MND Association | MND Views

Ian and Deanne
Access to healthcare

Ian
It was quite heavy going at first because in Sheffield we've got so much support and that was from day one. A big folder, was given, medication, was told to just carry on my life as it was as normal. Just lots of appointments which can get quite tiring. But the support was brilliant and we didn't have to ask for support. The support was there, which was a great relief because we got people turning up and talking to us about various aspects.

Deanne
If we had got questions then there'd be somebody at the end of a phone to answer those and people we could get in touch with. Plus we'd got a dedicated MND nurse within the team and that was great because we knew she was, we could get in touch with her and she would answer any questions we'd got.

Make sure that you go prepared if you're speaking to the dietitian or you're speaking to the neurologist, especially as time goes on, you might want to ask more questions. It can be overwhelming a lot of people, which is wonderful, you know, putting – giving you lots and lots of information as well as support. And I think just give yourself some time to let it absorb it process it. It takes a while to process things and then just see where you go from there.

Ian
I was disappointed in my hospital experience because I thought with having such a good team around me who knew me when I was in hospital, a lot of that was ignored because of hospital routine and health and safety. And it did seem quite odd.

Deanne
I think it was just that there seemed to be no communication between the team in the MND team and understandably, you know, in the ward. But it was like different dietitians, different speech and language therapists, different physio.

Ian
But first they wouldn't let me get up out of bed.

Deanne
Without the physios.

Ian
And the physio came and said, oh, hello Ian get out of bed and I did. And as soon as I could sit up, I felt a lot better because it's uncomfortable for me to lay down because of my swallowing.

Deanne
And you can't take anything orally, can you?

Ian
Didn't seem to be totally understood by the staff on the ward.

Deanne
Yeah, it's such a something, something simple like I can do push myself up to sit up. Ian can't do that with his arms. So he was just laid there for ages, you know, thirsty and couldn't, couldn't use his tube at that point because they'd still got the bag, the drainage bag.

Ian
So I didn't have water for like over 24 hours.

Deanne
And it was just lack of communication and understanding if they'd have put on his board this patient can't, you know, sit himself up. It might have been different.

Ian
In Sheffield, we're very fortunate. And so, for someone in Sheffield, I would easily say take what's offered to you. The variety of support is beneficial and it helps a lot. It does get a bit confusing at times, especially at the start because you've got an avalanche of things hitting you, but over time it does get more routine. For the rest of the country. A) if they've not got this support, I suppose really asking why not? But there are other things, like the MND Association. Who have got lots of resources that can help you. There are things on YouTube and sometimes you might be reluctant to look at them, but your family, your partner, they might want to because it's not only you understanding what MND is about, but the people around you.