

My story - from Loretta

I thought I was doing well, I said to my boss. He said in another year to 18 months that I could be ready to be promoted but not at the moment. I was very upset, left work, and went home, late again. I was really upset and my husband could see that I was very upset.

That night, I woke up and couldn't feel my left leg; I must have slept funny on it, went to the bathroom and went back to bed. In the morning, I woke up and my whole of my left side had stopped working, my leg, arm, hand and side of my face had all stopped working

However I had a very busy day at work and had to go in. I got to work, with my husband driving me, as I couldn't drive, and phoned the GP for an appointment later. When my boss came in, he looked at me and said, "What are you doing here? Go home you're not well", he didn't want to add to the failure I was in the role and he sent me home.

I just thought I had a virus or something, but when I got to the GP, she sent me straight to hospital. I started to get a bit worried. In Accident and Emergency they took me straight into the major care area, and then started talk about strokes. Surely I hadn't had a stroke I thought?

Well they did blood tests and moved me to the ward, and at 3am I was still waiting for the doctor to come and see me. When they eventually told me they thought I had a stroke, I couldn't believe it. In the weeks that went on I had every test under the sun, a MRI, a CT scan, a visual evoked eye test.

Then after 6 weeks, I had feeling in my arm, but my left leg was still not working. Then the real problems started. I would have some days that both my legs where completely numb. My right arm would just not work, 2 days a week, and I was unable to write or hold a pen. I couldn't walk very far at all, and was completely housebound.

All the tests can back ok, and no one could find anything wrong. That's when the doctor looking after me in, the stroke ward, decided I needed to be admitted to see the neurologist that visits my local hospital one day a week. I waited to see the gentlemen that would get me better I thought. Then when he arrived, he did a lot more tests, and then sat down with my husband, mum and dad, to say that he had seen it before, you have functional gait disorder. At last, someone who could get me better.

Then he said, "It's in your mind", I said "what, so I'm making all this up, I'm making it up that I can't walk, I can't feel my legs". He said "no, I'm not saying that but it's in your mind that something is stopping you - we have to look at your past to see what has happened to cause this". I sat there once all the family had gone, and the doctor and just sobbed and cried, my eyes out. How can I get better, from something I don't even know how to get through?

The months and months went by, physio started at home, and I was set distances to make, using a walking frame, I looked like I was 90 years old, not 35! I could slowly walk 5 metres, in 20 minutes and so built it up. I went swimming, and I joked with my colleagues at work that if I could live in water I would be fine, as I could feel my legs in water!

My GP and all the other doctors at my surgery had never heard of FND (functional neurology disorder). So something else would happen, like the whole of my body up to my chin had gone numb, no one knew what to do. So I was given pills for my back pain, pills for my muscles, pills for the depression, and pills for the pain etc - 26 pills a day!

A young GP, who I went to see one particular day, said to me, "well you have this, I don't know what you want from me", she said, "it's in your mind - there is nothing I can do for you". I sat there and cried, and cried, my mother who came in with me thank god, said, come on Loretta, don't get upset, but what was I supposed to do, as I left the surgery, with again, no answers.

Then 8 months after the start of the disorder, my bladder went, I couldn't feel anything, going to the toilet. I had finally lost all the control I had left. My poor husband, who had half a wife working, lost the rest of me, as we could no longer have a "romantic" moment, if you know what I mean.

So, a year after this horrible condition started, I was seeing the mental health team, and talking through my problems, looking at my life, and changing, what was wrong, like having time, for me, and not working all hours god sends. I also had family time, something that before I became ill, we didn't really have.

So, it's now 14 months, since I became poorly. I cannot drive, I have just stepped down as my supervisor role, as I need to put time into "getting better", I have a taxi to work and back again, and my husband has to get me dressed some mornings, as I can't even do my bra up, one handed.

I have the odd accidents with my bladder, but the tablets help, my bladder control, if I try and go every hour. I'm now waiting, to see a neuropsychologist to see if they can make any more roads, to recovery. The new neurologist, I have seen 4 different neurologists in all, to have second, third and fourth different opinions, they all say I will "get better", first six months, then a year, then a year and a half, now they say, 18 months to 2 years.

I now have problems with my walking, problems with my hands, muscles not working, pain in my back, migraines, bladder control, and pain in my legs most of the time. I can only hope and pray that this disorder, gets the knowledge that is needed and to try and get as much help as possible. I may get a mobility car, to help me be able to get out the house by myself and hopefully get my independence back. I have a mobility scooter and a wheelchair to use, and these have become my new best friends. So this is my story, I only hope that if you are reading this, is that you are also going through, this nightmare, I just hope and pray, that like me, one day we will all get better again.

(Note from Dr Stone: Thank you Loretta for sharing your story which illustrates how bewildering and disabling these symptoms can be. Although the doctor in this story said that functional gait disorder was 'all in the mind', readers of this story should read through the website carefully to see that this is not how researchers in the field think of the disorder. Psychological factors can be important but there isn't always identifiable stress at the time symptoms come on. Physical treatments combined with a good understanding of the diagnosis often have as much or sometimes more to offer the patient with mobility problems.).