

How MS makes you feel

Diagnosis

Chloe: Sad, angry. I was very depressed at the time, actually, as well. I think, I was very, very depressed. I didn't know what it was at first. At first I think I asked about, like, seven different doctors if I was gonna die. 'Cos that was, like, my main thing. 'Cos I was sat there going, like, what was I gonna do now. Am I gonna die? And obviously they said, you're not going to die, 'cos it's not, like, a condition that can end your life. So I think that was, like, a bit of a relief, but I guess I just kinda learnt a deal with it, in a way. I felt like I just learned that this is how I am. This is how I feel. And I'm gonna have to sort out, manage the pain, manage my stress, then try and sort it out.

Haley: I think we were, we were really shocked, weren't we, as the only people I'd known diagnosed with it were a lot older. So I didn't put it towards a childhood illness, so that was quite...

Matthew: Yea

Haley: It was really shocking. I think was the first thing.

Matthew: So, didn't know enough about it.

Haley: No, we didn't have, you know, the only thought we had was, you see people in wheelchairs and that's how you think it's gonna be. But the more we learnt the more you realise that's not all there is...

Matthew: No

Haley: To it, is there.

Deon: Initially, when she was diagnosed, I was angry that it had happened to her and frustrated because she's my mum and I didn't feel like, well, she doesn't deserve it. No-one deserves it, but over the years we've, sort of, learnt to cope with it and to not be frustrated. To just deal with it and take each day as it comes, because we felt that there's no point feeling anger towards something as it's not gonna change it.

Life with MS

Chloe: MS may be, it's a part of me, but it doesn't control me. Like, I can do whatever I want, whenever I want and it doesn't stop me. It's just, I'm gonna have to, the next day, I might have to, like, not do as much as I did the day before. Or, do as much as the day before, but just take, like, make sure I have

painkillers with me, make sure that, you know, I at least rest throughout that day. Like, I still go out with mates. I still have fun. I still do things that a normal teenager would do.

Haley: So, it can be quite difficult, but being honest, being open, discussing, you know, how you feel that day and asking, you know, getting Maddie involved in as much as we can and teaching Maddie as well, isn't it, about, about everything that she, you know, needs to know. It's her life. It's gonna, what impact it's gonna have on her. I think everybody having some understanding and always just being there for each other, really. You try not to wait around to do anything now. You just get out there and you just do it. It's made us appreciate so much more, hasn't it, for both of the children, for Maddie and her sister. We've, we feel really lucky to be surrounded by, like, the school that we've got, the family that we've got, the hospital and all of those type of people. If you can feel lucky, than I think we are.

Deon: We've had to make changes and adapt to help mum with her MS. So, we used to live in a different house, which wasn't disabled accessible and, initially, that was fine, because mum's MS wasn't really bad and she could still walk and do all things that normal, well, able-bodied people, can do. But as it progressed we had to make changes, so we, as a family, moved to this house that we're in now. And here we have a ramp for our front and back door, so mum can get in, in her wheelchair. And we also have a stair lift in this house and, like, wider doorways, so she can fit through in her wheelchair. And we all come together so, on a Monday she still loves to work and she works for a Slimming World group as a consultant. But she can't do everything on her own, so nan will come and I will come, and we will help and we will, like, put out the tables and the chairs and help do the physical side of it that mum can't do.

It's good to talk

Chloe: I talk, I talk a lot to my mum, about how it makes me feel and how sometimes I can get, like, upset with myself, over anything. 'Cos it, it's very strange, just of how, like, your emotions can go from, like, just from, like, being sad to bursting out in tears, in, like, two seconds. But, yea, I mainly talk to mum and I talk to my friends. I even talk to my boyfriend about it.

Deon: I'd talk to my mum, dad, brother, nan, grandad, all of us together as a family, we can talk to each other. So my brother, he's younger than me and he likes to talk to me sometimes about it if he's worried or something, if he doesn't want to talk to mum about it. And, like, if I'm worried or, I don't want to speak to mum or dad because I'm scared that I'll make them worried about me worrying, then I know I can speak to nan or grandad and that, as a family, we can all speak to each other.

What's your advice?

Chloe: Not to let it, like, worry you. 'Cos it will come at a point where you will think, like, you know, am I gonna have another relapse, or what's gonna happen next? But, I've kinda learnt, if it happens, it happens. Just do as much as you can with the time that you've got. And don't let MS control you, or don't let it stop you. Don't think, "I can't do this because I've got MS", 'cos it gets really annoying, especially if you hear people go, "Oh, be careful, you've got MS". 'Cos then you think, well, no, it doesn't stop me. So don't let it stop you from doing what, what you wanna do.

Haley: Remember, you are still normal and you're the same as everybody else and you've got MS, but MS hasn't got you.

Deon: Find someone you can trust, to talk to, whether that be a friend, a teacher, family member. Whoever it is, speak to them and be honest with them, and if you're having a day, where you just want to go talk to that person and cry, then you find the time to talk to them and cry, because bottling up all of your emotions is one of the worse things you can do. As it will play on your mind and you might over-think things, whereas if you speak to someone you won't have all of them worries, because they can explain to you and you can get a better understanding of it all.

Voiceover: All the emotions described in this video are completely normal. The important thing is to be open about your feelings and not suffer in silence. There's so much support out there for you.