

Meena

Emotional and psychological support

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So my dad, my dad is very sensitive. Asian families are very, especially the generation that my dad comes from, they are not very good at recognising, asking for help, or recognising where they are maybe needing help or feeling weak or not strong. You know, I think it's kind of inbred that they should be very strong. And so dad found it very difficult to accept all the changes that would entail to his lifestyle, to his health.

And I think the worst thing for my dad was because he's always been fiercely independent, it's the losing his independence that hit him really hard. He was very, very down for quite some time, took a long time to get him back up to kind of seeing the positives. And so it's yeah, it was very tough on him, but he is a very sensitive man. And I think it's been a hard journey for him.

The massage therapist actually suggested dad befriend another client of hers or another patient that she was dealing with, because she noticed in the conversations that they had similar interest, namely travelling. My dad used to love travelling before the condition, he still does. So she suggested dad speaks to this other gentleman that's always been very nervous about meeting other MND patients, because he was concerned about what he would see and how that would affect him.

You know, he wanted to kind of live day by day rather than kind of seeing a mirror of how bad it could be in future. But luckily we did a video conference after much, much discussions with the MND team and also the therapist. And that has been a godsend for my dad, you know, because the share of the interests obviously got the conversation going. But then as part and parcel of that, what happened was they were naturally discussing their symptoms, how they were feeling. What aids are we using? So a lot of useful things have come up and it's been an emotional support key.

That's the key thing for my dad, it's having somebody who understands how he feels because they're also living with MND. And I think that's been the most useful suggestion ever, and it's helped a lot. I think for me personally, it's an emotional roller coaster.

I've grown up seeing my dad as this great big strong character and has made me who I am today, like the strongest man I've ever come across in my life. I hope my husband doesn't mind me saying that.

But seeing his initial reaction to the diagnosis and because neither of us really had enough information about it. And imagining the immediate worst outcome of that scenario, which was, we were told he was going to die. There was no kind of, you know, this is a progressive condition. So that initial shock kind of was very hard for me to deal with.

And seeing my poor father struggling with having to depend on me and losing his independence, that was very difficult because it really changed him, you know, as a person. I saw him shrinking.

And that's not an easy thing for a child to see their parent in that situation. And it continues. It's never going to stop because, you know, as soon as we stabilise for a while and then he gets worse and then he kind of gets shaken a bit, a little bit more again.

So it's difficult because I have to control my emotions so that I don't, if I look nervous, dad's just going to be falling apart and, and trying to do that while you're still trying to care for someone is a very difficult thing to do.

It takes it out of you too. But on the flip side of that, I'm just grateful because my dad's done so much for me my entire life. Like I literally wouldn't be here today if it wasn't for him. So that the chance to be able to repay him, not repay him as such, that's the wrong word to use, I guess. But to be able to be there for him when he feels weak, He's not, but he feels it.

So sorry, I'm going to get emotional. I think that's the hardest thing is seeing him like that. But I obviously can't be like that with him because then he gets worried that he's putting all this on me and that's not what it is. It's just seeing him really suffering and there's not really much I can do in terms of the physical anyway.