

## MND Matters: Episode2: Family Support

**Intro:** You're listening to MND Matters, a podcast from the MND Association.

**Nick:** Welcome to MND Matters, the podcast from the MND Association. I'm Nick and I work in the research team at the Association.

**Steph:** And I'm Steph. I work in the fundraising team.

**Nick:** And we have two very special guests with us today. Laura Willix, our Children and Young Persons Service Development Lead for the MND Association.

**Laura:** My role within the Association is looking at what support and services we can provide to whole families affected by MND, and that might include children and young people up to the age of 25.

**Nick:** And our other guest. Megan Donoher is 22 and her dad was diagnosed with MND in April 2020.

**Megan:** Hi. So, I'm Megan. I'm from North Wales. That's where I'm currently staying with my family because of the pandemic, so I'm home from university. I study English Literature at the University of Aberdeen. I'm in my second-to-last year now. Yes. I've been in contact with the MND Association since last October, personally, even though Dad was diagnosed last April.

**Nick:** That's a long way, up in Aberdeen from North Wales. Gosh.

**Megan:** It is, yes. I mean, Dad came with me, actually, to every single university open day that I ever went to. You know, I went to Liverpool, Cardiff, London, and then, when I chose Aberdeen, he actually drove up all 400 miles with me to help me settle in and start my adventure in Scotland. So, yes, it's a long way but it's beautiful. I do love it up there.

**Nick:** Is that the Granite City, is it?

**Megan:** The Granite City, yes, and it is. It does live up to its name, especially in the winter, it's very grey. So I'm not mad that I have to be in Wales at the moment.

**Nick:** And those, sort of, drives up there with your dad. I guess that's always a good time to chat in the car as well.

**Megan:** Yes. No, definitely. I've always had a really close relationship with my dad. We've always been a very close family. We've always had very similar interests. You know, even the most mundane things, we'd always, kind of, go and see the same new films in the cinema. We were always huge Game of Thrones fans. We were the two people that would get up at two o'clock in the morning to watch the new episode, but, no. Dad's always been really supportive of my education because, before he retired, he was an A-Level biology lecturer himself. So he even taught me in college which, you know, when I was fifteen, was mortifying but, now, it was actually such a blessing to, kind of, watch as your parent does what they do for a living and to be a part of that. So, no. He's always just been amazing with my education, so he was quite happy to drive me up to Aberdeen and see Scotland himself as well.

**Nick:** And what year are you in at uni?

**Megan:** I'm in my third year at the moment. So it's four years up in Scotland because it's a Masters of Arts degree, so I still have one year left. I'm hoping that Covid doesn't ruin that for me.

**Nick:** Yes, and have you been at home all year then, this year or?

**Megan:** So far this year, yes. I came home for Christmas, towards the end of November. I decided to come home early because I wanted to, obviously, help out with dad, and I don't like being that far away from home at the moment, and then I decided to just stay here for this semester, and then I'm hoping to go back in September.

**Nick:** And what's it been like, being at home and being able to be closer to your dad and helping out? What sort of things does that involve?

**Megan:** I mean, it's amazing for me. I think one thing I struggled with a lot, and one thing I've spoken to Laura about a lot, was the guilt that I felt being, you know, that far away. It's not like I could come home every single weekend and support my mum and my sister, who look after Dad when I'm not here. It's been really difficult to, kind of, adjust to that but we're used to it now. So, at the moment, I'm with Dad at home by myself, because my mum has gone back to work and my sister has gone back to college, so it's a full time, kind of, job as well as doing uni online. So, obviously, doing the meds and the feeds and it's a very, kind of, structured routine every single day. So it's quite difficult to balance both of them but I think you just get used to it. It's one of those things.

**Steph:** Yes, of course. It sounds like you've definitely got a lot to juggle. I'm sure your dad absolutely loves having you there with him and, obviously, what's it like on a typical day with your dad? I know you touched on different things there but, fitting everything in, what sort of things do you do for your Dad and then, obviously, you balance your work with that as well?

