

My name is Mary and I am a 54 year old woman from West Lothian.

Four or five years ago I began to feel very clumsy, I had fallen several times and put it down to wearing high heeled shoes, rushing, slipping etc. Around the same time I started to take panic attacks and could not go into crowded places. I avoided shopping centres, cinemas and busy towns and my world started to get smaller.

One time on holiday I was in a market place with my husband, it was very busy and we got separated, I began to panic and couldn't breathe, my husband saw me but because of the crowd could not get to me before I blacked out. I was really ill for a few days and was totally embarrassed about it. I felt I was going mad because I had these really irrational thoughts – there were too many people and there was not enough air for me – I was going to die and nobody cared – I was angry that I had put myself in that position – I blamed my husband because he had taken me somewhere that was too busy and had put me in danger.

That was just the start, over the next few months I began to black out more often, sometimes at work, and more often when I was on my own but there was no pattern to it.

I saw my doctor who at first put it down to tiredness and stress then referred me to a cardiologist who tested me for many different illnesses. Eventually I had a tilt table test and from the results of that test I was diagnosed as having malignant vasovagal syncope. The treatment for this was to have a pacemaker fitted. The cardiologist told me that the condition was not life threatening but would be life changing. By this time my family were all worried about me and my husband was uneasy about me being on my own.

How right he was. I had the pacemaker fitted, but the first pacemaker was faulty causing me a lot of pain, this was changed and a second one fitted, It did nothing to help my condition and by this time I was blacking out 4 or 5 times a week. I was always covered in bruises and nursing some minor injury but never did any real damage to myself. I felt that I had escaped major injury because I had “learned how to fall”.

I was still working thanks to the understanding of Hanover Housing Association, who did everything they could to allow me stay in their employment. After the second pacemaker was fitted I began to feel a lot of discomfort and it turned out that my body had rejected the pacemaker and it had to be removed. As it had not helped I was not too concerned about this but was worried about how the illness was progressing, I had lost all confidence about going out on my own and had never been anywhere by myself for about a year. I wouldn't go out socially because I was frightened I would have an attack and panic other people and was embarrassed. My social life had gone, but luckily my husband and I worked together so I was able to carry on with my job at this point.

I knew that we were going to be made redundant because the sheltered housing development that I managed was closing and I was determined to see the residents moved out and settled in their new homes. I had been in the job for over 15 years and wanted to be there till the end. It was stressful and I don't think that helped because

at that point I was probably at my worst. The cardiologist told me at this point that he could not help me any more and referred me to my neurologist.

The neurologist told me he thought it had been a misdiagnosis and that he thought I was suffering from dissociative attacks. When he told me that there were no magic pills to cure this and that I would have to try to help myself through it, I felt a bit of a fraud. The first questions I asked were I am imagining this? If I can sort it myself, is it me that is causing the blackouts to happen ? Am I causing a fuss for nothing? My doctor reassured me that the illness was real and helped me to understand what I could do to help.

The first move was to recognise the signs, the hot flushes, the unexplained tingling down one side of my face, and the buzzing in my head were not symptoms of the menopause as I had thought but were in fact warning signs of an attack.

I am not a stupid woman but feel quite silly that it took me nearly four years to recognise the warnings. The horrible feelings of helplessness and uselessness were also signs. I don't always get these warnings but now when I do I can sit down safely and cope better with the blackouts or work myself through it to stop it happening.

My doctor told me to try to hold onto the horrible feelings as long as I could because the blackouts were sometimes the body's way of getting rid of these feelings, I didn't believe him but gave it a try. I have now been able to ward off most of the blackouts- it is not pleasant but more acceptable to me than blacking out and dealing with the feeling of fatigue that follows them. Now I take myself away to somewhere quiet and try to work through them, it doesn't work every time but there has been a great improvement.

Over the last year I have had a lot fewer and now have only blacked out twice in the last six weeks. My confidence is growing and I am now going out on my own. I have started a new job and am coping well with it. I still avoid crowded places and still don't go out socialising unless it is to somewhere local where people know me and know how to deal with the situation should I have an attack. I am a lot more positive about the condition now and am setting myself new goals every day. I hope that my story is comforting to other people and also gives them a more positive slant on the illness.