

MND Matters: Episode 25: Wheelchairs

Intro

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Pauline

Welcome to MND Matters brought to you by the MND Association and sponsored by Toyota GB and Toyota Financial Services. My name is Pauline Marks head of national care, at the MND Association. I'm joined today by Maggie Hevicon, one of our specialist MND wheelchair physiotherapists is going to talk us through her role at the Association. And I'm also really pleased to be joined by Simon Asprey, who's living with MND, and has been helped by the Association's wheelchair service with some financial grants. So welcome, Maggie. Hi, Simon. Thanks for joining me. I just want to start by sharing that it's estimated that over 80% of people living with MND will need a wheelchair during their time living with a condition. And last year, the association funded almost £70,000 worth of grants for people living with MND. And those grants were used to pay for wheelchair accessories that aren't funded by statutory services - So the NHS - but make a significant difference to people living with MND. And these include things such as risers, power packs, attendant controls, and powered elevating leg rests. So that's in the main of how the Association's funding supports people. So I'm going to turn to Maggie now, Maggie, it'd be really great to hear a little bit more about what your role is and how you work with the Association. And really what that involves.

Maggie

Thank you very much. Well, yeah, I'm one of three people we work as a team to on the wheelchair project. I'm a physio as as you said, by background, Lynn Hills is an OT. The two of us have worked as therapists in adult neuro disability and neuro rehab for many years, but have specialized for many years, also in wheelchairs and posture management. And then we have Annie Buchanan who joins us at the head office. And she helps us she feels all the inquiries that come in through through head office. And she's very often she can manage the inquiries. But she also then sends them across to Lynn or I if it needs to have a clinical opinion. And also Anne is very important in managing the grant process up at head office. So Lynne and I are, we're based in Carshalton in Surrey, at the Queen Elizabeth Foundation, which is one of the disability driving mobility centers around the country. And we cover two of the specialists motor nerve clinics in London as part of part of our role, that's a multidisciplinary clinic where people living with MND come in for their first appointments or their reviews. And so we get referrals from them. But we also get referrals from the helpline from throughout the country, which is England, Wales, and Northern Ireland, so that we can offer remote advice to people themselves living with the disease and also to wheelchair services and the wider health care professionals that are supporting the person with the disease. So we provide training and support to the local wheelchair services, and the wider community team as well and try and work out the right wheelchair solutions for people living with with motor neurone disease. Thank you,

Pauline 03:34

Thank you Maggie, and you started to answer my second question, but I'm going to ask it because it might be useful just to expand a little bit more. So you started to talk about the work that you do with wheelchair services and some of the support you give to them? Can you sort of describe some of the other stuff that you do to support wheelchair services.

Maggie

Training is quite a big part of our support. And that training has been going on for a number of years this project has been, It began when it was felt that wheelchair services around the country were a bit variable in their response times for people with MND. And it was important that, that they were aware that, you know, some people will need to be seen quite quickly if they're going to make the best use of a manual or powered wheelchair. So the training in the appropriate equipment that that we feel is right for people with the disease and also to raise awareness with them with those services that they need to pick up these referrals as as on their urgent list so that we can help people quickly. We train people in the wheelchair pathway for MND, which has been developed to also give them a good roadmap as to what we feel is the right way to support people with their MND and we also can support them perhaps with short term loan of equipment and hire equipment if they are struggling, there have been issues with the supply chain, certainly in the last few years with COVID. And I think Brexit has also been a problem with getting stuff in from the from Europe, certainly. So if we've got some small amount of stock and equipment at QEF that we can help support services with loan or hire or while they're waiting for their equipment to come, we try and keep on top of the most recent technology, because that changes and develops so quickly. And there are some really exciting pieces of technology in the mobility world that we also try and an update in support services, if they can supply that that equipment to make driving a power chair, for instance, extend that as long as possible for the person. We will also arrange the grant support system if people do need to have equipment that is away from the statutory service. So Pauline as you said, the risers the powered elevated leg rests, sometimes people feel they would like and wheelchair services feel they haven't got the capacity to fund those. Attendant control is something that we also support people with the grant applications in sort of partnership with the wheelchair services so that people can have an attendant control on the chair, if it can't be provided by the wheelchair.