**Megan:** Yes, so he has, I mean, my mum does a lot of the medication, like she does more of the medical side to it. So he does have meds, I think, three or four times a day, and that varies week by week because-, well, it's like trial and error constantly of finding what works for him. And then he had a PEG tube fitted in July, last year, and he didn't start using it until October, so we had a few months, you know, in between which is really good, because it's one of those things you never know when somebody is actually going to become completely dependent on a PEG tube. So we were really lucky that he had that fitted a few months before we started using it. So, we do that four times a day. So, usually, we alternate between who does it. If my sister is at home, she'll do it as well. It's something that we needed training for, initially, to be able to, kind of, get the hang of it because it's really scary when you first see it all. So we do that as well and it's just, kind of, someone has to be with him all the time, you know, just in case he falls or there's an accident or, it's just one of those things and keeping him company as well. Obviously with lockdown, there's not a lot that you can do anyway, so it's just being there with him and it's just trying to make the most of it, you know, being at home.

**Steph:** It sounds like you do a great job and I'm sure he enjoyed your company as much as I can tell you enjoy his and like being at home with him. And what sort of changes have you seen to Dad since he was diagnosed with MND last year?

**Megan:** So, he was unofficially diagnosed in April. I say 'unofficially' because I'd say he started showing symptoms in November, I think, in 2019, and then, because of the pandemic, you know, it came at the worst time because it was, like, April. That's, kind of, when we went into lockdown. It meant that appointments were being delayed and things like that. So, I came home November 2019, I think, going back now, and, initially, it was, you know, his speech was very slurred and he felt a weakness on one side

of his body. So, we thought, you know, perhaps he's suffered a mild stroke. They were the symptoms that we associated with a stroke, and then, during those first few months, before we had the diagnosis, his speech gradually became worse. He'd stutter a lot more, and then I'd, obviously, gone back to uni so, when I came back in March when lockdown hit, it was very noticeable and apparent to me just how much he'd changed from Christmas to March. So it starts really, really slowly and it's just his speech, his movement was a lot slower, and you can't really see the physical changes, I think, when you're here with him every single day.

You know, at that point, we didn't really have any answers so finding out, like the diagnosis. There isn't one conversation that really sticks in my mind as being, you know, 'That was the moment we found out,' because we had discussed it and addressed it as a family beforehand, you know, just with these mild symptoms. We all had a rough idea of what to expect but I remember my mum sitting in the garden one day and I could see, I was just watching her reaction, she was on the phone to the neurologist, and it was just that moment of, 'I know that he's, kind of, confirming what we already suspected,' and then we had so many questions. Everything just, kind of, becomes a blur after that because I can't remember exactly how much I knew about MND at the moment that we found out he had it. We knew that it was going to be a very heavy defeat but I think I still had the mindset, I don't know whether it was denial or just not knowing enough about MND, but my instinct was because there's still treatment, there must be a cure or there must be some way for him to get better. I think that was the mindset I had for the first few months of, you know, the whole process. And then, when someone's diagnosed, there's no time to, kind of, emotionally process anything, because everything goes at like 100 miles an hour. You know, you're introduced to the Association, you have so many teams of people of like neurologists, dietitians, the ventilation team, physiotherapists. You know, like lists of people.

This is not a very good way to put it but it feels like an invasion of privacy at a moment when you are at your most vulnerable. You know, your whole family becomes known to a lot of different people. You become, like, another statistic, and that's not how you're made to feel by these people at all, you know. I don't want that ever to come across in the wrong way because I think the help that we've had from the Association and all these other people has been like a lifeline. You know when you're thrown into the deep end of something that you've never asked or wanted to be a part of. So to, kind of, have people guide you and support you, even if it is over the phone, which it has been for, you know, most of this lockdown, that's just a silver lining of the whole thing, you know, if there is one for MND. It's better to go through something like this with other people, I think. I think I've said to Laura before, I know she's amazing at what she does with people like me, and she's helped me feel a lot less alone throughout the whole thing, but I think I remember saying to her once, 'I wish I didn't have to know who you were'. You know, it's such a blessing to have to know who she is and to have all of these people but I think it's one of those things that you really wish you were still naïve and, like, the only cases of MND you'd ever heard of were of, like, high profile people in the news and things like that.

