

THE ATTACHED TRANSCRIPT

And the MRI scan what did it show?

It did show that I had some lesions on my brain, which is how they diagnose MS, I understand.

So in effect you were diagnosed with MS, you presumably went back to the hospital, did you?

I did yes.

What did the doctor say then?

He basically told me I had MS and then has left me to deal with it over the past two months.

So more time has gone by without you seeing MS specialists?

I haven't actually yet seen an MS specialist.

Have you asked to see a specialist?

Yes I've got that in the next two or three weeks but it's actually taken two months for that to come through. I'm very fortunate to have a very supportive family but I think it would be fair to say that I was absolutely devastated at being told that I had MS and I didn't know anything about it whatsoever. And I've really found the hospital have not been any help. I've been told that I couldn't get to see anybody sooner because I just knew nothing about it, I haven't even been given a leaflet about what MS is or was and I've been very much left on my own to find out all about it and come to terms.

Has your GP been any help?

In fairness to my GP they've been very good but they don't know very much about it either and so really are unable to give me any kind of support or be able to discuss long term prognosis or anything like that.

So how has it felt Rebecca, it sounds from your story you've been frustrated in your search for information as to what's happening to you, frustrated at every turn?

Very frustrating indeed. Very frustrating. And it's very difficult to try and pull yourself together after being told something like that, to then try and set about finding everything out yourself about what is likely to happen to you and I think it's fair to say that it was probably a week or so that I just - I didn't know whether I was going to be in a wheelchair within years or what really.

Rebecca Linsale. Well I'm joined now by Mike O'Donovan who's the chief executive of the MS Society. Rebecca's concerns there Mike, well Rebecca's plight really, does that sound familiar?

From work that we've done John, Rebecca's plight sadly is very familiar. About half the people in her position are left relatively high and dry - they're told they've got MS by a neurologist, he's a very busy person, he hasn't necessarily got time to spend with them and then they have to cope with that decision on their own, information generally isn't available to half the people who get that diagnosis and they're left very, very frightened and disturbed.

Not even a leaflet - some people would say that almost beggar belief.

I'm afraid it does. We know that nine out of ten people who are diagnosed with MS essentially find out what they need to know on their own, many of them thankfully come to the MS society or to other voluntary groups and they find their way but that's not right because when you're diagnosed, someone's told you you've got MS, you know somebody who's got MS or you know people, you probably know it's a very variable condition, you don't know what's going to happen to you and that's the point more than any other when you need good information and it's generally not available. And I'm afraid it's still something where the NHS falls very far below what we'd like them to be.

Now your survey highlights these long waits to get this expert information from the likes of MS nurses and other MS specialists, what specialists are there available and why aren't they available more quickly?

Well there are obviously neurologists but the country has about, according to the British - the Association of British Neurologists, about a quarter of the neurologists it needs. Not all of those are

service framework for long-term conditions, which will focus on neurological conditions. But there's a great deal of work to be done. Of course we'r