

MND Matters: Episode 13: Think Tank and Storybook

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

Beck: Welcome to MND Matters, brought to you by the MND Association.

Alongside, members of the MND community, we bring stories, information, and expertise direct to your ears. Remember to subscribe to ensure you don't miss an episode.

I'm Beck and I'm an Area Support Coordinator at the MND Association and I'm delighted to introduce today's guests who, in this episode, will be chatting to you about the Next Generation Think Tank and how collaboration within technology can make a difference for people living with or affected by MND.

So, say hello to Nick, Stuart, Diana, Mike and his partner Mary.

Nick's the Director of Care and Improvement at the MND Association and he's joining us with Stuart Moss who is the Head of IT Innovation at Rolls Royce. Together they have established the Next Generation Think Tank and are here to share some of the incredible tech for good innovations coming out of that collaborative work.

Diana and Mike are here and they're both living with MND and are going to tell us about how they have helped to shape the exciting new project coming out of the Think Tank called 'I Will Always Be Me', the book that banks your voice.

Mike's partner Mary also joins us and she's going to share how the storybook has made a difference to their family.

Throughout this episode we mention "a book" and by that we mean an e-book called 'I Will Always Be Me'. It has been beautifully written by an award-winning author and illustrated to help explain to loved ones what MND is and what's changing around them. The person with MND reads it aloud and as they do so, it records their voice ready to be used in the future with a communication device. So, more on that as we delve into the episode of the podcast...

So, Stuart, if we could come to you first. Could you tell us about how you became involved with the MND Association and your story really in terms of MND and your experience of it.

Stuart: Yeah, so, my father had motor neurone disease. When he was diagnosed, we didn't even know really what the heck it was. We had no concept of it. I suppose the thing that we were told at the time was that, you know, Stephen Hawking, that was as much as we knew. He passed away on Christmas Day in 2014. From that point on I kind of, I work in innovation for Rolls Royce, and we try to solve complicated problems. I can remember actually saying to him on the day that we found out that he was diagnosed 'I'm sure there's some innovation that can help this dad, we just probably don't know what it is yet'.

Quite a lot of time passed after 2014. About 5 years later, I was given the opportunity at work to lead a, what we'd call an outreach programme so, you know, a community investment type of programme for the company, and, being as I was lucky enough to get the finger pointed at me and be put in charge of it, I said I think we should do something around motor neurone disease. My particular outlook on the world if you like, and the best way to do innovation, is to collaborate with others, so, work with other people who don't have a blessed idea about the thing that they're trying to solve. Because they're the people who will probably come up with a new and novel approach that, in this instance, naivety is a superpower, you

know. Being kind of from the medical community might, in the instance of a medical problem, not be the best position to be in to try and solve it.

At that point when I was given this opportunity and I said we should do something around motor neurone disease, there was a campaign running at that time from the Motor Neurone Disease Association that I have to admit I didn't necessarily read all of the things that came from the MND Association, the newsletters every month, but I'd read this one and it was about making sure that people retained their voice. And, so, I picked up the phone and I tried to get hold of the guy who'd actually posted, who was credited in the newsletter as putting it out and well, unfortunately, or somewhat now in retrospect fortunately, he wasn't in that day. He was out of the office and Nick Goldup picked up the phone and I said to him about this crazy idea which was 'what do you think about Rolls Royce, who are an aerospace company, working with some other IT companies as a sort of combined effort to try and help people with motor neurone disease. I haven't got a clue what we're going to do yet but what do you think to that as an idea?' and I'll let him speak for himself, but you can probably guess, you know, spoiler, that he obviously said yes or we wouldn't be here today.

Nick: I didn't need to be asked twice, put it that way Stuart. I thought it was an amazing opportunity.

Stuart: In most big corporations now when you're dealing with IT, which is the part of Rolls Royce that I work in, a lot of that is outsourced now. So, you'll have your big companies like Microsoft, and in this instance Dell and Intel who will, in Dell's case, you know, they provide the laptops for Rolls Royce but it's not all necessarily Rolls Royce people who are doing it. We work with these partner companies to provide IT to our employees and so it seemed like a good idea to say 'if this is going to be our IT function's Outreach programme, why don't we do it with everybody, even those other companies. So, we held an event in Derby in my office at one of our main sites and we invited all of those IT companies to take part. Nick and I effectively stood at the front of the room and told them the idea, about how about if we all collaborate on trying to improve technology for people with motor neurone disease and, I dare say Nick much to our surprise, they all said yes didn't they? We actually have a photo somewhere of them all with their hands in the air saying we want to take part in it. So, we've been doing various things for the last 3 years now, across Covid we've been working on various different activities with that group.

