How is MS diagnosed in young people?

Eden: Hi, I'm Eden. I'm 18 years old and I have MS. In this video we're going to be talking about how MS is diagnosed in young people and explaining a bit about the tests are usually done.

I was diagnosed when I was 14. My first symptom was double vision. I had a chat with my mum and dad and they took me to my local doctor, who's also known as a GP. My doctor asked me a lot of questions about the symptoms I experienced, like when they happened, if they're getting better, worse or stayed the same. The doctor then tested my blood to make sure my symptoms weren't being caused by an infection or because I wasn't getting enough vitamins.

Then my doctor sent me to a specialist children's doctor at a hospital for more tests. This doctor is called a paediatric neurologist.

Cheryl: Hi, I'm Cheryl Hemingway and I'm a paediatric neurologist. That means I have a special interest in children and young people's brains and spines and problems that can arise with those children. I'm here to explain a little bit more about the different tests that we use when we diagnose multiple sclerosis.

Eden: When I first saw my neurologist we had a chat about the symptoms I'd been having. I'd been keeping a symptom diary to take with me so I didn't forget anything important, then the neurologist did some simple tests, known as a neurological examination, to check things like my vision, reflexes, strength and balance. Cheryl, can you explain a bit more about these tests?

Cheryl: So a general neurological examination takes generally about 10 to 15 minutes to do thoroughly and each part of it we want to test a different part of your brain and spine.

So we'll be looking at your cranial nerves, we'll check how your eye moves, we'll check how your pupils respond and make sure you haven't got any double vision and if your face is moving symmetrically and your tongue is moving normally. We'll then test your motor power and strength and your reflexes which gives us an idea of how the signal from the brain is being sent down to your arms and legs. We then test normally the back of the brain, the parts that give you balance and we'll ask you to do that funny finger nose test which I'm sure you've done lots of times. And lastly we'll want to test sensation to make sure that you can pick up sensations such as vibration, which we know can be vulnerable in young people with multiple sclerosis, and position sense that you can test whether your toes going up or down. I'm sure you've heard all of those tests done.

Eden: After this I had an MRI scan. Cheryl, can you tell me a bit more about why an MRI scan is carried out and what it's looking for?

Cheryl: So an MRI scan is magnetic resonance imaging and it's a really useful test for somebody with multiple sclerosis. We are looking to see exactly what is happening inside the brain so it gives us a really good picture of the different types of problems that can happen in a brain.

In multiple sclerosis we can see areas where the fatty covering, which is the myelin which covers the nerves, has been removed from the nerve. It comes up as a slightly different colour because the water is different and when we take a picture with an MRI machine we can see those areas where the myelin has been removed. So if you're having symptoms, for instance double vision, we can look and see where the part of the brain where your eye movements are to see if there's any area where that myelin has been removed.

So an MRI scan for us is really helpful. It can help us making the initial diagnosis and it can also tell us how well your treatment is working.

Eden: That's really interesting but can you explain what's involved and what it actually feels like for someone who's never had one before?

Cheryl: So you'll need to come into a hospital to have your MRI scan. Most of the time you'll come in at a time that suits you. You will be asked to change into a gown. You will be asked by the radiographer and your mum and dad will be asked whether there's any metal in your body and you'll be asked to remove any metal earrings or any piercings that you've got so that it's safe because actually it's one big magnet.

Once you go into the room it can be quite noisy so you'll be given earmuffs to wear and you'll lie on a bed in your gown. You can have a blanket over you in case it gets chilly and you'll have blocks on either side like little pillows on either side to keep your head still because it's really important that you lie still because even small movements can make a big difference in the quality of picture that we get.

The bed then moves slowly into the MRI machine. It can be a little bit frightening because it is noisy and also it's quite a small space. Most hospitals now have videos that you can watch and you can choose your favourite movie to watch or you can listen to music and you also always have a buzzer that you can call if you feel scared and you should be able to take your mum or dad or any friend that you want provided that they're safe to go into the MRI scanner.

