

David

Eating, drinking and tube feeding

David

I've had to maintain a high calorie diet and I have volunteered at the beginning of my diagnosis to do an optical study, which is about nutrition and keeping your weight up and maintaining your calories. Yeah, were hard. I were always told before MND I'd got an high BMI and I've got to look after my weight.

Like no, yeah, eat what you want, but not literally, but just yeah, keep your calories up because this study proves that people who maintain more weight have a longer survival rate. So yeah, I'm part of that.

That were hard for me to accept because I was like "How does that work?" like being heavier and eating what and dealing with a team at the Hallamshire, they'd done my calorie count and said it was about, I've got to get in between 3800 and 4000 calories a day.

So I were a bit like yeah, that is a lot. But yeah, I've found it hard, but at the same time I got used to it and it was just about reconfiguring me brain to do them things and like look after myself at same time. It's yeah, it's about managing it and like doing it in intervals through the day, like in morning and making sure I'm, I'm like listening to me body.

We have discussed with the NOTS team [Neuro Outreach Team Sheffield] about me having a, I think a PEG. And I've spoken to some people with MND and they're not for it. It's not for them. But for me it ticks all boxes because I'm 50 year old and I think if I have that done, that procedure, that'll keep the calories going in.

Because at the moment I can feed myself and I can still talk and swallow. But I know there's going to come a time when my arms aren't going to get up to my mouth. I'm going to get, the weakness is going to get too much. So I've, I've discussed it with NOTS team about having that procedure and we're all in agreement. I asked them what the procedure consisted of and they told me and I was like, yeah, let's do it.

The NOTS team when they did a home visit, they asked me how I was, how I was managing to feed myself. And I were honest. I just said it's tiring. I'm having to use a spoon, make sure my food's chopped up. I'm struggling doing me food.

And yeah, it were a case of crossing T's and dotting I's and thinking right, what's going to be the right course action for yourself here?

And it were a PEG, to go down that route, which I'm waiting for referral at the moment with the hospital to go down that route and have it done. But I will be looking into that. So yeah.