Geeta and Sheena
Social care

Sheena
I think it came quite late for us, or when mum's condition had got a little bit more advanced. Because at the start we didn't really have much sort of assessment and it was just more us going to the consultant and saying this has changed, that has changed.

And only then it would trigger the escalation of the occupational therapist coming to assess the equipment or our living facilities or things like that.

But as mum's condition progressed and when she'd had hospital admissions before discharge, it was mainly there that they had escalated and that these services were involved and these plans were put in place.

So I do feel like we struggled initially before we got to that point because things were changing. We didn't know how to manage it at home. So I feel like there could be some better arrangement of engagement with patients who have MND.

So they've got regular checks, or someone can go frequently to check and see what adaptations and or what help or support they do need.

We didn't really have a massive amount of information at the start, so we didn't really know where to go for the different difficulties that we're encountering, and it's something we've learned along our journey.

It's a lot easier now, and now we're part of sort of a hospice and the specialist nurses, we can just go to them and they all sort of arrange everything or put us in touch with the right people.

But at the very start, we just felt like we were just googling everything and trying our best and just managing with what we had. Yeah. So with regards to the carers, so we again had a bit of a difficult start.

Mum was–it was mum's legs that went first. So mum was in a wheelchair but she wasn't ventilated. She didn't have any cough assist or any other sorts of support.

So we weren't really directed in any direction. But we knew we were struggling because we were manually moving mum. We weren't given a hoist or any equipment to help move mum so we privately funded carers that we could only afford an hour in the morning and an hour in the evening to come and help change, get dressed.

But during the day we were struggling, partly taking her to the bathroom and things like that. It was only once mum started to get ventilated that the hospital had escalated this and we were put in contact with the CHC and mum qualified because she was ventilated, that we were able to get sort of the funding to help with the care.

And it was only at that point we realised how much we were actually doing to try and help mum. That led to a lot of frustrations for us, and for mum, because we didn't know how to handle or manage mum appropriately so she would get upset.

Then we were getting really tired and burnt out and we have full time jobs. So it was mainly my father who was also elderly, who was trying to help her, and that led to a few tumbles with both of them when they were trying to move, and a few A&E admissions.

Oh yeah, it was, it was difficult. So it was mainly from a hospital admission. And upon discharge, the discharge team had sort of arranged that for us. Prior to that, there was no real sort of assessment.