave way and I fell flat on my face several times. Every time I attempted to get into an all fours position, all of my limbs would give way. Following this I was unable to raise either of my legs from the bed or wiggle my toes. My speech remained slurred without returning to normal for some weeks afterwards. Nothing like this had ever happened to me before.

In the weeks that followed I developed recurrent stroke-like attacks in which my speech would become extremely slurred, my pulse would suddenly race and my breathing would become very shallow and sporadic. It was as if basic automatic movements such as breathing and keeping the eyes open needed constant conscious initiation. These attacks would often awake me from sleep. Often my first reaction in the face of an ensuing attack would be to get up distract myself by doing household chores. This only resulted in a number of falls. Symptoms were clearly exacerbated by my sitting or standing up and relieved in a lying position. The attacks felt like I imagine having a

stroke must feel. I felt as if I was on the brink of death. I do not say that lightly.

During this time I was admitted to hospital for one month. The neurologist who admitted me told me I had a 'classic case of hysteria'. This was before he had even done any tests. My family and I found this comment unhelpful. I had attacks whilst in hospital, one of which was recorded on a blood pressure monitor: it showed an extreme and sudden change in blood pressure with a very high reading. This change had occurred in a lying position and without moving or any apparent external stimuli. It was the worst of all my attacks and I honestly felt in that moment that my life was about to end. It felt absolutely catastrophic.

On being discharged, I gradually began to increase exercise levels. I continued to work from home. I challenged myself to walk everyday, even though I nearly always fell and often didn't even make it 10 meters. I never missed a day of exercise and I always kept to a consistent program. Following my diagnosis, I felt that if it was indeed 'all in my head' as so many medical practitioners had stated, then I should be able to simply ignore it and get on with my life. This resulted in 14 unnecessary trips to the emergency department. These trips were instigated by passers by who had seen me collapse in public and were worried by my slurred speech and lack of balance and coordination. Despite my vigorous protestations and reassurance that I had already been thoroughly tested with no positive findings, they insisted on my immediate transportation to hospital, only for me to be discharged some hours later, unable to walk, care for myself or make it up one flight of stairs to my single-occupancy flat.

During this time my general state felt as if I had been dropped from a great height head first on to a concrete pavement. The simplest daily tasks became traumatic. My limbs had become so weak that I was often unable to feed myself or go to the toilet alone. My balance and coordination was so bad that often, I couldn't even crawl on my hands and knees in a straight line. I had a great problem accepting my physical limitations, which was very much compounded by my diagnosis. Since it had been explained to me that my symptoms were the result of my giving too much attention to bodily sensation, my reasoning was that if I completely ignored my symptoms then eventually they would vanish. This attitude led me to ignore my limitations to such a point that it resulted in a direct worsening of my symptoms.

In December 2011 I developed problems with chewing and swallowing. At times I inhaled my food and frequently choked. This seems to be mildly alleviated by having the head supported. Activities such as peeling an apple would begin normally but would rapidly slow down, coordination and strength becoming impaired within a few minutes. Continuing the activity in the face of such symptoms would result with my falling off my chair and being too weak to get up unaided. The symptoms improved greatly with rest from physical activity, especially in a reclined position. A fall would often require several hours or overnight rest before speech etc. would return to normal. However, I still continued to work from home and gradually increase my exercise levels, despite symptoms being constant. I often fell over. Life was a struggle.

In August 2012 I took a part-time teaching job in a foreign country. It seemed an ideal solution as the hours were relatively low and I had worked there previously and so was familiar with the language and locality. Sitting without my feet raised was an immediate issue. Coupled with the fact that rotating my head leftwards meant that symptoms were so exacerbated that I would faint within 10 seconds, I suffered a chronic head ache for the first six weeks that was subsequently alleviated by keeping my feet raised and avoiding head rotation left.

However, car travel to and from work severely exacerbated symptoms. By this time, I had been told by a number of physicians that it was illegal for me to drive with my condition. Even as a passenger, sitting in an upright position in a moving vehicle often resulted in rapidly increasing

neck weakness causing my head to drop repeatedly. This was particularly exacerbated by going over speed bumps and pot holes in the road. Doing so would cause my speech to become slurred, coordination etc. to worsen, and if the impact was sudden, my vision would become extremely blurred to the point that I was unable to distinguish between large objects such as cars and houses. Consequent examination by my doctor confirmed that even eye movements in any hard direction, left, right, downwards and particularly upwards, caused my symptoms to worsen. It was also noted that I would fall over if I closed my eyes while standing up.

By the third month of my new job, I had completely lost my ability to walk. Falling over was a daily occurrence. My speech was almost permanently slurred. The only factor that seemed to relieve symptoms was lying down. However, lying down then caused problems with breathing. Returning to the UK, I became increasingly intolerant to food. By November 2012 I was barely able to eat and was losing weight fast. Yet, I still tried to continue a much reduced exercise program and work from home as best I could.

At the end of 2012, I changed my diet, eliminating - amongst other things - dairy, complex carbohydrates, additives and refined sugar from my daily food intake. I don't go in for fad diets and I didn't think it would work. Within a week the feeling of fatigue in my legs was much improved and I could walk easily for up to 10 minutes without needing to sit down. My speech was consistently clearer and physical activities took on a greater feeling of ease. The feeling of the weight of an object changed dramatically: during the fatigued periods, the weight of a cup would feel the equivalent to a 1kg weight attached to the end of an outstretched arm. The rapid recovery of muscle strength in my arm meant that the expectation of the weightiness of an object I was so accustomed to feeling resulted in the cup inadvertently flying off over my left shoulder when the same amount of effort was habitually exerted under these new, partially recovered circumstances.

During this time I also made the decision to significantly reduce my physical activities. Crucial to this change in lifestyle was accepting my new physical limitations. This meant letting go of my old identity: the person who pushed hard and always succeeded no matter what. I find with exercise that I can build it to a certain threshold but that pushing beyond this threshold results in my getting worse, however gradually and consistently I build it up. I therefore stay within my limitations and am feeling much better as a consequence. I still sound like a paralytic from time to time, but at least I can walk more than 10 meters! At present, while my daily activities are still very limited, I hope in the fullness of time I may be able to return to work at least part-time.