

Debbie's story

My story is as follows. For years I had been getting migraines and it started off with pins and needles in my face which I thought it was normal for this. I was then in a car accident and after it, it was as if my symptoms became worse even though they had started before the accident. I found after getting the migraine, the pins and needles now went down my left side of my face and I got pain in my left side of my chest as if someone was sitting on me and down my left arm. The pain was terrible making me cry. This lasted a few days, then it would go into like a heavy paralysis down my left side. This started off as a weakness then total paralysis where I could not use my arm at all and could not feel the left side of my face.

The first time it happened I was admitted into hospital with suspected stroke and/or heart attack, I had numerous tests, and a CAT scan then I was told to go home as they could not find what was wrong with me. The paralysis lasted about three weeks and then when coming out of this episode (as I call it now) it went back into the excruciating pain then pins and needles which I felt as if my nerves were on fire. Over the whole experience I was totally floored and spent most of my time on strong pain relief so I slept most of the time or cried with the residue of pain which was left.

Over the years I was in and out of Hospital with this each time getting scans, CAT and MRI and nothing. I myself felt the doctors were looking at me thinking I had 'put it on' and each time getting told the diagnosis that it was "non-organic" I think the words were. This was more so with one High end doctor at the Royal Infirmary in Edinburgh who I seemed to end up with every time I went into the hospital accident and emergency. I was treated for heart attack, stroke each time and no matter how much I told them my symptoms, no one understood what it was I had. It got to the stage where I would not even go into hospital when an episode came on and I would stay at home on strong pain relief putting up with the pain and working my way through the paralysis. It was not until I had a severe episode one new year when I was through visiting family, I was by now married and my husband understood all that was wrong with me when it came on and was a godsend, as he did everything for me when I was paralysed. I ended up in a different hospital Glasgow Western General under assessment and the doctor came over and said to me that he thought I should really be seeing a specialist and not speak to anyone else. He felt it would only upset me with getting told either they did not know what it was or being misdiagnosed. This was the first doctor to tell me this and the only one that showed that he believed there was something wrong. It was then I was referred to another specialist in neurology.

I was only in the room 30 – 40 mins and the neurologist did tests on me and I was diagnosed with functional weakness. I went home and cried that day that I had finally after years and I mean years of getting told that doctors did not know and the feeling that I had been putting it on that now I had been diagnosed and was seen not to be putting it on I actually had something wrong and was not imagining it. Since then I am used to my episodes and know how to handle them.

My episode starts with pins and needles in the left side of my face slowly getting stronger, and then I get sharp pains in the left side of my chest and down my arm. My chest feels like someone is sitting on it and I find it hard to breathe. It then goes into severe pins and

needles, this is when the pain really kicks in as I feel my nerves are on fire and pain is excruciating, then it goes into a heaviness then paralysis totally. It is then I have to get help from my husband and family to help me with things like dressing, cutting food up, cooking, cleaning etc. My episodes time range is from 2 weeks up until 3 months being the longest. Now I know what I have I know not to worry that it is life threatening or I have something seriously wrong with me, I can live with what I have in the hope that it may eventually right itself or I can now know I can live with this regardless.

When I am not in an episode I can function fairly well, I can drive and live more or less normally but I find that when trying to open tight things with my left hand I cannot or when using my left arm I find it suffers fatigue fairly easy.

I am now at college and my tutor knows about my problems and is accommodating about this. When writing I find I have to rest as my hand easily tires but I am managing to live with this and try not to let it get me down. The best thing I did was tell my doctor I wanted to see a specialist and I thank the doctor who diagnosed me as I no longer feel others are looking at me as if I am 'putting it on' and I really do have something wrong.

Debbie