MND Matters: Episode 32: Caring for someone with MND – Martyn's experiences

Steph
Welcome to MND Matters brought to you by the MND Association and sponsored by Toyota GB and Toyota Financial Services. I'm Steph and I'm joined by Martin, whose wife Anna is living with motor neurone disease. They met when they were 16 and 17 and have been together over 20 years and have three daughters. Anna was diagnosed with MND in May 2023. And Martin is now her full time unpaid carer. Martin, thanks for joining us. Do you mind just tell us a little bit more about what life was like before MND? And did your family and before Anna was diagnosed?

Martyn
Yeah, I will do but first of all, I just like to send my condolences really to Lindsey Macy, Maya, Jackson and the Burrow family and friends for the sad news this past week. You know, I'd personally like to thank them for what they've done for my family and the wider MND community and raising awareness, and also to Lindsay for her efforts in campaigning for carers. So yeah, my heart goes out to all of them this week. But yeah, going back to your question, life before MND? Yeah, me and Anna, we met when we were teenagers. She was 16. I was 17. We used to work together in a little clothes shop in a in a retail in one of the biggest shopping centers in the UK. And yeah, we met there. And the rest was history really, we had a bit of time together. And she left work and didn't have the courage to ask her out. And so I went and hunted her down. And then yeah, we ended up getting together. We then over the next couple of years, we we then got married in 2006. We've got three daughters. Three children. So our eldest tiller, she's 19. Eve, our middle child, she's 15. And then Fallon, who's our youngest? Who is 14. So all about family, you know, we're very family orientated family. Everything was about the girls doing what we can for the girls. Yeah, just a lot, a lot of family time. And a lot holidays enjoying them together. But yeah, we that was pretty much like before MND, just like any normal family going out working.

Steph
Lots of lots of lovely family time. And obviously, you know, you just you just told us how your ages of your children sort of how young you and Anna were when you met. And obviously that's sort of you are, you're a carer at a very young age, really. So presumably, your other family and friends are in quite different situations to you. I just wondered what sort of an impact being a young carer has had on you and your family, really.

Martyn
The first thing that I say about being a young carer is, you know, I'd rather be doing it at this age, I'd rather not be doing it at all, but you know, at the age that I am, you know, I find that probably a little bit easier. You know, being a young carer, you know, I've still got my wits about me, I've still got my strength, and that helps a little bit. But yeah, it does sort of just put a spin on on life, really, you know, the, all the plans that you have, and what you want to do. And, you know, when when you're older, and,

you know, with the kids getting older, and it kind of just flips that on its head a little bit. So you just have to think from the point of, you know, Anna being diagnosed with MND was right, reevaluate, and what does that future look like now? And so forget about what was planned and what you want to do. But what does the future look like? But yeah, you know, and I think, being being a young carer, it's, you know, there's probably 1000s of us out there. And it's a challenge. But, you know, me and Anna always say we find ourselves very lucky sometimes. And we use that word lucky, loosely. You know, so I do find that I'm just a little bit lucky in the fact that I am a little bit younger and to be able to adapt a little bit but yeah.

Steph

I think obviously, you've got a very inspiring outlook on everything, Martin and Yeah, same. I'm sure you and Anna support each other through it all, as you know, and you girls,

Martyn

Always have done, always been a very close knit family. You know, and that's how we, you know, we said when Anna was diagnosed, we'd deal with it, how we deal with everything as a family positivity and humor that's everything that we've, we've done, since we've been together. We don't take ourselves seriously in some ways, you know. And, you know, we said in one of the things we said, you know, as long as we laugh more times, than we cry, then we're winning. So, yeah.

Steph

That's a really nice outlook to have definitely, yeah, laughing is definitely better if you can, and obviously, you know, you'd sort of touched on sort of facing lots of challenges, no doubt in your time caring Anna so far, but obviously, you talked about how you have that positive outlook when you can, but would you mind talking us through some of the challenges that you've gone through and how you've dealt with them?