**Steph:** It's really interesting that you say that as well because we hear that from so many people across the Association who are reaching out for support from the charity. They say, 'oh, we've met so many wonderful people on this, sort of, journey that we're on. However, we just really wish this wasn't the way that we'd met people', but I'm really glad you've been able to get some support. Do you want to tell us a little bit more what that support has involved for you and for your family?

**Megan:** Yes. So, I was put into, I think literally the day that the neurologist called with the diagnosis, that was the first day that I heard of the MND Association. We had no idea what it was. So, I know my mum and dad did a lot with, you know, the Association beforehand but it was the first week of October, I think, I was put in touch with somebody called Jo Cunnah because that's the week I came home from university. That's the week my dad switched to PEG feeding completely, you know, that's when he became dependent on it.

Even though he's progressed a lot since then, that's the week that stands out for me that I had thought, 'I really need to, kind of, speak to somebody who knows more about it'. So, I knew that I was going to need support when I went back to university.

So my mum gave me Jo's email and we spoke quite a few times and she eventually put me in touch with Laura because, obviously, Laura works specifically with people my age. We've spoken quite a few times since October, I think. Just, you know, if and when I feel the need to just, kind of, vent and unload. Especially when I was in university, it was just a lifeline for me to just have somebody that I knew that I could go to, even if it was just something really really stupid, you know. If I had, like, a dream where I heard my dad's voice. That was a thing I went through in October to December, where I really, really missed just hearing my dad's voice, and I used to just say that to Laura on the phone, all the time, and it was just knowing that somebody could understand and, like, listen to me. You know, it's just really comforting to know that somebody already has a background knowledge of what MND is. Because I think that's the most exhausting thing, is just having to explain what goes on. And then Laura also has mentioned lots of other people, I can't remember who, like, you know, organisations that can also help my sister and I if we need it.

And I know the Association have provided grants as well, so my sister and I received a grant in October, everything just seems to have happened in October, which made it easier for me to come home that week and visit my dad. You know, because that was the time when my family needed me, and then the grants have also gone towards my dad's mobility scooter, which we could not live without, you know, because that is what helps him get out of the house and that makes a huge difference to us. And then, only a couple of weeks ago, we had a new chair that, kind of, raises him, because he struggles to stand by himself. You know, and somebody, I think, came to the house to evaluate, like, all the equipment that we've been given to make Dad a lot more comfortable at home and they arranged for the chair and then we had, like, handles placed outside the door, just to help him get in and out, and they even, like, raised the bed to make it easier for him. Which I know is my mum's favourite thing because she feels like now she has to jump out of bed in the morning to get down because the bed is just really high. But, you know, they're all things that the Association have given us or they've helped towards that have made just the biggest difference. Dad would not be able to move without, you know, all of these things in place, so, yes, they're the things that really stand out.

**Nick:** Do you feel like you are, kind of, looking after your dad as well as your sister and your mum to some extent?

**Megan:** Yes, I think so. I think that was a huge thing when I was in university. I felt awful because my sister's only 17 and that is a lot for, I mean it's a lot for anyone, of any age, to, kind of, support a parent going through something like this, but we do take it in turns now that I'm home. Obviously, I've just said, my mum and my sister now are back in work and college, so we do take it, my mum leaves me notes in the morning. You know, at nine o'clock, 'can he have this medicine by ten o'clock'. But it's something that I never want Dad to feel as though it's ever a chore to take care of him. You know, I don't want him to ever look at the three of us and see us as carers. I still want him to see us as children, and my mum as his wife, so it's trying to get that balance right. But, no, I do genuinely love taking care of him and I wouldn't want anybody else to ever do that for us, even though it is an exhausting thing to do.

**Steph:** What sort of things do you manage to do with your dad, or as a family, that make you feel like you are just a family? I know there's still that parcel of things that you would do to help and care for your dad, all of you do that. What sort of things do you still manage to do that make you feel like, 'oh, this is my dad and we're spending time together'?

