

MND Matters: Episode 28: Eddie Redmayne meets Lesley Connor

Intro

You're listening to MND matters, a podcast from the MND Association.

Helen

Welcome to MND Matters, a podcast by the MND Association sponsored by Toyota GB and Toyota Financial Services. I'm your host Helen, and today we have a truly special episode in store for you. We are honored to have two remarkable individuals join us who embody the compassion, resilience and dedication to the fight against motor neurone disease. Our first guest leads little introduction. He's an Academy Award winning actor and patron of the MND Association, known for his incredible performance as Professor Stephen Hawking in the Theory of Everything. Please join me in welcoming the brilliant Eddie Redmayne. Today we have the privilege of listening to Eddie as he interviews Lesley delving into her inspiring journey as a volunteer and the invaluable role she plays in supporting individuals and families affected by MND. Throughout this conversation we'll gain insight into the challenges, triumphs and profound impact Lesley has experienced during her 20 year journey. While also exploring the importance of volunteers. I have no doubt that you're going to feel incredibly moved inspired and enlightened by Lesley. So if you want to start your own MND volunteering journey, please visit www.mndassociation.org/volunteering. We've also put that link in the show notes. So without further ado, let's dive into this captivating conversation between Eddie and Lesley right here on the MND Matters podcast. Eddie and Leslie, the stage is yours.

Eddie Redmayne

Hello, Lesley. Hi. It's so lovely to meet you. How are you doing? I'm

Lesley Connor

I'm fine. Thank you,

Eddie Redmayne

Lesley. What a treat to meet you. i You have been volunteering for the MND association for 20 years, I've heard which is an astonishing thing. And it is such a treat for me to get to meet you to as a patron of the MND association to say such a huge thank you and to and as a way of celebrating global MND Awareness Day and all the work that yourself and so many volunteers do, but I was wondering how it started for you. How did you? How did you start working with the MND Association?

Lesley Connor

Well, I was an occupational therapist working for the NHS and I, I was working in end of life care. And I was always really impressed at how the MND Association supported us with the patients that we treated. And I just felt I wanted to give a bit back really, and I just felt the role of the volunteer would

enhance my role as an OT, and that my OT role could feed into my role as a volunteer as well. So that's how I started. It doesn't seem like 20 years, and I feel I'm sitting here today representing all the volunteers that the MND Association have got, because they're such a fantastic Association at supporting us as well, once we are volunteering. I mean, I think historically volunteers aren't an easy bunch to manage. But I think because of the training that and the support that we get from the Association, I think they do keep their volunteers.

Eddie Redmayne

And can I ask also, because am I right in thinking you've you volunteer in different capacities? Could you tell me about those different those different things, the different aspects of the association that you sort of helped with I suppose.

Lesley Connor

I started off as an association visitor. So we we had people living with MND, that were identified to us by the area coordinators. In the early days it was it could be support, sort of emotional support. And we used to be quite practical, you know, there were people I used to visit. I used to help feed or I used to push out in a wheelchair that that's changed somewhat now. And then I had a bereavement myself, and I stepped back from volunteering. And then it was suggested that perhaps I help on the helpline, the Connect helpline. So I've been doing that now for about 10 years, I think. So I do both now and I just, It's not a lot of time. It's a couple of evenings a month. For the helpline, the association visitor, I'm supporting three people at the moment, but that might be monthly, it might be weekly, it varies.

Eddie Redmayne

And can you tell me a bit about the helpline. So So what does that involve?

Lesley Connor

Well, we log on at seven o'clock in the evening, the line is closed, I think from five till seven, the day staff go off at five, we come on at seven, and then we're on till 1030. And we log on to we use their own mobiles or our own landlines, numbers are anonymous when they found through so we, you know, we don't we can't call people back. And it varies as to who you get phoning the very first call I took, in fact was from America, I learned a lot from him actually, about what facilities were over there. But the night calls can be very different. I mean, more recently, obviously, with a raised awareness, we do get calls off people who probably wouldn't have been aware of MND a few years ago, but now are identifying that perhaps they've got symptoms, and they're quite concerned. And because the diagnosis process is so lengthy, they're waiting for test results and, and they just need somebody to talk to really on the phone and somebody to listen or somebody to signpost again. Or we can refer to the office staff the following day, if we feel that we can't address what they're phoning about, we can then get the office staff the following day to address that. I had a phone call once off a guy who was very concerned about his father's breathing. And obviously, that's an emergency situation. So it's directing them to what they were they've got anybody to contact, any medical support. And so it can be a variety of different calls at night.

Lesley Connor

I suppose one of the things I was curious about, I've been working with the Motor Neurone Disease Association for about 10 years now, since I've made the Theory of Everything, which is what introduced me to MND, and the community. You've been working with the MND association for 20 years, how would you say things have changed as far as the disease, the awareness? And I suppose the support in that time?

Lesley Connor

Well, I think awareness obviously has changed. I mean, it's it's on the news constantly with Rob Burrow, and Kevin Sinfield and yourself and the film. So I think the awareness is it's much people have heard about it now. And it's not just end of life either. Now, it's, you know, I've got friends are still working, you know, people refer to rehabilitation services now, not just end of life services. I think the research side of it obviously, is really important. And I, I just feel that probably having an army of volunteers like myself, we help mitigate some of the costs that go to the support, although there are still a lot of costs that go to support. So that that can be freed up for the research, which, you know, that's what we're all striving for a world without MND.

Eddie Redmayne

I, one of the things that I was also curious about was individual people, you it's such an intimate job you do with people at such a vulnerable moment in their lives and the families coping with with so much. I imagine you've met extraordinary people over the years and families and I wondered if there's any anyone specifically that you, you you hold fond memories of or that you're working with now?