Pauline

That sounds really interesting. I think it'd be really good to come back to that in a bit more detail some of the reasons why those pieces of equipment might be really, really beneficial. And it very much sounds like the work that that you and Lynn and Anne do is really to complement the NHS and to really kind of support people with MND through that journey, which is absolutely fantastic. And you touched on something which I just wanted to mention as well just in terms of services being different and services needing to understand, you know, having to fast track things for people with MND. And that very much ties in to some of the work that's been undertaken by the wheelchair Alliance. So the wheelchair Alliance exists separately to the MND Association. But it's something that we have two MND Association staff members myself and my manager, Nick are actually on the board of the wheelchair Alliance. And the wheelchair Alliance commissioned some research last year, which unearthed a postcode lottery around the provision of wheelchairs, including for people with motor neurone disease. The wheelchair alliance made some very strong recommendations to NHS, England's all of which, as an association we really you know, wholeheartedly support and you know, I can see that the work that you're doing Maggie and Lynn and and is helping to drive up some of those standards for people with

MND. So I just wanted to mention that because it felt quite relevant. Going to pause for a moment, and, and turn to you, Simon because it'd be really good to hear from you and understand a little bit about your journey. So when you were diagnosed with MND Simon, can you take us back to how you felt at the time and what symptoms you first experienced?

Simon

Yeah, I was first diagnosed in 2005. And obviously I have a very slow, long running variant. It's actually not the normal ALS variant but a much more rare type called PLS. Yeah, so my, my first symptom was actually a slight slurring of my speech. And obviously you can still hear it with the way I pronounce S's but curiously that that voice issue didn't progress anywhere near as fast as might have been expected. Instead, my my legs began to get affected and yeah, it began with just getting very tired on walks. I like doing fell walking and I used to like doing fell walking and things. And, yeah, it was getting very difficult. I couldn't They even keep up with octogenarians and some such like, and then of course, I find that hard to keep upright. And I've gone on to catastrophic, catastrophic falls, one in particular, where I broke a few ribs trying trying to step over a wire. And because my legs were weakened, I didn't make it over the wire. That was one of the first indicators, I needed some kind of support for mobility. So as far as that's concerned, I started with a walking stick. And soon graduated to a manual chair. I was teaching science at the time. The school lunch had split sites. So I used to have travel by via wheelchair between one site and the other manually with a user, usually one of the older students pushing me. I mean, I guess that was probably not the right thing to do. But that was the way it worked. Anyway, um, so very soon after that, I realised, because my arm muscles were getting a bit tired as well. And weak, clumsy, so maneuvering a manual chair and even just getting up a mild slope was proving impossible. So yeah. Initially, well, I approached access to work, which was, I've done? I don't know if it's going now.

Pauline

State much. Yeah. Well,

Simon

anyway, access to work for branded the launch of the funding for a wheelchair, power chair. I have that chair for five years, starting in 2009, which gives you an idea of how fast my particular variant was progressing. So, yeah, that that one lasted five years. And then I got an NHS wheelchair. The Association very generously funded the riser on that? Which, honestly, it's an amazing piece of kit.

Pauline

What sorts of things does a riser will enable you to do Simon?

Simon

Oh well I mean, the the official line is, it enables you to reach the top drawer filing cabinet. Well, that was not really important to me. So, yeah, but top shelf of supermarkets. And then, most important to me is that they raising me up to a level where I can converse with other people standing with you at eye level. So you have no idea how awful it is when you're down below a conversation whenever things go above your head, eye contact and speech and everything, particularly if there's ambient noise. It's it really is very hard, particularly if your voice is weak as mine to interject any any comment and you first to hear it. And then then you have to summon the effort to actually make a comment. What happens is

you end up just listening in the end, that's not a very nice feeling to be frank. And so, what the riser does in lifting me up to the level of conversation is it means I can have direct eye contact with interlocutors I can I can speak. And even with my soft, husky voice, at the level that will enable me to be heard.

Pauline

It's all very things that that possibly you would take for granted? How would you describe the difference that having the riser was made to you? So you started to kind of share some of the things that you've you found challenging? And but I guess how would you describe that difference, perhaps to your quality of life?

Simon

Oh well, enormous. Really. I mean, obviously, it's not essential for mobility, which is why the NHS doesn't fund the riser. It really makes a big difference to me. Yeah, I often chat with groups of friends who are standing around in drinking coffee after some meeting or other. And it's, it's just so very important to me, personally.

