

Meena

Carer and family support

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So this is the thing. I think carers have a very complicated role. We not only have to ensure we're, you know, respecting and carrying out the wishes of the person we're caring for as much as we possibly can and allowing them to have independence, but at the same time we are the ones providing care. So we have to be prepared, more so than perhaps them.

So for me, it's always a constant battle because I need to know what the progression is going to look like so that I can start planning, you know, what other aids we're going to need, any adaptations to the property that might be required, further adaptations to the vehicle that might be required, that kind of thing.

So it is a constant battle between what my dad prefers and what I prefer. But somehow we've managed to meet in the middle and actually able to discuss a little bit more openly than perhaps when he was initially diagnosed.

MND is very good at this because the team recognise the conflict between the two of us and quite often they will first deal with what dad has and wants and, and any concerns he has. They will then later actually ask me direct. Would I like to know anything? Have you got any concerns? Do you want to know anymore? Is there something we can do to help you?

And she's just been amazing with everything right from the withdrawal of the pension parts to getting some aids to, you know, understanding what I need to do to be a better support for my father. So I think for me, they are a very big source of my support and information as a carer, which is lacking in other areas. I think plenty of information available for maybe the person living with MND, not necessarily for the carers, but this is where I think the MND clinic does it really well.

I think if I'm honest, the most important person to help me as a carer is myself. And, and the way I do it is to ensure that I'm taking care of myself primarily first. And I think a lot of care, and I'm sure I speak for a lot of carers out there now, we don't, we're not very good at that. We don't like to put ourselves first.

But I think it's, it's one of those chicken egg situations. But in this case, actually it is very important that we look after ourselves because if we're not 100%, we can't possibly offer any kind of good level of care.

Along with that, I would say it's really important for us to stay ahead and be informed and keep being informed, whether that's through the, you know, web. Nowadays everything is out there in the web or asking the consultants going through the MND Association and they're really good source of information too.

There's a lot of videos with people that have been carers for, you know, people living with MND. So they're really good sources of information. So I think the combination of making sure you look after yourself and you have enough information about the condition and how it progresses and what's coming helps you prepare both mentally and physically. And I think that's really important.

It's hard emotionally, it's very hard and kind of it makes you realise, you know, what my dad must have gone through as a father to raise us because I guess it's the flip side of that, isn't it? We kind of have had a role reversal now where I'm now kind of the parent and he's my kid.

And yeah, yeah, there isn't an awful lot of support for, for carers to be honest, of any, you know, carers, not necessarily just MND, but carers in general. I think in this country there is a very serious lack of consideration for people like myself, like unpaid carers.

You hear that term all the time, but there isn't really much the people do about it. The government, when I say the people, I mean the government doesn't care, doesn't want to know. And it's sad because I know there are carers organisations that do run, you know, sessions where you can go and have a coffee or whatever, but it kind of still puts the pressure on me.

So if I want to go to these meetings, I can't necessarily cart two people with me to the meeting. So it doesn't really help me. But I've been having chats with the MND Association and I think they are considering more virtual support for carers, specifically for MND carers.

But obviously eventually, hopefully other, but I think that would be really beneficial just to be able to talk to another carer because I think sometimes you just want to whinge about something and you just can't. Because if I whinge to my dad, he's just going to feel bad about things. And that's the worst thing I can do. And the last thing I want to do is to, you know, make him feel bad.

The best advice I can give to a carer of somebody who's just been diagnosed is find out as much as you can about the condition because information really is very useful. Get in touch with the MND Association and with the team. I'm hoping at that point you will have contact with the team that deals with MND in that area.

I think without that, it's a very scary, scary, scary process and journey. And I don't think carers could do it on their own. It's impossible without that, that support around you. So yeah, information and definitely get in touch with what's out there to help people with MND and carers.