



Speaking from Experience *Multiple Sclerosis*

Transcript for chapter 1 of 8: It's MS

Chris - When I was diagnosed I think originally I didn't know what on earth was going to happen. So I basically packed my bags, left my home, went back to the country where I came from and simply withdrew from life for about six weeks.

Antonella - It was relief mainly because at least I knew what I had and it probably took about a month leading up to diagnosing MS. I did know a little bit about ms because my cousin was diagnosed a year before me so I did know what some of the symptoms were, so I guess my main reaction was relief as well as shock too.

Anna - When I was first diagnosed I was relieved because what had happened was there had been a series of little illnesses that didn't add up to anything, and finally after this long period of thinking I was crazy, I was diagnosed with MS. Even though I didn't understand what the consequences of that were, at least I could put a name to everything I had been experiencing for the past months, maybe even years.

Helen - The first I had an attack was 8 years previously to the one when I was diagnosed. Like most people who had attacks prior to MRI scanners, I was told to see a psychiatrist. I was pretty sure that I wasn't insane so I was actually quite relieved.

Noel - Well it took them three years to find out what was wrong and I was told part way through that it could be MS so it wasn't really a shock that I had it, it was probably a relief. They told me that one of the reasons that I went on was that a brain tumour could be causing the same symptoms.

Mieke - When I was diagnosed I felt a relief when the neurologist told me, because when I had to go into hospital for the testing I thought it was cancer, and they looked for cancer of the spine, so I felt an enormous relief when it was not cancer.

Brian - When the neurologist told us it didn't feel quite real, it took a while to sink in.

Anna - When I was diagnosed my families were there, and it was hard dealing with their grieving and their emotional reaction to the situation at the same time as dealing with mine.

Mieke - My mother was highly upset, because she felt guilty, 'did I do something wrong' you know, you have MS. A little bit of a worry to if other family members could have it, and my daughter worried about it a little bit in case she perhaps could have MS a little later on. Friends reacted sometimes with horror, absolute horror, once again because of not knowing what the disease involved.

Antonella - It was difficult to let them know of the disease, I come from a very close family, a very big family. They just asked me a lot of questions when I was first diagnosed and I answered what I could and what I didn't I sort of took on board to follow up with the neurologist.



Brian - If you don't know, you tend to assume the worst. To have a clearer understanding of what could happen was sort of a relief.

Mieke - I went straight to the library, not knowing anybody with MS I tried to read up on what was happening.

Helen - The first thing I did was get as much information as I could on the disease, and what I could expect. In some aspects it was interesting and some of it was scary, I also contacted the MS society and from then realised that the majority of people with MS don't end up in wheel chairs.

Mieke - When my husband heard that I was diagnosed with MS he was pretty horrified too. Not knowing either what MS really involved, he denied it - I denied it - but he especially denied it.

Brian - Looking back part of me sort of was in denial, and sort of didn't want to accept the fact that it was going to change our lives.

Anna - So I didn't accept it at first and I spent a lot of time going through that process. I did inform myself well about the disease. I think some people don't want to know, they can't handle the information, I did want to know everything that I could find out about it and eventually processing that information for myself was a positive thing.

Helen - For most people there is a general process of getting to the acceptance stage. I've been through it all myself, but every now and then I still get the self pities and think why me, but that quite a natural thing to do and suppressing those kind of emotions is really not good for your psychological health or physical health.

Mieke - I have accepted the fact that I've got it, it won't disappear, it's there. But the hard part I find is that it's always in my mind, I'll never be not thinking about it. Because of the physical condition I feel that there is something wrong with my body, and that is the part I find hardest to accept.

Noel - I was given pamphlets on it and I've read up in the library, and I had all the symptoms - they're varied, because everyone's different - but I accepted it.

Antonella: I was still able to work and drive and do the things that I normally did, so it was pretty easy to accept it in that respect. It wasn't until later on that I started to get resentful about it and it did stop me from doing in life

Chris - For the next I suppose, seven years, I was able to go wherever I wanted, and do whatever I wanted to do and not consider my physical predicament at all. I still had numb hands and numb legs but I was able to walk without a walking stick and if I wanted to keep my predicament to myself then no one else could tell that there was anything wrong with me.

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