

Meena **Managing symptoms**

Meena

It's generally, I just show him how far he has come and because, you know, he initially he was so scared and so worried. And, you know, he was diagnosed in 2017-18, so we're kind of what, 8-9 years down the road. And he has lost his upper limbs almost, well, one and a half arms, I say, because he still has a little movement on his right hand. And you know, in that length of time, there have been people that have unfortunately progressed a lot further.

And also I kind of continue to push him to do things that he's always liked, like the travelling. He was really upset because he felt like that's it. I'm never going to be able to fly again. I'm never going to be able to travel anywhere in the world. And since his diagnosis, I think we've been to Egypt, we've been to India, we've been to, I don't know, loads of in Greece, Italy, France.

So I think for me it was important to continue to support his interests, to make him feel life isn't finished until it's finished and you can't just give up. You have to keep fighting.

And it's just realising that you have to do things differently. I think that's the thing that's really helped him understand, is that it doesn't mean he can't do anything at all. It just means that he has to do it slightly differently.

And once he's... once we started travelling again, it made him realise, yes, it's not as comfortable because it's a bit more long winded. You have to get to the airport a lot earlier than you normally would. And then you get the kerfuffles you get with the planes, where they put you in the back when you're supposed to be loaded from the front, and all the fun that comes along with, you know, accessibility. But at the end of it, he gets to spend a week wherever he's gone.

So and, you know, the world's becoming very acute... sort of familiar with accessibility all around the world. And it's just been no hassle at all.

We've been able to do... there's few things that he can't, obviously he can't jet ski anymore, that would be a bit difficult. But Dad was never really a jet skier anyway. So yeah, I think it's, it's just showing him that he can still do things that he wants to do and he shouldn't let the condition tell him not to do what he loves to do.

That's what's been the key, I think, because I think initially in his head he just kind of thought, right, that's it, I can't do anything anymore and that's not the case.

Then my brother took part in the London Marathon. There was a lot of people there that were supporting the charity, and people were actually running the marathon in wheelchairs. So seeing all of these kind of things, you know, I kind of encourage him to get involved in these things because he can then see that life doesn't have to end just because you've got a condition that limits you. Yeah.