

Gayles story

In the last two years I have gone from being an active, productive member of society to being practically bedridden needing daily care support. I used to walk 5 miles a day, work 12 hours a day and enjoy landscape gardening. Now, at my best, I can walk a few metres using one stick, spend a couple of hours working on the computer and occasionally sit at a window looking at my half finished garden.

Up until July this year (2010), I was told by well respected medical consultants that there was nothing medically wrong with me despite needing a hoist to transfer in and out of bed and an electric wheelchair to get around. I apparently was the healthiest 45 year old on earth as every single test the doctors did came back absolutely normal although by this time I had to wear nappies day and night because I was incontinent and I had lost half my body weight.

I am one of the fortunate ones suffering from Functional Neurological Symptoms though, because now I am getting the physical and psychological support I need and have a much greater understanding of how I can re-teach my brain to work after I have a 'crash'. It has taken a lot of time, effort, emotional upheaval, financial strain and constant pushing for answers, but I feel I am now able to hold my head up and say 'I am not doing this to myself, I am suffering from a medical condition which I do not want and which I can overcome'.

The saddest part of my story though, is that a neurologist recognised what was wrong in the summer of 2009 but did not explain to me or anyone else what the problem was, leaving me believing there was no medical reason for my symptoms. For the next year I tore myself up inside believing that what was happening to me was self-inflicted and I was completely to blame for the condition I was in. My symptoms manifest themselves in periodic 'crashes' where I suffer migraines for 4 or 5 days followed by weakness and unresponsiveness in my muscles from the neck down and difficulty responding to the world around me (almost like my brain has short circuited and forgets how to work with my muscles and society) then a gradual improvement for 4 or 5 weeks before I have another 'crash'. I have Fixed Dystonia in my right hand and both ankles, needing orthopaedic splints and daily physiotherapy to keep moving.

Six months ago I was totally bedridden and a consultant liaison psychiatrist came to my house to talk with me. While still not fully explaining what was wrong, she agreed that I needed to regain some independence. She got me into a local neurological rehabilitation centre for an assessment and we agreed to meet on a weekly basis to discuss what was happening. I spent three months at the centre and it changed my life completely. Everyone there, from the consultant to the nurses to the physio and O.T. staff believed me when I said I couldn't remember how to make my muscles move in a co-ordinated fashion. And what is more, they knew how to help the problem and taught me the techniques to regain some independence. Now, physically I can recover from a 'crash' in about 10 days to the point where I am able to walk using only one stick for very short distances in the house

With the physical side taken care of, I just had to make sense of the psychological effects of the disorder. For the last two years I had been desperately holding on to the tiny little bit inside that was me, the sense of who I was before I had any problems and started to have difficulty with memory, time, concentration and relating to the world. I was so scared I would lose all of who I was, that I couldn't acknowledge the severity of the disorder, making the psychological and physical effects worse. Overcoming this attitude, along with recognising what it means when the veil descends over my mind and I am disconnected from the world around me has taken a while and at times, has been really painful. Now though, the consultant and I are working together to understand the psychological effects and I am making progress to understand and work within the constraints they put on me.

Up until recently I believed I was unique in how I was feeling and what was happening to me. Then my consultant told me about this website, and I discovered there are many of us in the same situation. Reading people's stories and realising that my symptoms are not unique has made me question many things I took for granted in the past including trusting that 'doctor knows best'. Why should we feel ashamed because some practitioners in the medical profession mistakenly believe we are faking the symptoms? Why should we feel responsible for the effects of the symptoms because doctors can't see an abnormal test result so they decide it must be self inflicted, psychological regression and therefore shouldn't be validated as a medical disorder in case sufferers believe they truly are ill? In the same way as other writers on this site, I have suffered abuse and ridicule from medical staff and been made to feel like a fraud over and over again.

With the knowledge gained from reading through this site, I believe it is important we get the medical profession to acknowledge we have a distinct medical disorder. We should endeavour to make more people aware that having Functional Neurological Symptoms is as devastating and valid as suffering the symptoms of other 'test-friendly' neurological disorders.