

## **Geeta and Sheena** **Emotional lability, and changes to thinking** **and behaviour**

### **Sheena**

I don't think we were given a lot of information in regards to changes in memory and cognition. We did come across about the behavioural aspect, because we were having periods where mum had a little bit of emotional instability.

So mum's cognitions are completely there, but sometimes she gets a little emotional for no reason. We noticed that mum was just bursting out crying at random times, even when we were laughing.

So we're a bit concerned. And it was at that point when we discussed it with the consultant, that we were made aware of this. It's actually only recently that I found out that some patients with MND, they do have a change in their cognitions, but I think we're quite lucky that mum's okay in that department at the moment.

Yeah. Do you feel like there's much change?

### **Geeta**

Well, there's very strong positive—

### **Sheena**

Very strong and positive.

### **Geeta**

Yeah I never cry usually, really. But now it just comes out.

### **Sheena**

Sometimes she says she's not crying, it's the air from her machine. So we don't know. There was a joke also that I was a crybaby. Now mum's a family crybaby.

I think I've assumed after finding out that there is obviously this side effect or presentation of this disease with the cognition. I think they just must assess it when we go to the appointment on how mum's behaving and mum answers.

We had a recent incident where one of mum's specialist MND nurses, actually sent an email and it saying that. And it's the first time I've heard it or read it, vocalised that they have no concerns with mum's cognitions and so I was like, oh, they must be assessing it in the background, but they don't always tell you everything that they are assessing during those appointments.

And I think because we've never expressed that concern at any appointment. So I think it's something that was just never touched on. I do feel like maybe it's also that they don't want to overwhelm a patient with all the possible symptoms or things that could happen as the disease progresses, so maybe that's why it wasn't mentioned as much.

I think because mum's, we don't have that much concerns with mum's cognitions. I don't think for us it is, but I can imagine it being for someone else's family who has those symptoms because it can be confusing.

It's difficult to understand how the disease progresses. So for someone going through that, it would definitely be important that they're made aware of it and can also relate to the patient because they will have some frustrations.

If somebody is not able to understand the changes in their behaviour or their normal sort of daily activities, I guess. Yeah.

### **Geeta**

I noticed that. Because they were kids, they noticed it as well.

### **Sheena**

So mum noticed herself and then the kids did. So we always used to just think mum was just being sad about her condition and saying why are you crying all the time? We're just talking normally. There's nothing to get upset about.

Then mum kept saying initially that I can't stop crying, I don't know. And at the start we just thought she's just masking her being upset about her condition because we all started to mask at one point, because we didn't want to upset each other about the progression or the prognosis or what's to come.

But then we realised that it was actually something mum wasn't able to control, because there'd be times that we'd be laughing and then she'd just start crying. So yeah.