
TX: 17.04.03 – SURVEY SHOWS NHS IS GIVING POOR SUPPORT TO PEOPLE WITH MS

PRESENTER: JOHN WAITE

WAITE
Almost half of all people newly diagnosed with Multiple Sclerosis say they're not getting adequate treatment from the NHS. A survey by the MS Society reveals poor levels of support and badly delivered diagnosis. Fewer than a quarter of the 3,000 people surveyed said they were able to access NHS Multiple Sclerosis services when they needed them most. And considering the impact that being diagnosed with MS can have this left many feeling fearful and helpless.

Well the National Institute for Clinical Excellence is due to publish a blueprint for standards of MS care later this year because it's so hit and miss at the moment. For example, one of the main problems that emerges from the new survey is that most people diagnosed in the last three years say they had not been given access to a specialist nurse, or even support worker, in the weeks after they were informed they had the disease. Like Rebecca Linsale, a 30-year-old solicitor from Sheffield, who suffered an attack in January of this year in which she lost the use of both her right arm and leg.

LINSALE
I saw the doctors to start of with and they referred me to an neurologist and they gave me some steroids to stop the rapid progression of losing my arm and my leg which was successful. But obviously I wanted to get to the bottom of what was causing this.

WAITE
Did you suspect it might be multiple sclerosis?

LINSALE
No I had no idea at all. Maybe that was very naïve of me but I really didn't know.

WAITE
To find out whether it was what would you have had to have done?

LINSALE
I had to have an MRI scan.

WAITE
And this MRI scan - was that provided for you?

LINSALE
No I was actually told that an MRI on the NHS, albeit urgent, I was going to have to wait about four or five months. So I chose to pay privately.

WAITE
And the MRI scan what did it show?

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

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

LINSALE
I did yes.

WAITE
What did the doctor say then?

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

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

LINSALE
I haven't actually yet seen an MS specialist.

WAITE
Have you asked to see a specialist?

LINSALE
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.

WAITE
Has your GP been any help?

LINSALE
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.

WAITE
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?

LINSALE
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.

WAITE
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?

O'DONOVAN
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.

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

O'DONOVAN
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.

WAITE
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?

O'DONOVAN
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 specialists in MS. So there's a shortage there. When you've seen the neurologist the kind of person you need to see is probably a nurse who can talk to you slowly about the condition, tell you how it's variable, what might or might not happen to you, how to cope with it. But we estimate there are about a 120 MS nurses, MS specialist nurses, throughout the country, we probably need two to three times that number before people with MS will have access, particularly when they're diagnosed, to someone who can help them to cope with this terrible condition.

WAITE
Well the Department of Health issued us a statement and it says that the DOH welcomes the report from your society - the MS Society - and I quote: "We are keen to improve services in this area and there are currently a number of initiatives underway. These include the national service framework for long-term conditions, the risk sharing scheme for beta interferon and the forthcoming guidelines from NICE - the National Institute for Clinical Excellence - on the management of Multiple Sclerosis." Are you reassured by any of those initiatives?

O'DONOVAN
I think we're reassured that they're happening. But what our survey shows is the size of the task they've got to address. The great majority of people with MS don't get the service they need when they need it. We're glad that NICE is going to issue the first guidelines for MS in June. I think our survey will show the size of the problem those guidelines have got to address and the need for better practice throughout the country. We're very pleased that in a year or twos time there'll be a national

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're glad these things are happening, we're glad that people are getting the disease modifying drugs but we're coming from a very low base and our survey points out just how much work needs to be done now and in the near future.

WAITE
Mike O'Donovan from the MS Society thank you very much.