Pauline

No, thank you. Thank you for sharing. So, Maggie, so just picking up on the points that Simon's made and the experience that he shared. How do you support people living with MND that need a wheelchair?

Maggie

I think Simon, you've made it sort of very clear that it's important that Lynn and I and and that we we have close communication with yourself so that we can ask you the sorts of questions about what what you need and want from your, your chair, we have the luxury of being able to be a little flexible, and not have to sit within the constraints that the NHS wheelchair services have. So so if it means we can offer advice, because I think sometimes wheelchair services, they know what they're allowed to provide within their individual criteria. And I think the concern is that, then people aren't always made very aware of what what they could have, or what alternative solutions they could have. So that if we can have a wider conversation with people, we will always be that we, you know, we try our very best to absolutely understand the constraints that the NHS are under, but also to support people with making their equipment work for them. It might be with the riser, some some of our clients really find the powered elevated leg rests are a very useful thing to have. Because if you can't move your legs yourself anymore, to be able to press a button to change the position of your legs is is something that is it relieves the discomfort of sitting very still.

Simon

And it also reduces the level of, you know, swelling around the ankles. Yeah. Ritual, although is not. not strictly necessary. It really does make you feel a little bit more comfortable.

Maggie

Definitely. Yes, yes, I agree. And then another area that we've more and more involved with is is equipment that is outside of statutory provision completely. So in the early stages of the disease, when people are struggling to walk perhaps outdoors any distance, then there are the huge range of folding

power chairs out there now that people are often very interested in in looking at equally people up think that perhaps a scooter is something that's going to work for them. And though it does, sometimes, it is a solution for some people's outdoor mobility. We have to try and offer people that the general advice is to finding a piece of equipment that would give them a longer mobility solution is where we would be aiming at where sometimes scooters are difficult with if your arms are beginning to get weak and your shoulders are beginning to get weak to hold a the the handlebars on a scooter can be quite tiring. So it's though we're happy to support people with their decisions. We'll try to give them a sort of wider picture of the pros and cons of pieces of equipment that perhaps NHS wheelchair services just don't get involved with, because it's not part of their range as part of their statutory provision. And beyond that, then, of course, it's about accessing grants, you were saying you you looked at Access to Work, that is something that, you know, people still are able to access, and they can be quite generous in their funding towards piece of equipment, if somebody is able to use that scheme for other charities, their ranges of different charities dependent on the person's background that they could approach. And then we're more happy more than happy to write reports and to support those applications for funding outside of the MNDA. Because it's not always sufficient the grant that the that the association can provide, some people have to gather up funding from a number of pots of money. And then that's something that we Lynn and I are more than happy in writing reports to support those grant applications.

Pauline

That's really good Maggie. And I suppose what I'm hearing is that your role is about enabling people to have an element of choice and control over over the equipment. And also, you know, you listen and find out about what actually matters to individuals living with MND. Because everybody's going to have different things that matter to them. So you know, if somebody's quite social, then you know, there might be features on a wheelchair that matter more than maybe somebody who spends a lot of time outdoors or who has dogs or children or even down to somebody's property. So I think, yeah, it's really important that as well as looking at an individual's clinical needs, it's about, you know, what you like to do, we will find out about the person and almost, look at that individual in that holistic way. And I can see Simon that that riser is something that is enabled you to do the things that you enjoy doing. So being able to have conversations, you'll be with your friends. So whilst that's not necessarily clinical, it gives you that you know, that boost that really helps your quality of life, which is so important and absolutely not to be underestimated. One of the things that you touched on Maggie was around the support that you and Lynn will give in terms of people's mobility solutions, and you give the example of a scooter. And it's sometimes that can be a really fantastic short term solution. But depending on how somebody's MND progresses, it might not be a solution that is even in the medium term is going to work. So that I suppose brings me on to the notion of the education and the idea of anticipating somebody's needs and how they might change. So can you talk a little bit about that, Maggie? So how, how might you do that. So whether that's with an individual that you're supporting, or with a wheelchair service?

