

# **My name is Jon. And this is my MS Story.**



April 2017

Dear Friend,

I've never written a letter like this before, but I wanted to thank you personally for your support of the Multiple Sclerosis Trust. Thanks to you, I am getting a new MS Nurse, and I can't even begin to explain to you how much this means to me.

## **Perhaps the best place to start is to tell you my story.**

My name is Jon. I am 43 years old and was diagnosed with MS ten years ago. It started with a loss of feeling in my left side. I thought it was all in my head, that maybe it was stress related. I had a six year old and a four year old to take care of at home, and a very demanding job at a local car engineering firm. Who wouldn't be exhausted?

My symptoms improved, so I just carried on as normal. Going to work, playing with the kids, big family get-togethers, the odd pint down the pub and supporting my beloved Manchester United at football matches!

But I was getting headaches and I was tired all the time. Something still didn't feel right. So when I lost feeling in my left side again, I sought help immediately, and after a week in hospital having tests I was diagnosed with relapsing remitting MS.

I was relieved at first – it was something to explain everything and I'd probably just need a few pills then be back on my feet again. But I quickly realised it wasn't that simple, and all I got from my neurologist was a quick "try this, don't do that, you'll be offered this, but do what you want" as they walked out the door. It was all so fast and went completely over my head.

I first met my MS nurse while still in hospital. She popped her head round the door and saw that I was struggling. What an understatement – I was scared stiff! She put me at ease immediately, provided reassurance, let me ask questions, and gave me her time when I needed to talk, just to say things out loud.

It still hadn't really sunk in. She told me "when you need me, I'll be there" and I remember smiling politely and thinking that I would be just fine on my own. But not long after I left the hospital, the reality of my diagnosis hit home and I was all over the place. How was I going to cope? Why me? How was I going to tell the boys? My marriage fell apart under the pressure and it was all too much. I have never felt so alone.

My MS nurse was a lifeline. She made me realise that I didn't have to deal with it all by myself, and she has been there for me ever since. When I have been hospitalised, she has been a friendly face when I have felt particularly vulnerable. And through every new symptom and change in medication, it has been my MS nurse who has pushed to make sure I am getting the care I need.

A blue circular graphic with a white border, containing the text: "It still hadn't really sunk in. She told me 'when you need me, I'll be there'".

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Like many people with MS, I've also suffered from depression and if you don't seek help things can spiral out of control. My MS nurse is someone to call during these times, someone who I know will get me back to a good place, and who will always go above and beyond to make things better.

In the years that followed my diagnosis, the boys and my work kept me going. Then about 3 years ago I was having to take more and more time off and I realised there was no let up from my relapses. I was told that I was now secondary progressive.

I had to leave work and started to use a wheelchair for the first time. I didn't want to. And somehow, having something physical that I relied upon made me realise just how much my own body was letting me down and that I had no control over what was happening. It was like being diagnosed all over again. I had spent the last 7 years coming to terms with MS, and this felt like I was back to square one. I was devastated.

Once again, it was my MS nurse who picked me up when I had hit rock bottom. Nobody teaches you how to be disabled, but she helped me to adapt. Little things, like I really wanted to be able to use the shower on my own still, so I told my MS nurse and someone came over the very next day. She knows how fiercely independent I am and how much this will have meant to me.

In fact, one of the things I treasure most about my MS nurse is that she helped me to see that my life isn't over, just different. I may not be able to get to see Man United as much as I used to, but I still love driving and music, and of course my boys – now teenagers! They have grown up with it all and have handled everything so well. I am so proud of them and how strong they have been.

No matter what stage of MS any of us are at, nobody should have to manage alone. I've tried at times and it is the worst feeling in the world. I consider myself lucky to have had an MS nurse, but my MS has changed so much and the future scares me a little.

There are of 1600 people in my area with MS, and I have seen first-hand the struggle my MS nurse faces to make sure everyone has the care they need. She works so hard and puts in long hours. And with an increasing number of drugs, and changes to how these are accessed and monitored, the demands on her just keep increasing. What if she no longer has the time to see me? Will I even be able to get an appointment? I am past the relapsing phase of MS, but I still need care and I still need someone to talk to. Perhaps now more than ever.



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**Knowing that there will be enough local MS nurses to get to everyone takes away this fear. I know that whatever happens, I won't be facing it alone. And thank god, as personally I know I would be in a very different place without them.**

Thank you for reading this. I really do hope that in writing to you, you will see just how important your support is in helping people with MS through the MS Trust. They are making a real difference - every single day – for people like me, maybe people like you too. And whatever we can do to help will mean they can do so much more.

Yours gratefully,



Jon Knight  
MS patient, Leicestershire