

Becky's story

Dear Reader,

My name is Becky, I am 46 and suffer from Functional Neurological Disorder. I would like to share with you my recent experience as an inpatient at the Western General Hospital in Edinburgh, being treated by consultant Dr Jon Stone and his medical team.

If you are a family or friend of someone with FND I hope this will be useful, if you are a practitioner I hope this will prove informative and if you are a fellow sufferer I hope my account enables you to look down that long, confusing and seemingly endless tunnel with fresh eyes.

In order to provide some context I will begin with a brief history of my condition and the situation that my family and I endured prior to this recent hospitalization. Almost four years ago I suffered sudden onset left sided weakness. There was absolutely no warning, no pain, just a leaden feeling in my left arm and leg! My doctor suggested immediate referral to hospital. On admission I had a CT scan, MRI and blood tests to check for any life threatening conditions,(stroke etc) , thankfully all came back negative.

But then the fun began! Two weeks later with no lead consultant, amid a lot of confusion and differing opinions I was moved to a hospital closer to home, initially just to be assessed fully before I went home. During this time I was placed under the care of a neurologist and also met with a psychiatrist who could find no psychiatric connection to my condition and therefore that single consultation was the extent of any required input.

Then things got worse, and I started having seizures. The first seizure was explained as a possible virus of unknown origin and unlikely to reoccur...until the following week! Then I experienced multiple seizures, some lasting only minutes the longest an hour. These consisted of thrashing about uncontrollably during which time I was unable to communicate, although I remained conscious throughout. I was medicated at one point with Haloperidol and then experienced more painful seizures that caused a lot of muscle contracture, this medication was abandoned.

I remained in hospital for a further six and a half weeks and was eventually discharged back home after my husband assured the neurologist that he would be take full time care of me.

And so our journey began into this complicated world of FND. It is so important to me that this reference to 'our journey' is noted because that is precisely what it has been. I have been so very fortunate to have had the love and support of my husband and four grown children. What has affected me has effected them, they have been vital to my care and their input cannot be underestimated.

In the following three years I continued to see the same neurologist as an outpatient about every six to nine months. We would discuss any new symptoms or difficulties and believe me there were some bizarre ones e.g. left eye constantly weeping for a few months, to more concerning e.g. flooding head pain and dizziness. Interspersed with these consultations were awful relapses. On average they occurred every ten to twelve months, again without any prior warning. During these episodes I would completely lose muscle strength, have multiple seizures and be unable to talk. Each event became worse than the previous one and I was also left with less and less mobility once these relapses had passed, which would take several days.

With this constant debilitation came a healthy dose of scepticism. It seemed the professional's around me, at all levels, could offer no treatment, explanation and what was becoming ever more pressing, any prognosis. How could they be right? My confusion regarding a diagnosis that had never been fully explained had become a battle ground of symptoms versus intervention. There seemed to be an unwillingness to debate or define what was happening and as with so many other sufferers, we (my family and I), had become more marginalised and isolated. We very much felt we were 'out on our own' and left to deal with whatever may happen next.

Then things got worse! Again with no warning I started having violent tremors, shakes and spasms. Within days the gap between episodes shortened from minutes to continuous. The only respite was eventual sleep following several jerks, although even sleep would be disturbed. I saw my doctor and an appointment was made with a neurologist that was new to my case as my previous neurologist had emigrated. I was prescribed anti tremor medication. The tremors became worse and in the absence of any further treatment or understanding we continued to cope at home, hoping everything would resolve itself.

Then things got worse! After a month of enduring non-stop tremors I would flip into total paralysis. I would literally share my day going from one extreme to another. What little ability I had left was decreasing rapidly, we could no longer cope at home and we were bereft of any answers. Eventually I was admitted to hospital as an acute emergency after we had reached our wits end.

Then the fun began! I spent ten days in a major hospital being completely misunderstood. The episodes of total paralysis became longer, exceeding twenty four hours at a time. My speech and swallow were badly affected, I could no longer eat or drink properly and at times I was unable to communicate at all. When the neurologist came to see me it was like being back to square one, accept a diagnosis without full explanation, accept there was no treatment apart from seeing a psychiatrist, accept there was no prognosis! My scepticism turned to absolute incredulity that this was it, life was just accept and endure, don't ask for answers there were none, just accept! We had endured enough! My health was deteriorating and unrelated medical conditions were starting to encroach, e.g. kidney function and blood pressure.

We did all that was asked of us, we met with a consultant psychiatrist whilst in hospital in the hope that some form of treatment would ensue, the result? No recognisable trauma to produce such symptoms! It seemed at last we had a consensus of opinion across the board with all professionals involved; it just wasn't the one we wanted! They had never seen these episodes before and there was no real treatment!

At this point and with no single profession willing to take control over an escalating situation the decision was reached to seek specialist advice from Dr Jon Stone in Edinburgh.

