

Hello and welcome to my journey with MS. My name is Adam Smith and this is a personal story.

I'll make clear from the outset I have absolutely no medical training and everything that I say is just my understanding of the situation that I'm in, and what I'm going through. So don't listen to this and think that you can learn about multiple sclerosis from this podcast. It's more about just what I'm going through on a kind of weekly basis, and what I'm learning as I go. So I really want to make that clear that you should do your own research about this.

But the reason that I've decided to record this podcast is that I don't think a lot of people necessarily know much about MS. I certainly didn't. My knowledge was limited to what I learned from the West Wing because the president in that is diagnosed with it and I'm learning as I go. So, if you want to come on this journey with me then please do so, and tweet me any questions you've got et cetera.

I'll tell you the story first of all of my own personal situation. And it begins really in July of 2018 which is when I went to Portugal on my stag do. And one of the things that was arranged to be done while we were out in Portugal was to play five-a-side football. And during this five-a-side process I noticed that the more I was playing, the more I was struggling to focus on the ball and on everything around me.

It felt almost like I was getting double vision really, and in order to be able to counteract that I was having to play with kind of one eye closed or something wrapped over my eye, the more the match went on. The match ended, I was fine, I enjoyed my stag do very much and then that was it. I didn't feel anything else, any side effects, anything else at the time.

Fast forward about a month and I was at home and I woke up and the room was spinning around and it felt to me like when I'd had an ear infection a number of years before. So I booked a doctor's appointment and I went in because I didn't want to have an ear infection. I was getting married about a month later. And I thought the last thing I needed right then was an ear infection. So I went to the doctor and they checked me out and said there was nothing wrong with me in terms of my ear.

They said that they wanted to they wanted me to start using a thing called Beconase which was a nasal spray. Essentially that they said should be able to deal with any of the problems so that's what I did. I started using that and still nothing changed and I was still getting dizzy spells.

The best way I can describe it is if you've ever been on a boat for a prolonged period of time and when you've got off that boat it still felt as though you're on a boat. Even when you're on dry land you still feel like you're swaying from side to side. That's what it felt like for me.

So I went back to the doctors and they said well if the Beconase doesn't made any difference and there's still nothing wrong with me, they wanted to send me for a CT scan. So I went for a CT scan and that came back clear and still the symptoms were the same for me, and the doctor said given that it had come back clear the best thing that could be done next was to send me to a neurologist.

But he did say that the wait to see a neurologist on the NHS was likely to be about three months, and as I mentioned I had my wedding coming up and the whole reason I wanted to go to the doctor was to get a sense of how I could be back to normal for the wedding basically.

And I was in a fortunate situation wherein I had some savings and I was able to say to my doctor, well, I will go private to see a neurologist immediately.

So that was on a Friday, and I went to see the neurologist on the Monday of the following week. And he declared to me that I he thought I had migraines from everything I was telling him. He said you've got migraines, he said migraines aren't just about headaches they can have a thing called aural migraines where it affects your vision and so on. And he said that's what he thought I had and if I gave up caffeine, gave it a couple of weeks, I'd be pretty much back to normal.

But he said in order to rule out the possibility of there being an aneurysm in my brain he wanted to send me for an MRI. So I booked in to go and have the MRI done the following day. And when I had the MRI done, the lady told me that the consultant would have the results from the MRI by the following Wednesday, I think. And the consultants had actually told me but he wouldn't see me for a fortnight because he wouldn't have the results in time.

I'd originally booked an appointment for a fortnight and I changed it for just the following week and that's what I decided to do. And I then went about the process of giving up the caffeine. Now I don't have a huge amount of caffeine and there's caffeine in chocolate and I do have that and I used to have one cup of tea a day pretty much. And every now and again a coke but I really what I'm not somebody, I've never drank coffee. I'm not somebody that's had huge amounts of caffeine in my life. And my

god giving up caffeine was a horrendous. I had such terrible - what I would associate with actual migraines - really bad headaches that left me absolutely you know feeling like I was disabled basically. I couldn't move, I couldn't get up I couldn't do anything, I was just out for the count and they passed after a few days.

