

Dear Gillian,

I am writing to tell you how my diagnosis came about.

I am now 63. I've been married for 43 years, have one married son and two grandchildren and I live in a village near Dunfermline in Fife.

Most of my career was spent in educational administration, work that I found extremely interesting and never dull. Still living in Edinburgh (where I was born) I had reached a very senior, responsible position in a large school some 40 miles away. It was extremely hard work. In November 1996, after planting bulbs in the garden, I noticed my ankle had become numb and thought I must have trapped a nerve.

The next day the numbness began to move and eventually I had little feeling in my left leg. Meanwhile I was driving backwards and forwards to work and just did not have time for this nonsense. I rang a physio, hoping she might be able to ease the trapped nerve but instead she insisted I go straight to my GP because she thought I had damaged my back. What rubbish - it was just a trapped nerve, surely?

After work I headed back to Edinburgh where I was examined and told to go straight to hospital where they would be waiting for me and would probably operate on my back that night. For goodness sake!

In the end I spent ten days in that ward, fuming. I had all sorts of diagnoses from a heart attack to a stroke. I put up with an MRI scan, lumbar puncture, and every neurological test available, all the while getting more and more frustrated. I had work piling up at school and there just was not time for this. I ended up helping the nurses make beds because I was so cross.

I remember listening to the lass in the next bed crying her eyes out as she had just been told she had MS - I turned to my husband and said, "Thank goodness that's not me." Not that I knew anything about MS.

Eventually a consultant sat on my bed and told me I had had a neurological episode and that it would go after about three months. And he was right - it did - but it returned some seven months later.

By this time it was February 1998 and I had changed my job back to one in Edinburgh. My GP sent me back to the consultant who listened to my tale of woe and told me that it was now definite that I had MS (at that time they did not diagnose on the first relapse). He explained there was nothing to be done other than see him annually but he suggested I wrote to the MS Society for information. Stunned, I went out to get the bus back to the office where I burst into tears in the arms of one of the staff, who never recovered!

The relapses began to come thick and fast so the diagnosis became late-onset aggressive relapsing/remitting MS and I spent frequent periods holed up in my bedroom or in hospital. Very sadly, within that year, I had to give up my career.

I quickly discovered that MS research was basically moribund and that drove me to become a complete pest in hospital, questioning the whole time (medical staff could be seen creeping past my ward to avoid me) until eventually they allowed me to take a well-known (cheap) immunosuppressant that had shown some good results in MS. At the same time I completely lost the ability to walk and had to learn firstly to stand, tethered to a standing frame and then to walk between parallel bars with my wheelchair behind me in case I collapsed. That was the lowest point of my life. However, once on that little tablet, I have never needed to go back to hospital as an in-patient!

It is hard to think that I have had this vile disease for 16 years. In that time I have become deeply involved with the MS Society's Research Network and have had the honour to represent my fellow patients on many occasions, including working with the media (on television and in the papers) and speaking in public on the patients' view of progress in MS research. Learning about my disease has definitely saved my sanity and just possibly my marriage.

I am convinced that for those yet to be diagnosed, the future will be very different to the day I was handed a slip of paper with the address of the MS Society and told to go back to my life!

Sue Polson