**Megan:** Yes, that's something that I think we struggled with a lot. That's something that Laura, I think, really has helped me with because, when I came back that week in October, I remember saying to her, you know, the same thing. 'I don't want him to start seeing us as carers', sorry, and I still want him to see me as being his child, so that's something that we've really struggled with.

But I think just being at home. I think the four of us being at home makes a big difference. You feel that a lot more, when I'm here as well, I always feel like not left out. I don't like being away from him at the moment. You know, we watch films together. I work, as well as doing uni as well, so I always try and make sure that I'm home on the weekends, as much as I can, so we can just spend time together. I love taking Dad out to-, we go out for walks and we take him, like, along the canal and down to the river and just, you know, fresh air and just, obviously, the mobility scooter's there and there's still always some kind of medical thing that we need to bear in mind. Honestly, just normal mundane things, at the moment, because obviously lockdown is still happening and there are not many places that we can go to together as a family, but, no, just spending time together. That's all we can really do, and have conversations that don't revolve around MND, which is difficult to do, you don't realise how much of your day it consumes, but, no, we always make a conscious effort to do that, as well.

**Nick:** Obviously there are many other people out there in a similar situation. Have you been in touch, or been put in touch, with any other children and young people in the same situation?

**Megan:** Yes. So, when I did my fundraising, I decided in September to do the Mission 5000 Campaign and that, for me, was the first time, I think, I was truly accepting that MND was a part of our lives. That was a, kind of, really significant point of our journey, for me personally, and that was also a moment when, obviously I was not put in touch but, I found other people who were also doing the fundraising and then, through finding these people, you understand their story and why they're doing it as well.

I mean, it's kind of a young people thing but on social media a lot, I've met a lot of people who reached out to me as well. There's a girl who sent me a message as well because she saw I was fundraising and she said, 'my mum has just been diagnosed'. She was my age as well, and she also had a sister, and it was the first time where I'd had a conversation with someone, who was in their young 20s, who was also caring for a parent who had just been diagnosed with MND. And that was just a huge sigh of relief because, I think, up until that point, I hadn't really been exposed to anybody else. MND is an awful thing anyway but, I think, to lose someone at this age is a little bit more rare. I think Laura and I were saying last week, it's just not as common for someone to be younger and have a parent who's got MND. But I've actually found that to not be true at all because I've found lots of other people. Gradually, you, kind of, meet. There are lots of, like, organisations and smaller charities that focus on MND and raising awareness and things and I think, the more you connect with those organisations and charities, the more people you meet through them who are also going through similar things. So it's, sort of, those things.

The girl who reached out to me in October, her parent has just had a PEG tube fitted last week, and she sent me a message. And she said, you know, 'I know your dad has gone through this. Can I call you? Can we talk about it?' Even though it's obviously a devastating conversation to have with somebody, it makes it so much more bearable knowing that, you know, there is someone else out there who now going through the exact same thing that you've already been through in the past. And she's just one person, you know. I know there are so many other people as well, so it's really really comforting to connect with those people, even though it's a devastating, you know, conversation to have, but it's very reassuring at the same time.

**Nick:** It is really interesting to hear you say that, and it does, kind of, show how important it is to have those connections, and I guess that's the real reason behind us setting up the Children and Young Persons

Service. So, thank you for sharing that. Laura, do you just want to tell us a few things about exactly what is available for children and young people?

**Laura:** Yes. So, all of the work that's been delivered by the Association has been completely family led. So, all of the work that we've done as come from the voices of children, and young people, and their families. They're the ones that have told us what we should be doing as an Association. So, we've really really tried really hard to listen to their voices and deliver what they want, not what we thought we wanted as an association. So, we have a really really wide range of stuff now. Some of the stuff is direct support and some is, now, finding the best support for young people and families that are out there, so signposting to other support agencies.

