

Tracy and Iain Eating and drinking

Tracy

MND has left me unable to drink and I only eat small amounts of a very soft diet with thickener such as soup, custard, smoothies and puddings. I have regular visits from the dietitian who advise me what to eat and the SALT team [speech and language therapy] assess my swallow.

Iain

Yeah, they do. They do like a scale of how many thickeners that we have to put into all the foods. Everything's thickened.

They're very good dietitians, because she can't eat anything that's, well, anything apart from not soft, even like mince. Can't eat that anymore.

But it seems to be getting worse and worse as the weeks go on. Now she's at a level where it's literally just custard and more custard. Yeah, sponge pudding, treacle sponge, custard. It's not bad, though I have to taste a little bit, obviously, to make sure it's not too hot.

They come, they come a lot. Maybe every two months and come and yeah, give me advice. And well, "Now she's at this level, so you shouldn't be giving her this and this and this. Have you tried this?" Well, no, I'll try that then. Then they'll be, oh, they do ring, "How're you getting on and do you need us to come and see you?" It's very helpful when they do ring.

It's just, no, they haven't forgot about you. Some of the times, actually, they just ring out the blue. "How's Tracy getting on? How are you getting on? Have your cooking skills improved?" No. "Are they going to do?" No. Oh, yeah. They haven't said you cannot eat that.

They've told us about the risks of choking, but at the end of the day, it's up to her. This is what I was trying to explain to someone the other day. It's not a case of just giving her something to eat. It's the whole rigmarole of it because it's so hard for it to eat because the tongue doesn't really move.

So you then have to, once she's had it, then it's cleaning up time, which involves washing it out with a little squirty bottle to wash her mouth out and catch in a cup. Then get the suction machine to suck it all.

Like if you leave any food in the mouth at all, it starts to like saliva being produced. So you're going to get it really, you know, really clean.

Tracy

It's a very messy process.

Iain

It's a very, it can be a very messy process. Yeah. We get through a lot of kitchen roll.