MND Association | MND Views

Geeta and Sheena
Medications

Sheena
So mum was given or prescribed riluzole at the start of her diagnosis.

Geeta
Yes.

Sheena
At the very start. Yeah, there wasn't much explanation about riluzole. It was just this medication that just possibly slow down the progression. It's the only one that's available. Take it or leave it.

So we obviously grabbed it with both hands. We did explore other alternatives as well. So after doing some research we inquired about stem cell therapy and some other medications, we actually went abroad as well to get some second opinions, some assessments and see if there was any other medication available.

We did try one type of medication whilst abroad that's not available in the UK. We noticed a bit of a difference with that but then mum was a bit unwell. But yeah so mum's still taking the riluzole.

Yes. And everyone that we asked about stem cell therapy they just said it was too experimental at the moment there's lots of side effects. It's not worth it.

Even when we went abroad, their only advice to mum was to just enjoy your life. Don't try and go down these routes. But at that time we were desperate because it was early on in mum's condition.

We wanted anything and mum was willing to try anything as well. But yeah.

Geeta
There is no cure for this. The medicine only slows down the progress, that’s it.

Sheena
Yeah, that's all we were told. And that was right at the start when mum was diagnosed. So it was obviously something we wouldn't turn down because when you told there's no cure but this might potentially slow it down.

So we took it. There was no further discussions about side effects or how it actually works, or the benefits of taking it just that one sentence, which we held on to and took the riluzole.

And then that's why we started to try and explore if there was other options available, other types of medications or treatments and therapies. Actually, initially when mum was diagnosed, we weren't really given a lot of information about the condition, the progression, things like that.

I don't know if they were mindful of not overwhelming us. Like I said before, because you get a diagnosis and prognosis in one go, it's a big blow. So maybe they didn't want to overwhelm us.

We were just basically provided with a pack from the MND Association about MND, which we were given to take away and just have a read. We read through it. I don't think my mum did.

I don't think mum could ever bring herself to read it. It was just placed on the side of her bed. I think it was too upsetting for her.

So a lot of mum's journey as it's progressed with her condition. It's just been like a new experience each time because we've not, we've not known which way we're going to go. Like we explained with the feeding I didn't think that we would need to change the route of the way mum's received her nutrition.

So yeah, I think maybe after a patient is diagnosed, there should be some sort of point when the family or the patients had time to digest that. I'm diagnosed with this.

Just to sit down and explain potential progression without scaring a patient in a in a tactful way, but also so the family and the patient have realistic expectations as well.

Because I think that's a big thing because as mum's condition changed, we don't have that expectation of certain things developing and it shocked us. And then we'd sort of have a really big drop in that sort of our emotional wellbeing and management of mum's condition.

So it is important, but I can understand why they don't overwhelm you at the start of all, because it was a lot all in one go.