What’s it like having a parent with MS?

Ella: Hi, my name's Ella. I'm 13 years old and I live with my family and my dad has MS.

Matthew: I'm Matthew. I'm 15 and my mum's had MS for six years now.

Alex: I'm Alex and I'm Matthew's brother and I'm 13.

Finding out about your parent’s diagnosis

Ella: I wasn't really told that my dad had MS. I just worked it out because from a very young age I could see him injecting himself with obviously the medicine he used, so I kind of figured out something wasn't quite right so I just asked him what it was all for. The first things that popped into my head were, was it life-threatening? How would it affect his everyday life? Would it get better? Would it get worse? Would it go away? Stuff like that.

Matthew: It was after a half marathon. She collapsed about a kilometre from the finish line and she then spent three or four weeks in hospital. We didn't find out until she got out that it was highly likely she had it.

Alex: I didn't really understand what it was.

Matthew: Yeah, we didn't really know what it was or how it would affect us, but given she'd been in hospital for quite a while, we weren't confident it would be good. We got told by our dad actually what it actually was and how it'd probably affect us around the house.

What emotions did you go through?

Ella: I definitely felt sadder and more worried for him because then I knew that he always had to live with it and I found I got a bit angry because it was like he couldn't do as much as I thought he could do when he first realised.

Alex: Well we were quite surprised at it and we didn't really understand what was going on.

Matthew: Of course you'd feel worried when you see that your mum's been in hospital for a while, but yeah we were definitely anxious. But once she got back it was a relief.

Who did you feel most comfortable turning to for support?

Ella: For support, I think my whole family was there to support me. Obviously my brother Archie was much younger and he didn't really know what was going on so I kind of had all the thoughts going through my head. My mum was really good but my dad was the one who talked about it and if I had any worries I would go to him about it because he was the one with it.

Alex: Our dad.

Matthew: Yeah it's always your parents. Always most reliable.

How did you learn more about MS?

Ella: I asked my dad what it is really and he explained that it was like a wire so it's like there’s the nerve agent in your brain, or the nerve in your brain, and it wears away so the inside kind of comes out. I found that really useful.

Matthew: Yeah, we weren't entirely sure what it meant so we didn't really know how to feel, but through some of the MS trust publications we gained better understanding. It's very helpful when you realise this is why she's tired, this is why she's got to lie down, or this is why she can't do something at some time. It helps you really just to understand what she's going through more.

Has family life changed at all since your parent’s diagnosis?

Ella: Well, no not really. Dad still messes around a lot and he still manages to play football with me and my brother, so not really. He just needs a bit of help here and there when he looks down to fold washing and stuff. I help him with that.

Alex: It's just meant that we can't do as much as quickly anymore and she has to take a rest sometimes.

Matthew: You just have to pace it and understand that sometimes she won't be able to do things, sometimes you'll just have to stay in or you'll have to do things without her. But it's only maybe once a week or something.

Alex: Sometimes we tell her to take a break if she's just not taking breaks and trying to do too much.

Matthew: She needs to slow down sometimes because she has got MS and sometimes she forgets that herself. She's going to harm herself if she just does too much.

Do you have advice for other young people?

Alex: You've just got to remember that you can get over it and try and keep life as normal as possible.

Matthew: Once you get over the shock if you just talk everything through and you're comfortable with everything that's happening it's just getting back to normal really.

Ella: Well the best thing to think is they're still the same old them, they haven't changed. Just because they can't do as many things doesn't mean they're not there for you and you can't still have fun times with them.