Maggie

Yeah, it's, I guess it's probably a little easier with talking to the clinicians in the wheelchair services, it's raising awareness to them, that if a chair is issued by the NHS, that is going to meet the needs of the person all the way through, then that's obviously going to save the wheelchair service time and reduce the frustration with the with the wheelchair user themselves, then they don't have to have a piece of

equipment now and then worry that the drive system isn't working for them. And now that another piece of equipments got to be ordered. And then they've got to wait another few months for that to come to be set up. But as far as supporting the individual with their choices, then it's difficult because everybody is different. And some people are incredibly proactive and really want to know what's out there and what they could have. That's going to even if they're they're walking seems to be pretty good and they don't need a wheelchair, then you know that they're still wanting to know what's out there. So that that's a probably an easier situation to deal with for Lynne and I because we can just help the person find out what equipment there is out there. There are dealerships around the country that have a huge range of equipment that people can go and trial and see if that's going to meet the needs. And we always try and say look, please keep us involved, go and try something. But see how it got on. If it didn't feel that it was quite right, then you know, we can probably find a different solution for you, or help you choose an alternative solution. But sometimes people aren't really ready to have that conversation and then that's fine too. Lynne and I will, we'll leave people with our contact details and just say look, just Call us. If you think that in a few months time things have changed a bit, and you would like some advice and support from us with what might work for you, then that's fine. Just just get hold of us. So we're there to support people, wherever they are in their journey through through the changing of mobility needs.

Pauline

Thank you my game. And Simon, you've, you've talked a little bit about the riser. In terms of other wheelchair accessories. Can you just tell us about the the wheelchair accessories you've got and pay the association have supported you financially with those?

Simon

Yeah. To be honest, I think they association has only provided funding for risers and a battery pack. Or maybe two battery packs. But I do have other accessories on my chair which are provided by the NHS? Would you like to know about those?

Pauline

Yeah, I'd be interested to know, because it's, every service does things differently is it's always good to understand. What services do. So yeah, please share, Simon.

Simon

Sure. Well, this has tilt and recline. It has to powered legs, legs lifter, and the headrest, which in my condition is pretty much essential. The the, the seat cushion is, I think that's some something special. I'm not quite sure what is special about it to be honest, but I don't, I don't get uncomfortable during the day. Obviously, I'm either in bed, or in my chair. So when I get up in the morning, I'm in the chair, just sitting in it until I get to bed. So it's really important that the seat cushion is absolutely top notch. also provided myself with a nice gooseneck smartphone holder and coffee mug holder. Which is pretty important as well. I funded that.

Pauline

That's brilliant. That was really good to know. And I suppose just make the point that depending on the wheelchair service, going back to the wheelchair Alliance report findings of the postcode lottery, in some areas, those things might not be available through the NHS. So that's where we could as an Association support if individuals weren't able to self fund. But no, thank you so much for, for sharing

that. I think we're coming to the end of end of the questions now. I didn't know if anybody, Maggie or Simon there was anything else that you wanted to share before we we wind up.

Simon

As far as I'm concerned, I just like to emphasise again, how valuable the Association this in terms of not just financial resource, but in every other way. Just it's an amazing Association.

Pauline

Thank you. Thank you, Simon.

Maggie

Thanks, Simon, I'm really grateful to hear your story. And yeah, personally, I've been with the Association for about 18-20 months now, I think. And it's a really enjoyable role to be able to support people with a whole range of their mobility needs. So it is the wider independence to enable people to access the community and do the things that they want to be able to do as the disease changes. So So yeah, I think Lynn and I have a very privileged role. But it's a role that is enables us to look at the whole picture of of how we can support people with their mobility needs.

Pauline

Thank you, and we couldn't provide this financial support to people living with MND without support from funders, including the Wolfson Foundation and the Alan Davidson foundation. So really key in terms of helping us deliver what we do. So I just want to finish off by saying thank you, Simon for being so open with us and sharing your thoughts and feelings about using a wheelchair and explaining the difference that the riser has made to you, and also sharing a little bit about the other accessories. Thank you, Maggie. It was lovely to chat to you more about the work you and the team do here at the Association to help people living with MND, when they need a wheelchair, or wheelchair service team at the Association are here to help anyone with any questions, whether it's about how to access the right wheelchair or whether it's about funding or personal wheelchair budgets. please do get in touch. And thanks again. Simon and Maggie. Thank you. Thank you. Thank you for listening.

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