Lesley Connor

I think they're all extraordinary. I mean, I just I don't know what it is about MND. But people who were living with MND seem so resilient. And I think as an occupational therapist, it was quite a rewarding role. Because, you know, there's, there's such a lot you can do with technology now and maintaining independence, and probably things that I was going into 20 years ago, like, there was one lady I used to remember. And I used to spend an hour with her just adjusting a pillow because she was uncomfortable. And, you know, I went to a funeral. And even at her funeral, there was this joke amongst the relatives that whoever visited her, spent the whole time adjusting her pillows, you know, and technology now, you know, hopefully that could be addressed. And she wasn't just having to wait for that hour that we went. I had a gentleman ring me recently on the helpline. And he just been diagnosed he was I think it was probably about 50 got young children. And he just talked to me for probably about half an hour about how he felt how he was going to tell the children. And then he thanked me and said that he was sure I've got something better to do in the evening than listen to him. And that stayed with me really. I mean, you know, to think that he was thinking about me when it was all about him really and what he was going through and the journey that we he was having to, you know, travel.

Eddie Redmayne

Extraordinary. There's, it's no it's an astonishing thing to and a privilege I suppose to bear witness to people and families with with with such courage. I, I met a man called Glenn Phillips when I was when I was preparing to do Theory of Everything. I went to the Queen Square neurology clinic. And spent time meeting was introduced to families. And there were many extraordinary people that I met. But I will

never forget Glenn, who was he was a sort of academic and film, and he just had such a vibrancy to him, and a kind of an overwhelming courage at a moment. But when you're volunteering and speaking to people and families, who, as you say, can be so resilient and strong, but there is there. Is there a cost to you when you come home? Like how do you look after yourself, I suppose,

Lesley Connor

I think I find it harder now that I've retired, obviously, when I was at work, although you didn't speak about people because of confidentiality, you've you've got the support from a team. Now that I've retired, it's probably more difficult. But with this, there's about 12, or 14 of us who work on the helpline. And I think it's the helpline, probably, that's more difficult, because you can, you can finish your shift at 1030 at night, and there's nobody to talk to really, we do have a reflection sheet. And if I find that I've had a really difficult call, I will write down my thoughts on that. So we can always phone, the Connect support staff the following day. Up until COVID, we were meeting regularly, and we all know each other quite well. We've got a whatsapp that we use for operational stuff. If we need to swap or shift or we're having technical issues, and we can't get on onto the phone. Obviously, we don't exchange details about people that we've spoken to. But we know that we've got a phone number there if we did need somebody to speak to about something.

Eddie Redmayne

Gosh, it's so amazing hearing also what you were saying about the changes and shifts in technologies. Certainly, even since I've been working with the MND Association, but I remember when I was spending time with Stephen Hawking and his family, you know, he had had one technology for, for communicating that involved. He had his glasses with a sensor on his glasses. And it was just the alphabet and this cursor going across the alphabet. And whenever he moved his eye, I would stop on one letter and, and it took so long for him to communicate things. But Dell were working with him creating a new technology that that would stay ahead of the disease. And I found that idea of you know, from my experience of people living with motor neuron disease, because time is such a complicated thing, you're always having to stay ahead of the disease. And it's interesting now that technology, you know, one of the great things about about furthering technology and investment in that and is those things that can be useful. But what's complicated I saw with that is you get used to your one way of doing something and then you've got to relearn another another new technique.

Lesley Connor

I think an example of that is voice banking, isn't it? There was no voice banking, you know, a few years ago and, and, and people people that I've visited and and supported, you know, they'll, they'll have voice messages on a phone that they don't want to get rid of. But the voice banking has brought a whole new perspective to all that. You know, when that person's not around anymore, they've still got the voice?

Eddie Redmayne

Yeah, no, it is so lovely to meet you.

Lesley Connor

Well it's lovely for me to meet you as well.

Eddie Redmayne

I don't know about that. But it's a real honor and 20 years, working with this brilliant Association, and with extraordinary people living in extraordinary circumstances, it's a really admirable and an astonishing thing and, and bravo on it.

Lesley Connor

Well thank you. Thank you. I feel I'm representing all of us though today, I'm just the lucky one that was chosen to talk to you . I mean, we I think we need to thank you as well because you know you do such a lot for the MND association I, I did a bit of background reading and I think it's amazing what you've done as well. So I think we should be thanking you as well.

Eddie Redmayne

I don't know about that. I mean, I remember it so much interestingly for me about about awareness and I agree with you like that that has shifted and changed. Certainly I remember what just off the Theory of Everything there was also the the Ice Bucket Challenge moment and there was but but but it's about retaining that awareness because I think for you and me it feels like that was only yesterday. But actually the sort of the years do move on, but the things that it's about the understanding of the disease, I find it extraordinary that during COVID people with motor neurone disease weren't on the like most highly vulnerable list and didn't have access. And it was extraordinary. We got onto a parliamentary call on Zoom. And I just couldn't believe that, that they weren't understanding that there was this was a disease that shifts can shift within days or weeks, you know. And so, but all of that felt about education, you know, and when it was for me when I was prepping to play Stephen Hawking, but the more we can do to make people aware of what the reality of of motor neurone disease is, I feel like it's a good thing but it's people like yourself and as you say, all the other volunteers doing such amazing things for the MND association that are making making lives easier for people living with them MND. Such a treat chatting with you and thank you for everything.

Eddie Redmayne

Well, thank you as well. Thank you.

Outro

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