Eden: Thanks Cheryl. My experience of an MRI scan was, of course, at the start very daunting, however I had my mother with me and it comforted me and I was also able to watch my favourite movie, High School Musical, while I was doing the scan.

I also had another test where little patches were stuck on my head and I had to watch TV patterns on the screen. I think this was called a visual evoke potential test. What's this test looking for Cheryl and what is it like for someone who's never had one before?

Cheryl: Yes, you're absolutely right. It is called visual evoked potentials or VEPs for short and what that is really doing is looking at how your optic nerve, which is the important nerve at the back of the eye, is sending the message through to your part of your brain which interprets the images that the nerve is sending.

So what will happen? You'll come in normally to the ophthalmology department and they will put a number of electrodes on the back of your head. It's not painful but it is quite sticky and you'll have to afterwards wash your hair really well to get the glue off. They then sit you in front of a screen. The whole test takes about 15 minutes and they're little patterns of black and white images that come in front of you. You need to sort of watch those and then the little electrodes, which are these little markers at the back, will pick up how the signal is moving from the eye through to the back of the brain and we look at the speed.

It can be very helpful to tell us whether your optic nerve has had any damage and whether there's any slowing in how the message gets through to the back of your brain.

Eden: Thanks for explaining all that. Are there any other tests that you might need to have?

Cheryl: You may also need to have a lumbar puncture. This is a test where we take a small amount of fluid that is surrounding your brain and spine from the base of your spine. We then send this off to be analysed in the laboratory.

Eden: It sounds a bit scary! What actually happens during a lumbar puncture?

Cheryl: Now I know it sounds quite a scary test but actually well there's always going to be somebody with you and we can talk you through exactly what would happen.

So again you would need to come into hospital. You would normally come in during the day. You can eat and drink because most of the time you will not need to have this under anaesthetic, especially somebody who's older. They can cope really well with the test being awake. We will though however put some numbing cream on your back and you'll change into a robe so that you out of your street clothes. When you're ready and the numbing cream's been on for about 20 to 30 minutes, you'll come into the room, lie on the bed on your side. You'll feel people sort of touching your back and feeling for the right space and then you'll get given a local anaesthetic injection. You'll feel the prick of the injection and then the doctor will come along and put a needle in at the base of your spine, so it's below where the spinal nerves have stopped, and we put the needle in and take about two to three mils of fluid (which is called the cerebral spinal fluid or CSF) into a couple of little jars to send off for testing. The needle is then taken out and we will clean the area again and put a plaster on so it stays clean.

You need to then lie down, keep yourself quiet and just rested for a couple of hours and drink lots of fluid. Sometimes we notice people can get a headache afterwards or complain about a bit of bruising but most of the time it's not nearly as scary as it sounds.

You had a lumbar puncture, didn't you? Can you tell me a little bit about how it was for you?

Eden: My first experience of a lumbar puncture wasn't as terrifying and horrific as it might sound. It barely differed from the traditional blood test. I didn't actually have any back pain or headache after the test had been done.

The important thing to remember with all these tests is that you can have someone like your mum or dad with you when they're being done so you won't have to be alone.

One last question for you Cheryl... why are there so many tests needed to diagnose MS?

Cheryl: Well as you know, when you get given a diagnosis of a condition such as multiple sclerosis it really does change a lot of things for you. It's a really important diagnosis and it's important that we get that right. So what we want to do, especially when somebody's very young, is look for things that can present that looks similar to multiple sclerosis but aren't, such as some of the infections or some other demyelinating conditions that can look similar to MS. We also want to make sure that we have the diagnosis correct.

Eden: Thanks for explaining all of that Cheryl. Hopefully you're a little bit clearer now on the tests that are usually done if your doctor thinks you might have MS, why they're done and what they actually feel like.

After you've had these tests, you might have some questions you'd like to ask your neurologist like, how long will it take to get the results? What happens next? Is there anything that can help my symptoms while I'm waiting for these results?

Don't be afraid to ask these questions or bring up anything else you're worried about. Your neurologist is there to get to the bottom of what's causing your symptoms, but also to help you and support you throughout this entire process.