Then things changed! I was transferred to The Western General Hospital in Edinburgh and put under the care of Consultant Neurologist Dr Jon Stone and his team. I arrived a shaking mess, exhausted, confused, angry, helpless and desperate, what on earth could possibly happen next! Immediately I was taken aback by the environment, this was the first neurological ward I had ever been on, and the staff understood the care I required! I was introduced to various doctors in this new team, all of whom took notes, listened, examined me and understood. Not only that but there were other patients with FND! Then Dr Stone came and introduced himself and began explaining FND, the myriad of symptoms that patients experienced, the reasons why the diagnosis was reached and crucially what could be done in such circumstances.

In my layman's interpretation what I now understood was that my brain was not diseased, nothing had physically broken, however sub conscious communication had broken down, automatic

responses had become overloaded by corrupt messages and now my brain had gone into red alert, causing my body to over react and therefore swinging between extremes. There was nothing I could do to rein in control, in fact the more I consciously tried to overcome the situation the more my symptoms would become exasperated. It was not my fault, it had just happened.

Even more importantly Dr Stone showed me how he had reached this diagnosis through physical examination of the symptoms and reflexes I was exhibiting. What I had come to believe was a default diagnosis in the absence of any organic discovery became an understandable and proven diagnosis because of positive symptoms I was displaying! Added to this was an honesty and openness about the condition that I had hitherto never experienced. I was assured that if I had any quite natural doubts about my FND diagnosis that Dr Stone would be happy to explain his findings, if indeed I believed that I required other tests these too would be discussed and investigated. The reassurance didn't stop there, Dr Stone had seen other patients with the same problems as me and then Dr Stone took the time and trouble to go through it all again and explain everything to my husband.

Then things got better! There was a treatment path available through neuro physiotherapy! Again total honesty, no guarantees, no quick fix, no magic medication, but with hard work, a slow, painful process could begin whereby those errant parts of the brain that had stopped communicating could begin to talk once more. This knowledge was based on experience with patients and research. I had never heard of neuro physiotherapy! Again it was explained to me that through years of experience of neurological diseases and disorders, physiotherapists had developed methods of understanding that allowed them to recognise how the body could under or over react in different circumstances and with different individuals. By thoroughly deconstructing movement patterns, an individuals gait and walking itself they were able to reintroduce techniques that enabled the sub conscious mind to access basic movements which should occur naturally. Forced movement or 'trying too hard' were completely counterproductive. It was not a condition that could be shouted into submission or coerced consciously, it would take time. I was met and assessed by the neuro physiotherapy team and a treatment plan was put into place.

Then things got better! Three weeks of intensive neuro physiotherapy ensued, with constant collaboration and guidance throughout Dr Stones team. The first week my tremor concentrated into my torso and the pain was awful, each movement felt as though I had run for miles and my throat was dry and raw, but there were also moments of relief from the constant full body tremors as my limbs were able to get some respite. My walking gait was improving all the time.

During the second week through consultation with Dr Stone I 'played' with the tremor/ paralysis, gently moving from one state to the other until I barely noticed the boundary any more. Always I was aware that there was the constant backup from a nursing and medical team that understood my condition. As my extreme movements began to subside I experienced an increase in head pain, but it was okay, I was beginning to function again!

By the third week my tremor had almost disappeared, noticed by staff and fellow patients alike. I was able to eat more than two or three mouthfuls of food without extreme exhaustion. I was back on my feet using my crutches and getting more independence back day by day! My seizures had stopped and I was able to relax without paralysis taking over. The results were simply remarkable! I had gained more lift in my right leg than I had had in years.

During all this physical hard work the rapport and good humour I shared with all the staff enhanced my healing experience. We cannot thank them enough! The neuro physios and myself had formed

the opinion that my right side was fully matured whilst the left was still in its teenage non co-operative years, I was just waiting for it to catch up!

Then things got better! Whilst I was in hospital I also had the good fortune to meet the president and vice president of FND Hope. Shared experience and agreement that the more awareness raised about such a complex and debilitating condition the better, for researchers and sufferers alike, the discussion was really illuminating and encouraging.

When I was ready to be discharged home Dr Stone consolidated all that had been achieved through my treatment at the Western General Hospital. This included a relapse plan for the future, although a relapse would be unwelcome to say the least, it was integral to continuing treatment to realise that that is the nature of this condition. Forewarned is forearmed and key to feeling a sense of control over such an unconstrainable condition.

And so, dear reader, I am now back home. After almost four years both my family and I feel more empowered to deal with FND. I am about to begin physiotherapy in the community with strong liaison links through Dr Stone and his team. I shall continue to see Dr Stone as an outpatient and am able to contact him should I have any further related issues to discuss. We do not feel so alone. There is no cure, but there is treatment. This condition has been life-changing for me and my family and will continue to be so, however we are so fortunate to have been introduced to Dr Stone and his research into FND. I believe, this little understood condition needs to be embraced by all practitioners in the same positive manner.

My name is Becky and I have Functional Neurological Disorder. If you are a fellow sufferer looking down that long, desperate tunnel, there is a light at the end, there is hope!

Becky Gordon December 2013.