

Ian and Deanne

Early signs and diagnosis

Ian

It was a number of years ago when I first had symptoms, and it started with my speech and my swallowing. I knew there was something also fundamentally wrong with how my body was working, so I knew it wasn't an isolated thing. I thought it might be MND or Parkinson's. The doctor referred me first of all to speech therapy, and the speech therapist came. She helped me a lot and she referred me to ear, nose and throat and also neurology.

So I went through quite a few tests. I finished up having a biopsy on the back of my tongue and I had MRI scans and then when I went to neurology, they asked me what I thought it was and I said MND.

I thought it was a good way of approaching it because they didn't come out with it. It was me who diagnosed and to be quite honest, I was relieved that I knew what I was up against. I do think if there was a way of diagnosing, earlier, it would have helped.

Deanne

I sort of half expected them to say it was something else. I know as I looked at Ian and I saw the – I saw the relief on his face. And I think that any questions I had were between us afterwards when I sort of, we were, we were trying to just answer our own questions. If you like, you know, what do we do now? Trying not to think too far in the future, but also just trying to be positive as we could and put in place things that Ian needed.

Ian

Well, we had a meeting with our daughters and we talked it a bit through with them and then we got in touch with our immediate family and also our friends. We met up and spoke to them about it.

Deanne

And I think really because our friends already had an inkling and knew we were going to the hospital and knew Ian was having tests, that to actually approach it with family and friends was probably easier. Because they sort of – I think possibly our girls knew that you were thinking down, that you, you know, you got that thought about MND in your head anyway.

Ian

It was obvious that they've been looking up symptoms.

Deanne

Yes.

Ian

And they probably knew more about MND than we did.

Deanne

I would say depends how you feel when you first, I mean, I to me it was a little bit of a shock. So there's that to deal with. And you might want to cry, you might not want to. And Ian said, said don't cry. So I didn't. And I sort of thought, right, OK, let's just get on with this now.

If you've got someone to talk to, talk to them. Might not be the person with the MND because you might just need some time and space for yourself as well. And usually, I mean, it depends on circumstances. Some people are all on their own, some people haven't got family around them.

If you've got family, use the family and use distraction. But also don't forget that professionals, they're really that. And the ones we've dealt with are so professional and so caring and really want to help. In that moment when you've had news like that and it's a shock, can't just think of everything you want to ask, make lists.

Ian

And just like say, also thinking about diagnosis. It might seem as though it's the end of the world, but you go home, go to bed, you get up and your life hasn't changed. And it's not running into a wall. It's a thing that you can gradually deal with.

Deanne

We're just really grateful. We're grateful to be where we are and the age we are because there are so many people that are younger, people who are on their own. And we're so grateful for the support we've had. And I mean, the team are absolutely amazing.