

## **Meena** **Genetic testing**

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So we have been approached by the MND clinic to consider genetic testing. And initially my dad was very kind of worried about it.

So he took his time to make a decision, called the whole family and kind of said, you know, what do you guys think? I don't know what to do about this. I'm really worried. And I think he was concerned that if it was a genetic thing, you know, he'd feel guilty that he's somehow responsible for potentially passing the genes to his family. But we're, of course, I don't know how we managed to be so different from Dad. We just were just like, whatever it will be, will be.

So eventually we did get him to get the genetic testing, which was really useful, although unfortunately, it wasn't genetic. So fortunately, unfortunately? I'm not really sure.

Dad was relieved because he didn't have the burden of worrying about it passing down to his children. But yeah, it's nice to know. It's nice to know. I mean, they were very, very careful in how to phrase it for my father. And they were really very sweet.

They offered a lot of information around it, explained that it can take a long time for the results to come through because it's so detailed.

So dad didn't feel rushed into making a decision. He had a long time in between and he asked a lot of questions to try and find out, you know what, what would it involve? Is it just a blood test? Is there anything else?

I think the team were really very good in how much information. I think they gauged it perfectly and they and they gave just the right amount of information without overloading him. And yeah, he they did give him a lot of information and he was quite comfortable to make that decision.

I think he just wanted to know whether it was just him that needed to have the tests. He was concerned that we would all get dragged in to have, you know, blood tests and poked and prodded around, and he didn't want to put the family through that.

But the team were really, you know, sweet and explained the process. Now, it's just you initially and then, you know, if anything comes out, then we can take it to the next step. At this point, it's just to figure out whether this is a genetic MND or if this is a non-genetic. And dad was saying, well why, why does it matter? What difference does it make? And they were very good explaining what the differences were. So yeah, it was, it was useful for him to know.

He struggles a lot with new information as well. So he sort of took it back and then fired off a lot of other extra questions. So he was very worried about what the actual test would entail and whether it would be for all of us or just himself. But luckily it was just him and it was just a blood test, so he was happy.