Dear Gillian,

I'm writing to tell you about the way I was diagnosed with MS.

Just to let you know a little bit about me first. I'm 35, married and was working full time while also in the final year of studying for an honours degree when I became ill. I've always been quite active and I love travelling, watching football, swimming, exercise classes and just relaxing at home with my hubby. I also like shopping and pink, sparkly wine! I planned to go into teacher training once I finished my degree, but following my diagnosis last year I feel that I can't take the risk of quitting my job at the moment. I know life is uncertain for everyone but it seems even more so now.

Out of the blue in March last year I developed constant numbness from the waist down, which then progressed to my stomach, hands and chest and then severe pain across my ribs and down my back. I went to the doctors and then waited on the hospital referral appointment for several weeks (and was even turned away from the hospital after calling NHS 24 when it got really bad and told I would have to wait on my referral appointment). When I finally saw a neurologist, I was referred for an 'urgent' MRI with no indication of what might be wrong. I remember crying every night when my husband was sleeping: I thought I was dying; my body didn't feel like my own and the pain was unbearable at times. It was the most horrendous time in my life.

After the MRI scan, I received a letter a couple of weeks later, which stated inflammation had been found in the scans, but there was no further explanation and no indication of what this meant. I then received a separate letter advising me that I had a return appointment six weeks later (over three months since my initial referral). In the meantime, I booked a telephone appointment with my GP to find out what could be ruled out from the results. On calling my GP, words cannot describe the shock I felt. I was hit for six, and listened on the phone as she read out the words in the letter she had. I just remember hearing, 'white matter lesions and demyelination which point to MS'. My jaw hit the floor. I'll never forget my husband's face when he came home from work that day. Neither of us expected it and the lack of urgency shown by the hospital had led us to think nothing could possibly be wrong. Hearing over the telephone that you have a chronic, life-changing illness was pretty horrendous. It was a day I'll never forget. My parents were absolutely distraught too.

I can't believe the neurologist was going to wait six weeks to tell me it looked like I had MS! I managed to get an earlier appointment and he referred me for a lumbar puncture and evoked potentials. So more waiting and more mix ups with the hospital but I finally received those tests too. About a fortnight later, my husband called the hospital to find out if the results were ready. He was informed they were being sent to my GP and that I should make an appointment with my GP for the following week to discuss the results. I could only get an appointment with the locum GP who advised me that my lumbar puncture results were clear. However, I looked at the letter she had and saw the term 'oligoclonal bands in CSF' and due to research I had carried out I immediately recognised that this was what they were looking for to diagnose MS. So the lacklustre approach to results had again resulted in me having to play detective to finally get some answers. I also received an appointment letter to speak to the neurologist about the results but it was for four months away. After many phone calls by my GP and I, I received an earlier appointment and was finally diagnosed and referred to commence treatment.

The hospital processes were such an additional stress at that time. It really made things so much more difficult and they need to realise the impact this has on people's lives. I had what turned out to be three relapses in a six-month period, and I'm pretty sure the additional stress didn't help.

Now, I've come to terms with the diagnosis, although it's very scary and I think having something that's invisible to others is quite difficult. I think people understood when I was ill, but once I received a diagnosis they thought that would magically make me better. I find it easier not mentioning it to workmates now as most people really don't have a clue what it's like and the things I go through daily. I'm grateful to have a great husband, parents, family and friends. My outlook has changed and in a lot of ways, it's changed me for the better. I thought I had a healthy lifestyle before but I've actually gone from being a 'raver' to a bit of a 'hippie' now! ☺ I really would try anything if it would help (and probably have!) and I appreciate every day.

Good luck with your project, it's been quite cathartic writing this!

Regards,
Denise