So, we've done lots of things. We have the direct support that I offer, which came a lot through the Covid crisis, where families reached out and said, 'look, we are really struggling, we're struggling with the pandemic, we're struggling with the diagnosis'. And what we've been able to do is talk to those families, guide them, support them, and give them access to other support services outside. We also have memory boxes now that we have for children and young people aged up to 18. That's been funded by the Nick Smith Foundation. But what they are, they're really tactile like shoe box sized boxes that allow families to create, store, capture really small bits of information. And everyone thinks, when they get the MND diagnosis, that they've got to go to the big Lapland and they've got to go to America and all of this for their kids where, actually, it's not about that. It's about being a family, about being able to talk openly and honestly, about a big cuddle and a cry, still being angry at them when you are. Do you know what I mean? And just still continuing to be a family. And what these boxes do is they encourage you to talk. Not about sad things, about funny things and pass life stories and then to record them and keep them safe in a little box that you might not look at at the minute, because it might not mean anything to you, but in years to come, you don't realise how important the little things are when you no longer have that person to ask anymore about those things. So that's a really lovely piece of work that people have been working on.

We also have a counselling service for children and young people, which is a really lovely partnership with Barnardo's, that's been funded by the James Milner Foundation, and this provides access to counsellors, who are trained in MND, for children and young people up to the age of 25, which was a really really important thing for me. Because lots of services for children end at 18, and there is a big difference, that transition period, between an 18 year old and up to a 25 year old where you, sort of, then fall into adult services. You are an adult but your needs are very different. A lot, like Megan, are in university and you've got transition periods, career choices, the fear of leaving home when you've got a loved one that's got MND. Megan is very good in the way she says she's okay with returning home but, actually, that's frightening to be having to deal with all that she had to deal with and what that means for her as a young person, navigating her way in life, and all of the other things.

So what we've done, we've set up a counselling service with Barnardo's that has direct access. So I can access a counsellor within five days of referral, which is actually incredible, because the waiting list for statutory services at the moment can be anything up to 18 months to see a counsellor. And that's too long. We don't have that time to wait. The service is about short sessions, remotely, in the young people's time, to just provide them a space to talk. And that doesn't necessarily need to be about bereavement. It can be about anything that the young person is experiencing so that's been a really really fantastic service that we've got.

We also do memory making days, because a lot of the young people that guide my work, so I have, sort of, a project team of young people, families, and professionals who guide what I do, and, when we were allowed, they told me that they wanted to be in touch with other people, but not necessarily being all about MND. So they wanted that commonality, of knowing that another person knew what was going on, but they

didn't want to be the MND kid with the t-shirt and the blazer, saying 'my loved one's got MND', but they wanted to be around them. So we did some really successful memory making days, which we do hope to continue when the pandemic allows us to do that.

And one of the other things that Megan is, kindly, going to help me with is we're looking to see if we can set up a young adult carer type support group. So for the 18 to 25 year olds who don't quite fit in to traditional adult caring roles but, maybe, want to be around others or have contact with others in similar positions. We've put a couple of shouts out on social media and we have had some responses from young people, so we're hoping to get, sort of, an informal session together to start to look at what that might look like and is there a place to support young people who are in the same, sort of, positions. So it's really exciting. We really have got a lot going on and it's all needs led. So, it's all family led work.

And I hope we're reaching more now than we ever have and I think Covid, in a funny way, has allowed digital to let us reach more people. So since April last year, since April 2020, we've directly supported 85 families, one-on-one, so very much like Megan. Direct support over the telephone, emotional support, and signposting. That is equated to about 570 calls from me, which has been quite a lot, but also we've delivered now 55 memory boxes to families over the whole of the three nations, and we've delivered five family days so far. At the minute, it's about 15 families who've gone through the counselling, and that's only been running since December. So we're doing some really nice things at the moment.

**Nick:** I guess everyone's journey with MND's very different and so there will be people who don't have such a great relationship with their families, as Megan does with her dad and her mum and her sister. So, I suppose, what you're saying is there's different ways to reach those people. You know, maybe they'd be more receptive to, you know, being called upon by a young person, for example, but do we know of people you can't reach and are there ways to try and help those people?

