

Dear Gillian,

Everyone's MS is different but the one thing we all have in common is our diagnosis story, the long wait between that discovery of something 'not right' and the official confirmation you have Multiple Sclerosis. My story was 1 year and 5 months of being prodded, questioned, examined, scanned, tested, doubted and patronised.

It was 1999 and I was rehearsing a play by David Greig at The Tron Theatre, Glasgow (I am an actor and director) in which I played two characters who were extreme opposites of each other. I would go off Stage-Left as one character dressed in black pvc and thigh-high boots then a minute later re-appear Stage-Right, coolly elegant in cream linen. The quick-changes were incredibly effective although physically strenuous and a challenge I would normally relish however, something was not 'quite right'. I stumbled several times in rehearsal and fell over, I increasingly found it difficult to walk in my spike-heels, in fact I found it difficult to walk full-stop - my feet didn't seem to move as they should. I had a creeping numbness and tingling in my limbs and around my torso it felt as if I was wearing an iron corset. I would go home, hardly able to stand and flop exhausted on my bed.

I told the stage-manager my symptoms and she immediately sent me to the nearest doctor who questioned me carefully. She wanted to know how I was feeling and prodded my arms and legs in various places. She asked me to stand with my eyes shut, did several more physical tests, asked me questions, asked about my family history and then sat me down. She said, "I shouldn't say this as you need to have more tests but I think you have Multiple Sclerosis." I burst into tears. My father had MS and deep, deep down this is what I had feared. It was 6th October 1999.

But that's not my diagnosis story.

I hardly knew my own GP as I only ever saw him about once every three years, all of which was about to change; he became an oasis in a desert of medical indifference. He immediately made an appointment with the neurologist at the Southern General and because that could take months of waiting and worrying, he also made an appointment with a medical consultant at the Royal Infirmary. Three weeks later I found myself sitting in front of a man in his 50s telling me that I absolutely didn't have MS and it was completely immaterial that my father had died as a result of declining health connected to his MS because MS was not genetic or hereditary and that my symptoms were psychosomatic: I was a neurotic and a hypochondriac. He made assumptions that because I lived in the East End of

Glasgow I must have a poor diet living on fast food, cigarettes and alcohol. In fact, I didn't smoke, ate healthily and for over a year I'd cut out alcohol, coffee, tea and wheat thinking it may help my low energy. He told me the unsteadiness on my feet was due to drinking and he had two wards full of people with what they used to call the DTs.

It took another six months before I saw the neurologist, during which time I had a CAT Scan and numerous tests. The neurologist asked me the same questions and did the same physical tests as the GP had done and then, exactly as the consultant had, dismissed any connection with my father having MS as inconsequential and told me I definitely didn't have MS but he would give me an MRI scan anyway and in the meantime I was to go to the optician.

More months went by and none of the symptoms went away. In fact they got worse and I got extremely anxious. I'd only told my eldest sister, my boyfriend and a few close friends, all of whom were convinced or perhaps trying to convince me it was stress and overwork. The optician revealed no abnormalities or evidence of MS; none of the scans including the MRI were conclusive. On the last week of February 2001, nearly a year and a half after my unofficial diagnosis, I was back at the neurologist after a lumbar puncture to be told that I definitely had MS. When I looked surprised he said well if it isn't MS it's something just as bad, followed by, "You're going to ask me two questions - how did I get it and what can I do about it? The answer is nothing. We don't know how you get it and there's no cure – go away live your life as best you can." Nice.

I went away and lived my life, but first I changed my neurologist.

Alison Peebles