

Stuart's story

FUNCTIONAL TREMOR - ACCEPTING MY DIAGNOSIS ENABLED MY RETURN TO WORK

I am a 55 year old registered child care worker in a residential school.

My problem began two years ago when I developed a tremor in my right hand. It was not there continuously but came to the fore when my hand was adjacent to my chin. This continued for a few months then the hand would tremor in any position. I went to the doctors and in the waiting room the tremor in the hand became uncontrollable. This in turn made me panic and I began hyperventilating; I had always enjoyed good health and was a very laid back person. This incident came as a shock and fear induced the symptoms, the doctor encouraged me to blow into a paper bag and then prescribed *Diazepam* and Trazodone.

Months later the tremor in the right hand was worse and I still had no diagnosis I began to convince myself that I had Parkinson's disease or maybe motor neuron disease. The uncertainty in my mind began to encourage fear and negative thoughts. I met with a neurologist who had his doubts that it was Parkinson's he thought that it could be Functional Movement Disorder, I had never heard of this before, the explanation of this illness did not relieve my anxieties and I did not accept this diagnosis. I still believed that it was the worst Scenario.

My GP was unaware of this condition and continued to treat me with the medication that he prescribed earlier. I spoke to two retired doctors and they were also unaware of this illness. I was recommended to go to a psychiatrist. On meeting with this professional I asked if they were aware of this diagnosis. It was evident he wasn't. I had two appointments and both occasions they continued to bombard me with questions on my personal life, for example asking whether I had suicidal tendencies. I informed them that mentally I was fine and that *my* anxieties stemmed from not knowing what was wrong with me. I cancelled future appointments.

The Neurologist had stated to me that Functional movement disorder was not a progressive illness and the symptoms I was displaying would not get any worse. A year passed and I continued to work. The condition had now peaked, the tremor was there in my hand all the time and now my entire body had developed into a constant shake and I had weakness in my left leg. I was now convinced that I had been misdiagnosed. This became embedded in my mind because the Neurologist had said it was not progressive.

At work it was alarming for colleagues and young people to see me displaying these symptoms, and on many occasions I was sent home. This in turn impacted on the rota and the care of the young people. My employer was extremely supportive and like myself needed answers. We agreed that I needed time off which would enable me to get a second opinion.

I was off work for six months and my condition became worse. My body was in a constant shake and my leg had shown more weakness than before. I felt constantly tired all day and my sleeping pattern was always disturbed. I met with two new neurologists for a second opinion. After an hour of examinations they agreed that it was functional movement disorder. Their explanation of this condition was put over in a way and manner that I could understand and immediately accept. My new neurologist convinced me that going back to work would be

extremely beneficial for my well being, it would keep me active and reduce my focus on the tremors.

I gave my employer permission to contact my new neurologist about my diagnosis as I felt his knowledge in this field would give my employer an understanding, of my condition. I thought I might find it difficult to explain myself. My employer and my neurologist were then able to discuss my capabilities and weakness and then my employer could do the necessary risk assessments which he has a legal obligation to do. My employer then took an extra step and accessed this website about my condition which gave him a greater awareness of my condition.

My neurologist and my employer agreed that a staged return was the best option. My employer informed my colleagues of my diagnosis and the strategies to adopt. In particular it was agreed that they would not need to continuously enquire if I was okay, if I began shaking they were to ignore the situation. Previously their focus on the issue had enhanced my focus on the tremors thus causing violent shaking. I stopped taking the medication that I was prescribed as I felt they were not helpful, this was a difficult process as I had been taking them for a year and a half.

I have now been back to work for over a month working four days a week. I have not had any major episodes though I do shake on occasions and I still have weakness in my leg.

My colleagues and the young people have accepted my condition and are aware of my disability. There was a time when I thought I would never work again. Acceptance was the key to my return to work by accepting the diagnosis and dealing with the issues that will occur through out the rest- of my life I have started the process of learning to live with it.

Communication between my neurologist and my employer were instrumental in assisting me back to employment and the support received from family, employer, colleagues and young people was second-to-none.