Meena
Early signs and diagnosis

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So our journey has been a little bit more different. We weren't aware of the first symptoms of MND because my dad also has type 2 diabetes. So our initial assessment was because of a spot he had on his back, which we thought was sign of a neuro damage – which sometimes happens with type 2 diabetes.

So we went to the GP who then referred us to a neuro specialist who conducted a lot of nerve testings and, as a result of which, then we were told that dad has MND. And it was only after the initial diagnosis by the consultant and then us being referred to the MND clinic who were brilliant.

And it was only at those conversations that we realised Dad had had a lot of those symptoms probably a year before, which were the slight tremors under the skin. So kind of we describe them as if, you know, you see like a little alien crawling underneath the skin, that kind of, it's very weird.

Cramping. He had a lot of cramping initially just in the legs, but it did eventually start to spread across the body, which we believe is actually a common MND symptom, now. Dad has ALS, so his symptoms predominantly start started on one side of his body, which is his left-hand side. And so initially his shoulder was affected and for a long time he was constantly diagnosed with frozen shoulder which just wasn't going. And then after a year we realised it just can't possibly be frozen shoulder and so that's how we progressed.

The initial delivery of the diagnosis was clinical, but not necessarily personal. And I think that really left a scar on my father because the initial diagnosis was just so, as I said, clinical. But very brutal as a layperson. It made him nervous about knowing anything because it just makes him worry. Whereas I'm more kind of I need to know so I can make the necessary moves that's required.