Martyn

I think the challenges, but you know, me personally, I think would be, you know, I've worked since I was probably 14 years old, and I'm very fast paced, and I like to be doing 20 things at once. And, you know, I've always worked, and you're in them routines. And so I think the challenge there is giving up work, you know, something that you've always done, but even though it's a challenge, it's always, I always see it as it's the right thing to do. You know, I wouldn't want to not not do it, even though it was a challenge. You know, so the challenge of giving up work, I think probably the biggest challenge is living with your, your wife who's going through this. And not, not being able to do anything about it, you know, I'm, I'm a sort of, I like to think of myself as a problem solver. But, then, unfortunately, this is a problem that you can't fix. You know, we've always, throughout, throughout life, been able to battle through things and battle through different challenges. But yeah, this is probably the biggest challenge that's been thrown at us, and we don't have an answer or a fix for it. So you've just got to make sure that you do the best that you can, in that situation. But yeah, them challenges, you know, around giving up work, challenges for the children. Because especially in, in my household, you know, I've got a house full of women, and, you know, I'm outnumbered and you know, there are all different ages are all different characters, they're absolutely amazing. And it's trying to be, you've always got to be that positive, you know, influence on them as much as you are through life anyway, but even more now, when it's heightened, and, you know, working with the kids on on their emotions and their feelings, you know, we always said from the start that with the kids that they're never always going to be feeling the same at any one time. You know, and that was probably a bit of a challenge at first is that we're all not in sync with our emotions. So we might be having a good day, and Eve might be having a bad day and Fallon's having a good day, I'm having a good day, Anna's having a good day. But then, you know, maybe one, one of the kids is feeling a bit down that day. But they don't want to say anything, because then they don't want to bring that mood on everybody else sort of thing. So try to be open with the kids and say, Look, you know, we're not all going to be in sync, we're not always going to be feeling the same at any one time. So just speak to us at that time and you know, we can deal with it, don't feel that you need to keep your emotions locked up. So yeah, that's probably a challenge just dealing with the emotions of everybody and, you know, friends, family, you know, the girls. Because I believe that as a carer, you're not just you know, you're caring for Anne, you're caring for the individual, you're caring for your family, you're caring for the friends and you know, the wider family, you know, you just want the best for everybody really, and you kind of just I think any carer takes that on their on their shoulders.

Steph
Yeah, absolutely. I guess people are looking to you for that reassurance and support, you know, you're giving that to Anna and supporting her, caring for her. But there's a lot more, you know, to that family circle, than they're just, the the one person everyone's affected and they buy motor neurone disease when this diagnosis comes into a family's life. So, and obviously you just spoke a little bit about having to give up work. And I know obviously you said that that's you know, that's it's without question. You were you're happy to do that for the circumstances. But, you know, the impact on finances is something we hear a lot from carers and carers having to give at work, and 47% of unpaid carers told us in the survey we put out in 2022 that they worry about money and and then the same survey revealed that more than half provide 75 hours of care every week. So we've recently run another survey to hear from carers about the impact of caring and on their finances. So we're currently waiting for those results to analyse them but I'm guessing is that something you've also had to deal with in terms of having to give it work?

Martyn
Yeah, 100% I think you know, me and Anna were in really good careers. We had really good jobs. You know, we loved our work. So Anna left work first. She left. She tried to go back to work and then she took ill health retirement back in August. I then started continuing to go to work and my daughter just left college and she was going to she was going to care for Anna for a bit. And then I just thought, What am I doing? She's 18 years old, go and be an 18 year old, so I had to leave work. In a way, we've never, I've never been money motivated, never, never chased, you know, never chased money. My thought process on it was that, you know, money is just an enabler for you to do things. So yeah, you'd have to restrict a little bit on what we do. You know, you can spend money and you'll get it back. You only get time once. That's a greatest currency in the world. Time. So, left work, but now we're probably 70% down on what we were bringing into the house this time last year, because, you know, I know, we're still in work this time last year. So it was. So 70% down on income. And you just have to adjust. And, you know, in certain way, you know, luckily, you enough, we bought our house when we were younger. So we didn't have much left on on a mortgage. So that was one of the things that Anna wanted to do first and foremost, was make sure that the house was was done and there for the kids

and, and everything like that. But yeah, so yeah, you have to restrict a little bit. The benefit system is an absolute minefield, when you've never claimed benefits before. What you can get what you can't get what the thresholds are. And so yeah, so we're looking at 70%, down Anna claims PIP. And then other than that, that that's it really, so yeah, I in a way, I'll lose my income. Anna's income's dropped. And yeah, that's something that we just have to adjust to and as a family and and work through it really.

