

## Gayle's Story – Part 2

It has been a while since I first wrote on this site about my early experiences of having Functional Neurological Symptoms, or, as more than one consultant put it, having 'nothing medically wrong...'. Now that I am a member of the '5 Year Plus' club I thought I would write and share how I am managing to live a reasonably productive life with what is turning out to be, a long term, perhaps life term, disorder. I guess one of the main changes is, now when people ask what is wrong with me, I can tell them I have Functional Neurological Disorder instead of shrugging my shoulders and passing their enquiry off with a light hearted comment. At first I said I had Functional Neurological Symptoms, the inevitable reply to which was, 'well why aren't the symptoms getting better if you know what they are?' So I decided to go one step further and make FNS a Disorder instead. Hey, I've suffered with this for over 5 years. I reckon by now I'm justified in classing it as a Disorder as opposed to just a long list of unconnected symptoms. Maybe by the time DSM5 is ready to be published FND will not only be recognised, but will also be more well established as a condition caused by neurological changes and not a Mental Health issue caused by purely psychological stressors. Anyway, the next stage of questioning inevitably begins, 'so what is Functional Neurologically...erm....Disorder?' This is where a lot of internet research, community chat room sharing and a certain amount of intuitive understanding help me phrase a suitably accurate answer in how FND affects me and my daily life and how I have mastered skills and techniques to overcome the excesses of the symptoms.

I explain Functional Neurological Disorder as being a neurological condition which affects the way my brain processes all types of information, from physical through environmental to cognitive interactions. Unlike conditions like MS where the structure of the brain is altered and causes degenerative changes, FND doesn't affect the structure of the brain, just the way it works. It is neither progressive nor degenerative – although the longer I live with it, I am beginning to alter my opinion on this statement. Anyway, faced with the inevitable blank looks at this explanation, I go on to explain how the more obvious effects happen – the physical and cognitive problems. Basically, it seems to boil down to the fact that, every ten days or so, my brain's processing centre 'forgets' how to interact with the rest of my body. One minute I am able to sit up straight and transfer from bed to chair unaided, the next, I can't move anything from the neck down no matter how much effort I put into it. At the same time, I find it difficult to understand what people around me are saying. Understand is the wrong word to use, because I know exactly what they have said, I know they have asked me something which needs a response, but I just cannot process what the response should be.

Have you ever had someone ask you if you want a cup of tea and you have to stare at them for five minutes before your brain has processed the appropriate response? The fact that these 'crashes' as we have taken to calling them, happen so frequently means my brain and body have very little time between to recover completely before the next 'crash' happens. I started having a 'crash' every six months or so,

now, after 5 years, I am having them every 10 days and this is one of the reasons I am beginning to question the non-progressive part of my explanation above.

One side effect of having 'crashes' so regularly though, is the speed with which I can recover after them. Before it would take a week to go from moving to being completely immobile – physically and cognitively - then another three weeks to regain mobility again. Now I 'crash' in a matter of minutes and it only takes a couple of days to regain the ability to transfer and stand unaided again, although the cognitive and environmental processing seems to be an ongoing problem with no improvement in either between 'crashes' and some deterioration in both as time goes by.

One of the fascinating ways in which I can regain control over my body is to have another person touch me. For example; if I am trying to lift my leg I find that I can't remember how to do it no matter how hard I visualise my muscles working. However, if someone touches my leg it seems that my brain then recognises spatially where my leg is and I can move it as long as that touch remains. This is how I manage to walk, with someone holding my hips so that my brain can identify which muscles to communicate with in order to make my legs go forward. It always has to be another person touching the affected part, if I touch it I still can't make it move. It took a while for me, and the people who have helped me, to figure this method out.

At first I was told to stop concentrating so hard because my brain was getting in the way of my body's natural ability to move. However, what is natural for the majority of the population, is now completely unnatural for me. OK, some things still come naturally, like breathing and blinking and coughing, but other movements and muscle contractions I just cannot do. I still need to eat with a bent fork and spoon because if I bend my wrists my brain implodes like I have broken a bone. I still need to drink from special cups with a straw because I can't tip my head back to drink properly – again my brain goes into shock if I try. Now though, I recognise all this as part of a Disorder I am going to have for the foreseeable future and, instead of trying to ignore it or fight against it, I have to accept that it is part of me, my electric wheelchair is now as necessary as wearing my glasses, and I have to adapt my lifestyle accordingly.

I hate not being able to work, so I have become more involved in working with the council and the NHS to help other disabled and long term sick people and their Carers. Every GP in my local NHS area now knows that Functional Neurological Symptoms are quite common and they all have this website address. I refuse to let any medical professional fob me off with the term, 'it's all in your head' because they don't like to admit they haven't a clue what is wrong. I also refuse to let anyone tell me I have 'Conversion Disorder'. How anyone can believe that someone could suffer from 'Conversion' for more than a short length of time amazes me. In fact, more than once I have wished it was as simple as my brain overreacting to a short term emotional, physical or psychological stressor – like a broken arm or a car crash. At least then I would know how to get better. I think there probably is something in the theory that early childhood abuse can alter brain processes which can come back

and bite you as an adult and one of these ways is as FND, just as other childhood traumas can continue to affect you through depression, anxiety etc. But I do not believe you have to be depressed or anxious to contract FND. At the time I got ill, I was as far from being depressed or anxious as it is possible to get. However I did have a really bad bout of the flu two months before this all started with tiny, insignificant little mouth ulcers – reminds me of something I read in a book, ‘for want of a nail, a kingdom was lost’.

From mouth ulcers to complete neurological shut down: who would have believed 5 years ago I would be cursing the day I got my first mouth ulcer. This frustrating, annoying, soul destroying, isolating condition has me firmly in its grips now, but I refuse to be its victim. I have learned – if I treat Functional Neurological Disorder with respect and allow it its place in my life, then I can have a life outwith the condition and I can maintain a low level of independence.

Anyway, that’s where I am at now after 5 years. Maybe next year I’ll write again and let you know how I’m doing, or maybe by then technology will have advanced enough to come up with a miracle cure – just because I’ve learned to live with it, I never stop looking forward to the day when I can wake up, stand up and go to the bathroom without 2 people hovering over me waiting for me to fall off the toilet!