

Marie... My Story.

I have had these attacks, as I call them, for so long that I cannot recall accurately when they began. But I do know that they did become much worse about three years ago but have improved again now that I have given up work.

So what are they? My symptoms vary usually I have right sided weakness but sometimes I am unable to move either side. My GPs have worked tirelessly to find out what is wrong but this has meant visiting Neurologists all over the country. And every time is an awful experience. I am “up to high doh” so am incapable of explaining myself properly. And I can’t magic up an attack to suit an appointment so often I seem fine. I believed they were suggesting it was all a Psychological issue because I was physically fine. The MRI and CTs were all ok. That belief fed into my anxiety and therefore on seeing the next “man” I was more anxious, less coherent, etc.

On reflection I think they were saying it was probably a functional condition but I had no idea what that meant and no-one seemed able to help diagnose, explain or treat.

Finally I had blindness in my right eye which led to a visit to an eye specialist and then the stroke clinic where a TIA was diagnosed. I was very grateful. At last I had something people could understand.

That led to my giving up work through ill health retirement. If stress was a major part of the condition then things should have been better, but the symptoms persisted: right sided weakness, memory problems, difficulty processing or retrieving information, inability to move.

Eventually I found a neurologist who diagnosed functional weakness with dissociation and memory problems.

Did it help? Not at first. I had seen so many specialists who didn’t know that it was hard to believe one did. And it was hard to trust someone with all of the symptoms having felt other people thought it was “made up” but now thanks to him and this website, I understand I am not alone or odd in this condition.

The next step will be to move from acceptance to treatment. I think we all know that treatment will vary for all of us but being able to feel an attack coming on and sit down immediately is starting to lessen the severity or time of the attacks. I have reorganised my home so that every room has a safe place to rest. My life style has changed a lot. Everything is now thought through with safety in mind. And it is working. I accept that I can't do the things I used to, going to the gym again is along way off. And I can't teach again. But there will be other things I can do. And I am finding out how to manage this condition.

Recently someone sent by my insurance company suggested that my symptoms were due to lack of confidence and that with more positive thinking I would improve. I think that people like this don't understand that long term conditions lead to lack of confidence. If we could magic these conditions away we would.

I do get angry sometimes or frustrated, or weepy. But not often, mostly I think that it is rotten but only sometimes but it could be so much worse.

I have a teenage son. He was preschool when this started and 15 when I gave up work. I think we need to look at supporting our families through these difficult times too. I was certainly trying so hard to be normal and keep things normal for him that I didn't see his need for an explanation of the events that we referred to as "stucks".

But we are getting there. I hope you are too.