MND Association | MND Views

Ian and Deanne
Tube feeding

Ian
I thought, if I can't feed myself, what does that say about the quality of life I've got? But then having discussions with the team, we've had several visits that helped us think of the challenges that we were going to face. And it made me realise, the process of discussing it, that it was going into hospital that I feared the most and not the procedure.

Deanne
PEG is the name of the procedure, isn't it? So, but you tend to call it that anyway.

Ian
Deanne and my ideas flipped, but we'd also discussed it with our daughters and they said do it. So that's what we did and the Sheffield team helped organise it. So it was done in a way that was less threatening to me going into hospital.

Deanne
And also we got a lot of support from the nurse and the psychologist throughout the process as we approached, you know, making that decision. And they went out of the way for us really, which was brilliant and really helped because I, like Ian said, I was sort of undecided.

But then I thought, well, if it's going – if it's having it while he's still fit enough and strong enough to have a tube fitted and that will give him a better life and a more meaningful life, then let's go ahead with it.

I think I was starting to think about the implications of actually how it worked and what my responsibility would be. And so I think that's probably why I was thinking, is this going to be a good idea? But with everyone else's support, I think, you know, that really helped us to make that decision.

Ian
Psychologically it’s a big thing because you've come out of hospital with something strapped here. There is a reminder all the time about your condition and about the future and the pathway that you're going to go down.

So I've got mixed feelings about it. We were forced into using the feeling tube for medication and all my needs, which we came out of hospital doing that, until I said to Deanne, wait a minute, this is wrong. This is here to help us and at the moment it's dictating our life.

Deanne
And you wanted, you said a week ago I was taking things orally so why am I not doing it anymore? So you made a decision then to I want to carry on taking things orally. So well with some anxiety we went back to how we was doing it before.

But the feeding tube was so important because Ian wasn't drinking enough. So, you know, that was vital that he had three lots of liquid a day through the tube and that's really helped your energy levels, I think.

Ian
But the also the sessions with the psychologist helped that we were seeing together. And so we did this as a team and it was very important because Deanne has a lot of anxiety about, is she doing the right thing with the pack?

Deanne
I just need reassurance still, because it's the responsibility, isn't it? Making sure it's clean, you know, making sure you remember to flush it and just. Oh yeah, all of that is it's like a quite a big learning curve at first and because it's you and your stomach and I don't want you to get infections.

So it's really important that you know. Well, I felt I could have done with a bit of training before. The nurses on the ward were brilliant and they were helping to show me what to do and letting me have a go.

But I mean, the first night we came home and the tube blocked and I'm thinking, oh no, I've got to use a plunger because it's gravity fed. And but we did it and I suppose it's like just like, okay, I'm just jumping in the deep end, but I will learn to swim.

Ian
We accidentally solved it because I coughed and it started going.

Deanne
You see the stomach, you forget that actually it's this organ that's working all the time. And sometimes it might be fuller than others and things don't go down as easily. And so yeah, I think we're getting used to how the stomach works a little bit now. But I’m still anxious about it, I must admit. But yeah, we'll get there.

Ian
The link nurse, the at the neurology clinic, she actually attended a session with the psychologist because we looked through a YouTube video of the process and the all about the PEG. And so there was a lot of joined up thinking.

Deanne
And I was involved in that, wasn't I as well? And it was really useful to have that.

Ian
And I was shown the actual PEG and talked through how the procedure was going to happen and then the anaesthetist on the day of the procedure, he was very helpful and reassuring.