

Tracy and Iain **Tube feeding**

Tracy

A few months after I was diagnosed, the MND nurse and dietitian spoke me about fitting a PEG tube.

Iain

She did have concerns about having it done because when it's really done she was still able to take her meds, though she was starting to struggle to swallow. So her meds would be a bit – we was hiding them in custard and things like that, but she was eating more or less normal diet.

Well, what are you having a PEG tube fitted for? Well, because she progressed so quick, it's so good when you're already done. Because I think when they do, do the PEG, you've still got to be able to swallow. So, if you leave it too late then, yeah.

And I don't think she'd be here now, if she didn't have the PEG fitted. Definitely not. Yeah, it was definitely fitted at the right time. Well, we couldn't get it any later really.

Obviously people progress at different speeds, though Tracy's progression was quite fast. There was only a couple of months. It just sat there for maybe two or three months. We didn't really use it.

And then all of a sudden it's like, oh, we'll start putting your meds down it. Then before you know it, oh, well, we'll start putting some – because she wasn't getting enough food – I would start putting feeds in it. And then before we know what we're doing, you know, overnight feeds.

Tracy

Fluid was really important because initially before the PEG was fitted, I got dehydrated and had to go to hospital.

Iain

It started to get hotter in May. Having the tube was in was just great because I could just, you know, she was getting three or four litres of water a day then. Completely different to the sort of, at the back end of the summer before, when she was just overheating.

Tracy

My dietitian convinced me because if I didn't have it, I wouldn't be able to survive, basically.

Iain

She laid it on the line. She was like, I know it doesn't look like you need it, but I can assure you this is where it's going to end up. She didn't force us, can't force you, but it was like, yeah, I think we better have that.

I think, yes, I think it was helpful being told really by somebody with quite strong will that says you really do need this, we can't force you to have it, but you really, really, really do need this. Because that convinced you, didn't it? Because I think you just said I'll be fine, I don't want that.

And she's still going through the whole emotion of just being diagnosed. You need somebody else to say you need the PEG fitting, the lesser party to say you really need this.

Tracy

I didn't want it initially.

Iain

Well, there were the complications as well, because they have to tell you about the complications. You've been fine.

Tracy

I think that the reality of dying sooner without it convinced me to have it fitted.