Dear Gillian,

Once I'd had my MRI here is what happened…

I was told that my results had not turned up at the hospital, but they had been dispatched the day after my scan, so where were they?

A letter summarising my results was eventually found, but there weren't any scans with it. As the neurologist was on holiday, his receptionist said she could send the letter to our doctor. She said that she shouldn't say this but not to worry, as everything looked okay to her.

Later sitting in our doctor's waiting room I was nervous, but at the same time relieved that soon we would know what was wrong with me. Our doctor read the letter, saying some of the medical terms out loud, then casually slipped the two words 'Multiple Sclerosis' into a sentence.

He said I had five patches show up on the scan of my brain and one show up on my neck. He mentioned a word, which previously we'd never heard of but now are very familiar with… 'Demyelination'. He happily told us about 'problems another MS patient was having'. Then he said, "I hope you aren't planning on having children, because they will be out of the question." To make this worse, if that is possible, he started laughing.

When we saw the neurologist, he said that without the scans, he had to go off the information provided in the letter. He explained that patches in the brain are common for people who get migraines, which I do, so he could not diagnose me with MS without carrying out a lumbar puncture. So I had this done.

Later we received a copy of the letter sent to our new doctor. It stated that 'the MRI scan had found white matter abnormality consistent with multiple sclerosis'. Also that 'a lumbar puncture performed showed positive oligoclonal bands and with the investigation results and the nature of her problems, fulfils the criteria for multiple sclerosis'.

So ten months after my first recognisable symptom (double vision), I learnt that I had MS by reading it in a letter.

Before I was diagnosed, I now realise, I took things for granted and I didn't really know what was 'real' and 'important' and what was just 'stuff'. I did the usual things: university, work, travel, get married.

After being diagnosed (12 years ago)…

It is difficult to know how much to tell people when they ask how I am feeling. Do they just want me to say, “I’m feeling okay at the moment,”’ or “I’m not feeling so good at the moment,” or do they want me to go into detail? Do they want to know each little symptom I’m feeling or just if I get a new one or one that’s been absent for a while.

Sometimes it has been hard to cope with all the frustrations. Lots of things are now a struggle. It’s the case of not knowing how lucky you are until you lose something. At times I have been very angry. I don’t remember having tantrums as a kid, but now as a person in my 30s I was having regular ones, out of frustration. Luckily this seems to have eased off and gets easier each year.

People cannot ‘see’ that I have a chronic disease, as at the moment there are no obvious signs. Others forget that I am living with MS - I may not be suffering every day but I am still living with it. If I am feeling well I am always unsure how long it will be till my next relapse. MS is always at the back of my mind.

Many positive things have come out of me having this disease.

We had to re-evaluate what is important to us and what we want out of life. We now have two lovely kids and I am a stay-at-home mum.

I try not to take things for granted anymore. I appreciate the little things, which are in fact HUGE.

I don’t put up with crap anymore. I know that my health has to come first. I need to listen to my body and not over-do it.

I have taken up Nordic Walking, which is fabulous.

I am a much more positive person now. When I was first diagnosed I was always thinking ‘what if’, whereas now I think ‘if it happens, we’ll adapt’.

I think having a chronic illness makes it obvious which family and friends really care and who is worth having around.

It doesn’t always feel like it, but I’m very lucky.

I can’t do all the things I could do before, but I’m a better person than I was before.

All the best,
Jenny Eaton

New Zealand