

Geeta and Sheena **Emotional and psychological support**

Sheena

So what's your advice for someone who has MND?

Geeta

My advice is enjoy your life. Don't think about the future. Just take it what's coming, day by day. Do whatever your dream is, just whatever's best.

Sheena

Whatever you. Whatever your wishes are. And your dreams complete while you're well. Don't be scared. Live your life for today. That's what you're saying? Yeah.

Whatever's going to happen is going to happen. You can't prevent it. So enjoy. Now, as difficult as it is. Yeah, yeah.

Geeta

Because you. You can't change...

Sheena

You can't change it. Yeah. So I think we touched on this yesterday as well. Whatever's going to happen is going to happen. Try not to think about that and get overwhelmed with that, because you're wasting precious time today, enjoying things that you could be doing and discussions and that happiness today. Yeah.

Geeta

Go out drinking.

Sheena

Go out drinking. Yeah.

Geeta

Enjoy yourself.

Sheena

Enjoy yourself. So when we actually went on this pilgrimage, we took mum on business class and mum was like, "take me to the bar". And then she pulled out the menu, and she was like, on this trip, I'm going to have every cocktail on this menu.

So I thought she was just saying it, but she did. She had every cocktail on that menu on the way there. And on the way back, I think the call button was pressed every few minutes. And I was mom's medical escort, and I was thinking, how is she going to be?

Geeta

I'm not an alcoholic.

Sheena

She's not an alcoholic.

Geeta

But I enjoy a drink.

Sheena

She does enjoy.

Geeta

We had a brilliant time. After a few drinks.

Sheena

Yeah. After, after a few drinks. It was challenging trying to get mum there because we had to go through her medical testing.

She had to be in flight tested, and we needed oxygen on board, so arranging that was really stressful for me, but it was worth it.

Geeta

Yeah, because two days before.

Sheena

Before that, we were in—

Geeta

We were going to go, leave, but things happened.

Sheena

Yeah, because mum was in hospital and said she wanted to go, but she was crying that she wasn't going to make it.

And I'd said, if you just get yourself, well, we will go. And one was like, how am I going to sit in the seat because I'm immobile? How am I going to do this?

And we were like, it's fine. We'll find a way. We normally travel economy. We'll, we'll go business so you can lie down. We'll get everything in place.

So we'd book the tickets and it was only two days before that we got the, the go ahead to go. So I told mum...

Geeta

One of my daughters, was against it. But it was one of my wishes. So I'm glad it got ticked off.

Sheena

She thought once mum's ticked that off her bucket list, she's not going to come back. So yeah. And I also think that's why mum was so well and then ended up in hospital the day after we came back, just to prove a point, that I came back and I said, that was you being stubborn, was it?

Geeta

I came back and said, "I promised I'd come back".

Sheena

Yeah. Promised I came back. But yeah. You can't change what's happening. As frustrating as it is. And look after each other. Try and be understanding and patient about how each of you deal with the diagnosis, because that's something we struggled with.

We all manage very differently. It led to a lot of arguments because we weren't understanding the frustrations that each of us were going through.

Yeah, it does feel really unfair. Really unfair, but... Get a PEG fitted, a RIG fitted early on if you're well enough. There is a lot of help and support out there. You just need to find the right organisation.

And there's lots of help and support from other patients and families. It's just about trying to network and resource where they are and how you can access that. And you're not alone.