Steph
No, of course, I think there are plenty of other families in very similar situations. But obviously, it's extremely difficult circumstances that you're facing, you know,

Martyn
That's where I always say, you know, like I said, I'll keep on saying it. And that's where I find us very lucky. You know, we are I know that there's, there's families out there that are in a worse situation than than what we are and but even so, it's still a challenge.

Steph
Yeah absolutely, I think, again, there's your positive outlook, but you are facing with it facing a huge lot as a family, you know, and I know, you managed to keep that positive outlook on it, which is really inspirational. And maybe that's potentially why you've got involved with campaigning work as well, you know, you're recognizing that it's, you know, you're in the situation, but others are and you want to make a difference. But obviously, you might not have been involved in the campaigning work if you hadn't found yourself in this caring role. So I guess, in the sense of, of getting involved in things like this, has anything positive come out of this experience of having to care for Anna?

Martyn
Yeah, I get to spend every day with her, you know, and be around my family more, that's a positive. School runs picking up girls or being here, you know, daughter is going through GCSE so being at home more. But yeah, you know, and we always we always laugh and joke as a family. And we talk about COVID. And we talk about lockdown. And everyone hated it, hated it. But as a family, we loved it. So the positive yeah, you know, I'm I get to spend more time with my family. And, and being at home with her. I think the positive about the campaigning work is that, you know, me and Anna say that. And we go back to age that, you know, Anna being diagnosed and such a young age and and we're a young family is the fact that we found that we believe that if you don't have a voice, you don't, you don't get in some way. So, you know, we've always said that while... I'll be open and honest, what I'm doing is for Anna, when I'm campaigning and what I'm doing, but I'm advocating for Anna, but if I can advocate for others, and that's how the journey started was, I want the best for Anna. But it came to realisation that people out there don't have a voice. They don't know how to speak up, they don't know how to challenge the red tape and just this is how we've done it. So this is what's happening. You know, we've not changed a benefit system since 2015. So it stayed like this or so for me it's very much about if I can do the best for Anna and advocate for others along the way then, you know, we're winning so yeah, so it's about so me personally, I'm speaking to you know, there's been a bit of a spanner thrown in the works at the minute with the general election but you know, making some headway speaking to local MPs, local councillors really engaging with them, trying to get them to understand the real world and the life that, not just me, and not just in the MND community, but others out there are facing. So

yeah, that's a positive been able to speak to these people and try to get a little bit of change or, you know, for them to understand and, hopefully, but it's going to take more than me and it's going to take a bit of a movement, but, you know, we just need a bit of change and, and like, like you said, I probably wouldn't be doing it if it wasn't in this situation, because I wouldn't understand the situation. So that's a positive but yeah, hopefully we can, we can try and make some difference somewhere down the line and, and help carers and help the MND community and to get what the what they rightfully deserve. And, you know, I don't believe that you should be fighting for something when the government should just be doing the right thing.

Steph
No, absolutely. No, thank you so much for your support. Martin, we're really grateful to you and for everything you're doing for the MMD community and for carers as well. And obviously, we've got our Support MND Carers campaign, which is calling on candidate stand in the general election to champion the needs of MND carers in the next parliament. And this speech is also in our general election manifesto. So obviously, thank you for your support of our campaigning work. And I don't know if you've also you and your family have received any other the support from the MND Association and how this has made a difference. And we've obviously got things like our carer's grants that we offer as well. But I don't know whether you've received anything like this or any other support that might have helped. Thank you. No, thank you for your support. Because without the things that you're doing, we wouldn't be able to offer ours but it's good that you know where to come and yeah, that support is there for the whole family. So yeah, there's lots of different ways that we are able to help with, you know, for carers and for the rest of the family as well and of course, the person living with motor neurone disease. I guess really just since you've become a carer what piece of advice have you found most helpful?