But the symptoms did not. I was still feeling like I was on a boat. If I did any kind of anaerobic exercise I would get double vision. So I went to my appointment the following Wednesday and beforehand my then girlfriend now wife - because the wedding has been and passed - we were sat outside waiting to go in talking about the questions we'd ask him about the migraines. When would I be able to go start having caffeine again, when would I you know be able to do all those sorts of things, how long would it take before the symptoms would relieve themselves. And we went in and the consultant said oh I've just been speaking to your radiologist you've got multiple sclerosis.

And I don't know whether it was the diagnosis or the manner in which it was delivered or what. But it felt like everything just moved away from me when he said it. I just didn't get it, I didn't get what he meant, I didn't understand how I could have that, what it meant. And I think I became a little bit , and he said you don't you don't need to be upset, it's fine, people live with multiple sclerosis, it's not a problem. And if I'm honest I don't really remember the rest of the meeting that I had with him, apart from the fact that he said that a colleague of his was a specialist in MS and worked at the private hospital in Liverpool, Aspire in Liverpool, and that he would recommend that I get to go and see him for a consultant because again it would take months for me to get to see him on the NHS. But if I go privately then I could sort of if you like skip the queue a little bit. So that's what I did. I went and saw him - by this point all of my savings were gone - and he essentially said you know, yeah, you've got multiple sclerosis.

Now for anybody that knows anything about MS, I'll tell you first of all how it's defined. And it's defined as a demyelination disease, which is one in which the insulating covers of the nerve cells of the brain and the spinal cord that send messages throughout your nervous system, are damaged. They're called the myelin sheaths and they get damaged, for numerous reasons they get damaged. The clue in the disease's title is 'multiple' sclerosis, and that's because the idea is that there are many attacks. And if you were to speak to a doctor, a GP, or you know whoever else you wanted to speak to, they would tell you that you can't diagnose MS off one presenting thing. You can't even diagnose it off a scan because the MRI doesn't necessarily show how often the attacks have happened.

So they will show what are called like plaques on the brain and that show up as white patches.

But they won't necessarily tell you, or tell the radiologist, when those attacks happened. So there could be 12 plaques on the brain but they could all have happened at the same time, or they could all have happened over 5-10 years, they just don't know. The only way to know through a scan is by injecting a dye which will make the newer plaques show up as a brighter white than the older ones which will show up as a sort of grey.

And so the specialist said to me, look if you've got multiple sclerosis, and I went in with a list of questions that - my friend is a GP - had told me to speak to him about. And I said to him, look, how can you say that you know when there hasn't been a passage of time. You know, normally MS is diagnosed over the course of a year or more because they wait to see what happens. And he - I'm paraphrasing a little bit here - but he essentially said technically that's right, technically you know you have to wait and all of those things, but I'm experienced, I know what I'm looking at and I'm telling you this is MS. I will still do all the tests, but this is going to turn out to be multiple sclerosis. And my thought on the matter was, I knew I have something wrong with me, I knew I was struggling with vision.

He made me do a test where I walked forward just one foot in front of the other. And I couldn't really do it without nearly falling over, and I hadn't been right for some time. I thought if I accept his diagnosis that this is multiple sclerosis, so move forward as if it's multiple sclerosis, and then do the tests to find out otherwise, in the meantime then I don't really lose any time. And we'll be in a position a month or two down the line where I can start to get treatment.

Whereas if I fight the diagnosis and say no it's not, I don't think it's MS, I want a second opinion, I want to do more tests, I want to do all of those sorts of things; then I might find myself two months down the line having proved it's MS, but then be two months behind the curve in terms of getting treatment. Whereas if I treated it like it was, did the tests, and found out it wasn't MS, then, you know, that's great, fine, wonderful, okay that's what it is. So that was where I found myself and it was a very weird place to be, as I'm sure you can imagine. Because I had a disease in which my body was attacking itself, and which was causing me all sorts of neurological problems. So I spent the next couple of weeks trying to accept it really, trying to get my head around the diagnosis and the idea and everything else, and in amongst all that I also had my wedding.