**Laura:** I think what's come to light, probably over this last year, is that there is a whole, sort of, proportion of people affected by MND who have never reached out before because they didn't feel that there was a service for them, or they were unsure whether there were others in the same position as them. Sometimes MND was always seen as the slightly older person's disease so there tended to be a lot of older people, but what actually has happened is there is a large population of people with families, we think roughly around 12-14% will have children or young people living within the family home. That's a big population of people affected by MND and what I've openly tried to do, over the last little while is include grandchildren closely affected, nieces and nephews, or relatives that all might be impacted. And I think what we're trying to do is make us more-, reaching out to those people and delivering the right support, making sure that what we're doing is right and making sure it's targeted in the right places, based on what the young people are telling us they want. There was no point me delivering something if the young person said, 'Come on, Laura, that's not what we needed. That wouldn't have helped me. You know, I didn't want that.' So, it's been much more about trying to reach and put our resources where it's needed.

Recently, I've been doing a lot of work with schools, with families. Their young person maybe has told the school about what's going on but not in, quite, detail what MND actually means to them at home, that, suddenly, their house has become hospitalised, you know. They're worried about sleeping. They're not focusing on their education anymore. And it's been about helping the teachers at school, and the pastoral support, to support the children better at school. So it's targeting our support, really, to make sure we reach people, but also letting people come to us when it's their time. You know? So that they know there's something there for them now, and they might not need it at the moment but, when it's their time, there will be a service for them, when they want it. So, yes, that's how we've tried to position the service.

**Steph:** That sounds really brilliant and there's so much, obviously, going on, and I know Laura's mention that, Megan, yourself, you're going to be involved in one of the new projects and in helping to get that up and running. What was it about that that made you want to be involved? Why did you want to help us with it? Thank you.

**Laura:** Thank you.

**Megan:** I think just because, ever since I was put in touch with Laura and I've worked a lot more closely with the Association, I think whether that was through fundraising or just having conversations with other young people affected by it, it's made such a difference and it has made me feel a lot less alone. It sounds like a cliché but it's such an isolating thing to go through and even though we all have our support systems, you know. My friends have been amazing throughout this entire thing but it's something that is so specific and I think, unless you have experienced it yourself-, even if you have. Every single patient, and every family, is so unique with their journey with MND and their experiences, so I think it's just having that just, kind of, you know. Like Laura said, it's there if people want it, and I think it's something that has genuinely just made such a difference to me and I've witnessed that first hand so I think if we can, kind of, do that and reach more young people. Because I think it's one of those things, you know?

I didn't know about the support that we could get until, like, six months after Dad's diagnosis. In the first six months, I thought the Association is just there for Dad. I didn't really understand how they could possibly, kind of, help me with it because Dad's the focus. He's the patient. He's the one with MND, so how could I benefit? How could I get that support myself? So I think it's so important because MND is one of those things that, while it's affecting the person who has it, to watch somebody you love become affected by it and to watch them deteriorate every single day, that takes a toll on you that no one can ever really prepare you for.

I think that one aspect of MND, and many terminal illnesses, that nobody really talks about is anticipatory grief. You can understand why that is, of course. You're always very nervous to talk about that with other people because if I said, 'I really miss my dad,' to anyone who has no experience of MND, to the people that remain outside of it, they'd think, 'but he's still here.' But, obviously, MND strips that individual of everything that they have and I think just that knowledge, to be able to share that and to talk about that with other people, I just think, is so important. So, yes. As soon as Laura mentioned it to me, I was just very excited. You know, obviously it's an awful thing to go through but I think if we can have some light in this whole journey somewhere then that's an amazing thing to do.

**Steph:** I think you're going to be absolutely fantastic at it and thank you so much, Megan. I know it will make a huge difference, and, even just hearing you speak now, I'm sure that that will make a huge difference to a lot of people as well so thank you for everything you're doing.

**Nick:** And how old is your dad, Megan?

Megan: Oh, I hope I don't get this wrong. 63, I think. It was his birthday last month so, yes. 63 years now.

**Nick:** Yes. It's great you've got that relationship that you've been able to, sort of, be friends as well as a parent. I mean, that's really special.

**Megan:** Yes.

**Nick:** Probably one of the things that, I guess, you know, most people don't have. If there is any positive, is the fact that you know that there is limited time and you are able to talk to each other and discuss and, you



know, take an interest in his life, what he did in the past, all those kind of things, which some people, you know, they don't really get that opportunity. So, I don't know if that's, I mean, something you would have thought of in any detail but I'm sure you've had lots of those kinds of conversations with him.

