

## **Vic's Story**

My name is Vic. I am 28 years old and was diagnosed with functional neurological disorder in October last year. I have always been a very active woman who previously has worked in the health, fitness and beauty industry. I have had other health difficulties throughout my life. However, i have been able to lead a fulfilling life. I was in hospital at eight weeks old suffering from wheezy bronchitis and soon after was diagnosed with irritable bowel syndrome. I also have had depression and anxiety. With these health problems, i understand these illnesses may have left me more vulnerable to other functional symptoms due to my genetic make-up.

My functional neurological disorder started back in May last year after having the flu. I was away in London at the time on a course with my work. It was for three days with very long travel and was not overnight. It was very draining and i felt so ill - autopilot mode kicked in! After the course, the next day, i was straight back to work. No rest for the wicked!!

I never recovered completely from that flu. It left me with this gruelling and burning pain in my left leg. No matter what painkillers i took, it didnt go. Walking became very difficult, By this point, i went to my doctors. She kept asking me how my back was (which was fine at the time) but she said she thought it was sciatica and was referred pain from my back. Made sense i guess. Away i went with some neuropathic pain killers (Amitriptyline, a tricyclic anti-depressant used at a very low dose for pain relief) and went to work as a aesthetic beauty therapist. For a while it worked and didn't think anything of it.

About two months later, that's when the pain came back. It spread to my left side of my lower back and weeks later to my left arm. This was then followed by weakness. It was very strange! My GP referred me to physiotherapy. The therapist could feel from examination things were not right and thought i had a herniated disc in L4 or L5 part of my spine. Whilst working on my lower back, it went into spasm and she said she would have to stop. She said she didn't know why the pain had spread to my left arm but would have a look at it next week. That never happened....

The physio made me worse and stimulated my functional neurological symptoms (i didnt know for some time this was what i had but i know now why i reacted. I started another type of physio called neuro-physiotherapy which i have written about below. The pain spread to my neck, other limbs and i started getting headaches... i can actually say i have never been in so much pain. I continued to work until at work, it got too much. I started falling over and feeling generally unwell. I would have no warning of the falls either. Next thing you know i was carted off in an ambulance!

X-rays showed the thoracic part of my spine was curved from muscle spasms which confirmed whatever was going on was neurological. The hospital discharged me and got in touch with my GP advising her to refer me to see a neurologist. I was never able to return to work.

Whilst waiting to see a neurologist, i continued to get worsen with other symptoms setting in. This included bladder problems; it would involuntary spasm causing much bladder weakness, vision problems,(for about a month, i only had tunnel vision) muscle wasting in my lower back, many falls without any warning, migraines, dizziness, pins and needles, memory loss, brain fog, my left side of my face would droop, neuropathic pain, muscle spasms, vomiting, vertigo. I could barely move my legs whatsoever and relied on my boyfriend to cook for me, help feed me, wash me, carry me where i could barely walk and hold me up. My left eye would swell up when the

spasms got bad and my neck swelled up to a size of a balloon which didn't go down until i started suitable treatment. Until treatment, i couldn't move my neck whatsoever.

I saw a wonderful and very experienced neurologist who admitted he found my case very challenging where all relevant neurological investigations came back normal. The neck swelling especially baffled the doctors and neurologists and couldn't understand why nothing came back in my MRI scans, especially where abnormalities were so visible throughout examination. In the examination, my upper reflexes were somewhat normal, but my lower reflexes were increased. Compression was felt throughout my spine and my plantars would go downwards on examination rather than upwards.

Where my neurologist felt my symptoms didn't add up with the scans, especially where mass swelling did not come up in my MRI, they were sent off to a neurologist conference where many neurologists looked through them with a fine tooth comb. Functional neurological disorder was diagnosed soon afterwards. It was later found out the eye swelling and neck swelling were due to severe muscle spasms. The neck swelling had much increased muscle tone from the spasms which eventually went down after i started treatment.

As well as much trial and error with medication, my neurologist referred me to neurological physiotherapy. As my neurologist told me, specialised treatment with a neurophysiotherapist is often best for these symptoms. He told me the treatment plan will likely be the same as someone who has had a stroke.

I am very lucky to have private health insurance through my boyfriends work so was very privileged to be referred to a top neurophysiotherapist. After the initial assessment, where my nervous system was so over active, i couldn't even start any physio for a couple of months as i would likely end up back in hospital, so they started off by trying to calm my nervous system down with a specific medical massage treatment. It cured my neck and did indeed help to calm my system down. It would even leave me bed ridden for many days! But that's to be expected. Its actually a good sign as it means my nervous system is trying to do things so just had to ride through it. My bed became my new best friend!

About two months later, i started physio. At first, it felt like it was killing me!! we started off gently, but it was still so gruelling. Through treatment, i have had to learn to walk again, make nerves and muscles work that have shut down, learn to lift my legs up as well as many other things. At times it felt tough as it felt weird learning to do things you learn as a toddler all over again in my late 20s. Life had changed so much.

Three months later after starting neuro-physio, i have made significant progress. I am slowly building back muscle in my lower back, building up strength in my left side. I can wash on own again, i am walking a lot better, things work again what haven't worked since last year! I still have a long way to go, but as my physio said, im like a different person to when she first met me. With my therapist, i am now slowly learning to walk without my walking stick.

My prognosis right now is looking good, but no-one can tell if it will ever 100% go away. I will likely have to do my physio exercises for life and may get relapses. I still spasm a lot. To be fair, it is funny to watch, it looks like i am trying to do a do a Morris dance sitting down! I still get many aches and pains but least its not as bad as it was. Beauty therapy will likely be out the question

as a career for me but i am starting an open university course in May in psychology which i am looking forward to!

I may have progressed but i have had to adapt to a new lifestyle which has taken time. I had to leave my job and i miss it very much. I

I don't know at this point what the future holds, but i know i have to take each day as it comes and just not to worry.

I still get a bit down about not being able to do all the things i used to be able to do and take for granted. Like going out shopping to get lots of bits on my own, going to the gym, dancing with my friends, walk for miles on end. I hope throughout my progression, i will be able to do this again one day. I have forwarded myself to see a psychologist which i am waiting to start as i know this is also recommended as treatment for this disorder. I also hope this condition becomes more recognised and understood one day as it saddens me to hear how many people get brushed off or do not receive any help whatsoever when they are obviously very unwell. I believe medical science has yet to come to terms with illness which is not visible on scans and other tests which can prove baffling for patients and doctors.

The neurosymptoms.org website is fantastic and factual and has been on great help for me. I would recommend it to anyone suffering from these symptoms.

Myself and my friend Kez Malloch have set up a support group on Facebook which neurosymptoms.org has linked onto this website. Our Facebook support group address is <http://www.facebook.com/groups/110873699030722/>