Martyn
Yeah, so like I said, first, the MND Association has been absolutely amazing for my family. You know, I worked in the charity sector prior to that. And, you know, the way the MND Association were with us, it was very much a, we're not in your face, we're here if you need us, but made it visible that we're here when you want to engage with us. It wasn't right, you know, trying to, engage with us. So I found that really sort of a breath of fresh air really, and the fact that it was right, we know we've got the MND Association if we need him. And our relationship with the MND Association was more of a an organic one. You know, I think it was our first meeting, going back to see the consultant at the hospital, and we met, we met Andrew, who is a volunteer. And, yeah, lovely guy. And just had a great conversation invited us to one of the meetings. And then it just was a relationship that built, he'd come around, we'll have a drink. And we wouldn't even talk anything to do with MND. And we just have a great conversation and his experiences and he'd get to know us as a family and everyone in our local branch in Manchester is absolutely fantastic. And you know, they all have that sort of mindset of you know, we're here when you need us. But yeah, I've, you know, we got told about some of the grants, it was very much like, I'd go off and try and do things, right I'm gonna do this. And then at the MND Association, like, you know that we can help you with that. And I'll be like, I probably read it somewhere. But, you know, it was just like, I'm a 100 miles an hour, And so yeah, riser and recliner chair we've had some funding for that for Anna, which was, yeah, she loves her chair. We've just recently been away and she walked through the front door, she said I can't wait to get back in the chair. We've had some children's grants for the kids, which we used last year to go and see an uncle over in

Spain, which was really nice. Cost of Living grant, which, you know, if that pays your gas and electric bill for a month. So it's all the small wins and grants at the MND Association are doing for us, it makes a massive difference. You know, it gives you something less to worry about. But yeah, so I'd say we've had, we've had a few of the err, and more so well like I said the grants are amazing. But I think the advice that they provide is probably more valuable than like I said I've never been motivated by money, it's just a pound note, and you know, yeah, but they've they've helped massively and yeah, I can't thank them enough for what they've done and what they'll continue to do for for Anna and the kids and myself. Speak up really, when, when you need to. Take a bit of time for yourself. You know, is, it can be, you know, it's full on but, you know, it's probably more, just take that time and try and keep life as normal as possible, you know. When people say to me, oh, you're a carer, I'm like I'm not, I'm just a husband. You know, that's, I don't see myself as a carer. You know, I'm just a husband. But yeah, it's just making sure that the advice would like, say that I took was just trying to take a bit of time for yourself when you can. And I do that, you know, I love music, love, love football, love sport. So trying to continue to do that. Still watching football. You know, when I even if I take, like, we have our routines during the day, and when it's with honor, and then when the kids are home and stuff like that. And then after tea is done I can go and not take myself away, but I can go and watch football for a bit. And I'll throw a few darts because everyone's on that bandwagon at the minute and you know, jump into, you know, picking up the guitar, went out and bought a guitar just to try and in that time to do something for myself. But yeah, just try and take that time for yourself really.

Steph
Good. I'm glad you're doing that, you definitely need that. And it sounds like you've got some fun things that you do as well. But yeah, definitely important to look after yourself where you can as well. Thank you, Martin, obviously, thank you so much for chatting to us. It's been really lovely to hear a little bit more about your experiences and thank you for being so open and sharing how this disease has impacted you and your family and, and for being so honest about the challenges that you face as a carer for Anna and also the challenges you face as a family, but also your really positive outlook on it as well. As I've said it is hugely inspiring. And if you're listening and you're a carer for someone with motor neurone disease, then please remember there's support out there for you. We've got a section on our website specifically for carers, which provides information about the support available, carers assessments, what you're entitled to, and also how to look after yourself. And I know you've just spoken about Martin the things that you do to look after yourself. And our Support MND Carers campaign, as I said, is calling on all candidates standing in the general election to champion the needs of MND carers in the next parliament. And we're also urging the next government to increase the rate of carers allowance to a level that reflects the real value of unpaid carers. As the statistics show increasing the rate of carers allowance will make a huge difference to unpaid carers, like Martin has just shared with us his story as well. So do get in touch if you need support or you would like any more information about anything we've discussed