**Megan:** Yes, definitely. It's one of those things, you know. And I think the pandemic alone would have made me realise this, but we laugh so much more now than I think we have ever done in the past, which sounds so odd because we're going through the worst thing we've ever gone through, and probably will ever go through, but I think it's things like this that genuinely make you value, like, the time you have together. So, even though we can't really go out and do as much because of Covid, even just the four of us being in the house together, that alone is something that would not have happened because of Covid but even without that. You know, because I was in university, mum was working all the time, and it's one of those things that just brought us together in the worst way possible but it genuinely has strengthened us so much more.

The admiration that I have for my mum as well. You know, she went from just being a teacher to being a full time carer overnight and it's not something that, you know, we couldn't get people on our doorstep, you know, being there to actually give us all this help, because of Covid and lockdown, so the way that she's, kind of, taken on that role, and she's so practical about everything as well, and so realistic about everything. It's like a superhuman kind of strength that she has in looking after him every single day, but it is a team effort, definitely. It's one of those things. If one of us is left alone with Dad, it becomes a little bit daunting, I think, especially for my sister and myself. I'm always petrified that he's going to fall or something like that but, no.

It's brought us together in the best way possible and, like I said earlier, it's such an isolating experience and every family is unique so, while we have the best support system around us, you know, we each have people who care for us and would do anything to help us get through it, no one can say that they wholeheartedly understand what it's like. You know, it's only the people living under this roof that can really understand what it's like so we'll always have that thing that, kind of, holds us together but it's, yes. Not a very nice situation to be put in.

**Nick:** Have you found you've had to explain what MND is then, to university and you said you work as well? Which is incredible that you find the time to do that. Does that make you feel angry or, you know, is it understandable that people don't know, or aren't aware, of MND?

**Megan:** Yes. It's so frustrating, and it's nobody's fault either, because, 12 months ago, even when Dad was diagnosed, I really was so naïve to it. But it's no one's fault because there is just so little awareness. I think that's why I'm so eager to be involved with the Association and do more work with them.

Yes, I remember calling Laura, I think, in September last year. I was just about to start my next semester in university and I was really concerned just in case I had to go home because Dad became really ill suddenly or, you know, just the thought of MND is always on your mind, so I thought, you know, 'this is bound to impact my education a little bit'. So I spoke to Laura about it and she encouraged me to reach out to my tutors and send them an email, and, at first, I said, 'well, should I just say that Dad's not well or shall I just say I've got personal struggles going on?' You know, she was so adamant to say, 'no, you tell them that it's MND. You explain what MND is and you be very specific about it, because it's not just like he's broken a leg or he's, you know, going to get better. You have to be very specific', and I was thinking, 'I don't want to do that. I don't want to put that on to other people as well. I don't want them to think that I deserve special consideration when they're marking my essays. I don't want any of that, kind of, attention', you know? I did, also, at the same time, want somebody to be aware of it, just in case. You know, and it was the case that I

did need to come in October, so I'm glad that I did reach out and my tutors were really understanding about it, but it's always that thing of, 'do I say what it is?'

Because, you know, you can tell someone that, you know, 'I've got a dad who has MND', and then you just have that, kind of, awkward moment. I've had it before where I've told someone, you know, 'my dad's got MND', and they've said, 'oh, that's awful. I really hope he gets better soon'. It's something I laugh about. I have to laugh about it when it happens because I just think, what do you say in that case, you know? Sometimes I'll just say, 'my dad's terminally ill'. That's, kind of, the approach I take sometimes because that just, then, just, kind of, stops the conversation. There are no more further questions and you just, kind of, that's my way of getting out of it a little bit. I do find when I do say, 'Dad's got MND', that people don't know what it is. And you don't want to then have to go into the whole conversation, you know, because you could go on for hours and hours and hours. There's so much depth to this kind of disease.

