MND Association | MND Views

Meena
Social care

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We wanted to adapt the property because Dad's needs are progressing and so we didn't want to wait to the last minute before we made the changes.

So we've had to withdraw his pension, which is something that we weren't aware we were able to do because of his condition. And it was thanks to the MND clinic who actually helped us identify how we can fund these things ourselves. Because obviously it's a lot of money and I don't have that and neither does my dad. So being able to withdraw from his pension pot helped us fund a lot of the stuff that we couldn't get from other sources.

However, that's kind of shot us in the foot because now dad has a lot of money in his account and therefore he doesn't really qualify for social funding as such. So even if we did get carers, we would have to fund it from that money, but then it would eat up the funds that we've kind of earmarked for various adaptations and things.

So it's kind of like a chicken egg situation. We don't really know which one to do either way. So yes, unfortunately not at the moment.

The specialist OT [occupational therapist] has been referred specially by the MND clinic to us and she visits on a sort of depending on how Dad's getting on. If he has, you know, episodes where he needs more support, then she will come more regularly. But generally it's around one or two months.

She'll pop in and visit and just assess how he's doing, watch him around the house asking various questions. He knows has he got any concerns etc. And she you know, she'll recommend then either aids to assist or she will recommend physio.

The, the lady we've had from the outset has changed lately, but the service has been the same. So they're amazing.

And it's really made my dad comfortable and confident in himself, which is something he lost when he was initially diagnosed because he just suddenly felt, you know, he didn't know what to do with himself.

He's never, never been in a position where he's not been independent. So having an OT who is specialist in MND is, is crucial for, for people like that because you can see the progression my dad has made just from having her around and knowing that she's going to visit in a month.

And so yeah, she's, she's really knowledgeable and has access and she's always getting us to trial different aids to see if, you know, they would help.