

Ian and Deanne

Emotional and psychological support

Ian

I can't cry now. Ever since I've had the symptoms, even if I wanted to cry, I know I couldn't. It's strange.

Deanne

I was trying to do lots of things for everyone and we did some activity that made me realise that actually if I try and do that, I've got to think of what my priority is because otherwise I'm going to not achieve any of what I'm trying to achieve. Whereas if I think, well, what's my priority? Where am I going to go? And that was really useful. It really made me think, right, okay, I need to do something about it.

Ian

And also the sessions with the psychologist helped us realise that we were trying to live the new normal life. But it isn't a new normal because things are changing and the red lines move. We've got lots of safe places like the local cafe because we can get there easily, our garden, our daughter's house. So the safe place makes us able to live our life better.

Deanne

And it's like when you walk outside the door and immediately something happens inside your head that makes you feel better, you feel happier, feel more relaxed. And that's why when we go just for a short walk and try and try and break it up, obviously with a rest somewhere, that when that's why when you come back, you say, well, I'm really glad we did that.

When with when we had meetings with the psychologist that she made me think about myself as well. And because obviously it's important that I look after my wellbeing so that I can be there for Ian. So yeah, it was important. And that was quite an emotional time because it's letting go of that independence.

Ian

And also I think as a mechanism you desensitise yourself from these things because it would have alarmed me to talk about not being able to pull my trousers up, which I can't do, I physically cannot do. And at first it, it really upset me and it was traumatic. But now I'm desensitised.

Deanne

And I'd say, look, come on, we've just got to get on with this. This is how we've got to live now.

And I'm with you because at the same time, you're grateful. You're grateful that we've got each other that that you're not on your own, that, you know, you've got support and we've got a wider family support and I think that's really important as well. That helps – helps you to keep positive.

There's a lot of sadness and it in a way that sometimes that's difficult to overcome, but other times, you know, you think, right, okay, come on, let's not go down that path. Let's, you know, let's either distract ourselves or, you know, try.

And it's, it's difficult for me because if Ian's really down, I never know whether to try and jolly him along or whether to just let it let it be and let him just okay, this is how I'm feeling and just let it be and, and come out, hopefully come out the other side, which he usually does.

But, and sometimes if I'm trying too hard, he'll say just leave me alone and get a bit, you know, frustrated with me and I think, okay, and I just walk away. But yeah, but it, that doesn't happen very often. But you know, it's how to deal with those things. It's really difficult.

Ian

I've just got a mind where if I start something on the computer, I want to finish it and Deanne will say, oh, leave it and come back to it, but I can't. I've got to sort it.

When we've got different opinions about things, we've done what we've always done in life, and that's it's about negotiation, isn't it? And we do sometimes misunderstand–

Deanne

Yeah, we do.

Ian

What we're saying to each other.

Deanne

But I think now I'm less – because of Ian and because of his condition. I now let things go. And I don't get upset or angry as much as I used to.

Not that I used to get very angry, but yeah, we've had arguments something in the past, but now I tend to think, okay, just let that go and, you know, sort of just control the emotions I'm feeling.

Ian

I think with MND, it's made me when I'm really tired, just want to be in my own place and, and that can be just that, but it does send me sometimes down a spiral and that's when Deanne tries to pull me out of it.

Deanne

I feel sad and I feel sometimes I feel anxious and worried about if I'm laid awake in bed and you know you, everyone does it and all of a sudden something hits you and you think, I don't want to think about that, and I push it away.