So, yes. I do find it quite frustrating when I have to, but I am also one of those people that really just doesn't want anybody to, kind of, bring it up at the same time. Even though I don't mind talking about it, it's still always an awkward conversation to have with, like, your manager or with a tutor or something like, but it's also important to tell them, because it's such a specific, you know, thing to be faced with that it's important that you get the right support.

**Nick:** And have you seen awareness raising? You know, have you seen additional awareness of MND in recent times? You know, there's some more high profile people. Rob Burrow, for example. Do you think that's made a difference?

**Megan:** I think so. Definitely, because I remember going on, that was really difficult to watch, I think, first of all. That was the first documentary I'd ever really seen of another family and I thought that was amazing that they included his whole family and you saw his children, and that just made me feel like-, I saw so many similarities between the things that their family were doing and what my family were currently going through.

And I remember going on social media after it and people that I go to work with, friends, friends of friends, were all, kind of, sharing it and saying, 'wow, I had no idea what kind of impact MND can have. Not just on the person who has it but on their family as well. It's a collective thing that you go through'. So that was, kind of, really reassuring, actually, to see more people talking about it. But then it's one of those things. They'll talk about it, you know, when you see, like, high profile people. I know that Charlotte Hawkins, when she's raising money for charities, it's always for the MND Association and that, kind of, is so reassuring and comforting to see as well.

But it's one of those things. I think people approach it differently when they know people who are going through it. You know, before all of this, I'd never heard of any real family that had ever gone through an experience with MND, and, now, my friends, my mum's friends, everyone, is thinking, 'right, well, I actually know someone now who has it'. You know, they pick up on it a lot more. It's more apparent, I think, when it happens, so, yes. No, definitely. It's important to get the conversation going, because I think awareness is just as important as raising funds for the Association as well.

**Nick:** You probably don't realise it right now but what you're actually doing for us, and the way you're speaking, is so incredibly brave and so open that it's, you know, another story of MND coming out of the shadows really. So, you know, I absolutely salute you and your bravery, and working with us in this way is completely outstanding so hats off to you.

**Steph:** Yes, thank you.

**Laura:** Yes. Thanks, Megan.

**Megan:** Thank you for letting me share my story as well, though.

**Laura:** You know, just make sure you keep that. You're still his daughter and he's still your dad, and you're doing incredible and I couldn't be prouder of you.

**Megan:** I think it's one of those things, you know, you kind of get used to it. It's something that you never fully become immune to the facts of, but, every time there's a new conversation, about even ways to make Dad more comfortable, or a new challenge arises that you couldn't have foreseen, you do get use it because you just have to get on with it in that moment. You don't really have time, like I said earlier, to emotionally process anything. You know, I say all these things and I feel like I'm just an outsider and I'm just watching someone else say all of these things, but it never becomes something that you're okay with because you are constantly made aware of how brutal and unpredictable MND is. You know, every single day, like, has the potential to be a very bad one, and then you get to the end of the day and there's still no time for like a sigh of relief or anything because, like I said, it's so unpredictable. It's not something that goes away every night. So I think it's just our job to, like I say, you know, time is so valuable for us at the moment, so it's just our job to make it all count. As cheesy as that sounds, but, no, it really is true. You really just don't take anything for granted.

**Nick:** So we will close off, shall we? I think, yes. It's been amazing to listen to your story. Your dad sounds like a great guy, and your family sound very much together, and you've got lots of friends as well. Yes, so it's been a very uplifting experience, actually, to hear you talk about it and the work that you're doing is great. So it just leaves us to say a really big thank you to you for the work you're doing, and thank you, Laura, for joining us and explaining exactly how, as an association, we're trying to help children and young people as they go through this experience of MND. So thank you both of you, very much indeed.

**Laura:** Thank you for having us.

**Megan:** Thank you.

**Laura:** Thanks.

**Outro:** You've been listening to MND Matters, a podcast from the MND Association. Find more information at [MNDAssociation.org](http://MNDAssociation.org) and, if you've been affected by any of the issues raised in this episode, contact our helpline, MND Connect, on 08088026262 or email [MNDCConnect@MNDAssociation.org](mailto:MNDCConnect@MNDAssociation.org).