Nick: Shall I jump in there. It's just been unbelievable. I mean the day that I picked up the telephone and Stuart was on the other end asking me whether I wanted to be involved, I mean that was one of those moments in time that just sort of put us off in a different direction and I suppose from my perspective I'd had some experience through my previous career working in technology and I could see the real benefit of looking at things from a different perspective commercially as well as inventing new innovative ideas. So, yeah, to be able to have that opportunity to be up in Derby at the Innovation Centre there with the likes of Intel and Dell and Microsoft and Google and all of these huge names in front of us, it was an opportunity not to be missed. To really shout about MND and to tell them, you know, this is it, this is what we need to do. And quite honestly, a lot of the big tech companies have big corporate social responsibility reasons for putting their technology into the hands of people to change lives and so it was a match made in heaven really.

Beck: And Nick, can you tell us a little bit more then about one of the projects that's come out of the Think Tank, the storybook.

Nick: If it's okay, can I just start a little bit further back which is sort of a bit further on in the journey which is, you know, we got everybody in the same room but what were the exam questions that we were going to answer? What were we really going to hang our hat on as an exam question to answer to change lives and we could have gone down the route of

looking at mobility, we could have looked at Artificial Intelligence, we could have looked at speech and communication, I mean the opportunities are endless really around how technology can support people. And we thought, do you know what, speech is something that is so important, and when you look at speech, it's just such a powerful medium of identity. It tells everybody about who you are, where you're from, your mood, your humour. You know, when people lose the opportunity to use their voice, up to 90% of people living with MND eventually rely on some sort of communication aid, it's really, really important to bank your voice, but also to think about how we can allow people to talk for longer.

And so, one of the projects we worked on, we worked with Google to try and help them and support them on Google Assistant which is a virtual assistant that people use to interact with their kit at home, you know, Smart TV, Smart devices, gadgets. I think there's over a billion devices, so what if we could use the lived experience of MND to work with Google to improve that so that it works better for people with dysarthria and that's something that we've been doing over the last year, year and a half. But Rolls Royce said look, what if we could come up with a piece of Artificial Intelligence that listens in to peoples conversations so that people can try to communicate at a speed closer to natural conversation when they're unable to speak and that's something I'm really interested in and that's perhaps something that we'll talk about around future projects.

But also then, thirdly, voice banking and how do we improve the process of voice banking? How can we make it so much easier, simpler and create an experience and I guess that's the challenge we set ourselves? How can we get a great end product with an amazing voice in a much easier way than was able at the time?

Stuart: The turn things on its head approach that we used. So, today, you know if you talk about diagnosis of motor neurone disease, it's a horrifying prospect and we said, well how about if that became, and I'm kind of aware of the people we're speaking to today, but how about if we could turn that on its head? How about if it could be 'you now qualify for things that you wouldn't have qualified for in the past?' We talked about things like, it's science fiction stuff, but what about the Iron Man suit? You know, you now qualify to have a suit that makes you super strong, makes you able to fly, funnier, more intelligent, you know, that sort of stuff. What about if that's what you were given on the day? So, yes, the future's going to be different but different in a sort of more magical way. So, we started looking at things from a different point of view because it was a different bunch of people who were looking at the problem. It took our naivety if you like as a group of technology companies to see this thing differently. All the big innovations in life actually came from the naïve, you know. Penicillin, nobody set out to find penicillin, it was an accident. It's that sort of mentality, not to alienate any of the professionals out there but sometimes you can stand so close to the woods that you can't see the trees, right? We just tried to provide an environment with this Think Tank to think about things differently. Now where we've got to with this particular project is somewhere that we never expected to be at because it's never been done before, right?

Nick: So, we said, you know, we want people with MND and affected by MND to be part of these projects. It has to impact people and people need to be part of the testing. That's so important. We can't just concentrate on one gadget that supports, you know, ten people, that's not what we're here to do. Also, we need to make sure it's accessible, so we put sort of an unwritten rule, well it was a written rule in the end, that we need to make this available. And when I say available, I don't mean just financially, I mean in terms of accessibility so that people can use it. You know, those principles were really key when we set up the Think Tank. Also at the time, well actually just before, 2018 the MND Association had a survey and that survey showed that, on average, it was taking people three months to bank their voice. And people were working on how we reduce this, how do we get it down and my goal was to bring it down to an afternoon. Wouldn't that be great? Wouldn't it be brilliant if we could save time for people and so, again, the stars aligned and we thought, yeah, we've got some kit,

we've got people in a room, we know what we want to achieve which is a much better experience for people. It's taking too long now, and people don't have time. They don't want to be spending time reading 'the rain in Spain falls mainly on the plain' alone in their room. So, what shall we do, and there the project was born.

Beck: That all sounds really exciting, and I wonder if we can bring in Mike here now. So, Mike, you're living with MND and you're here with your partner Mary, and I don't know if you two want to talk about your experiences of voice banking and what this means?

Mike: I want to say that obviously voice banking and getting your voice as close to you as possible is very important. Because voice banking, I had an experience of trying to bank my voice with an app on the internet and after saying all these different words, hundreds of them, when we played the recording, we were disappointed with my voice. I sounded like some crazy European Caucasian something, no disrespect but my voice is supposed to sound like me because your voice is your identity. It tells people where you're from, yeah. You have to get it right because when you try to talk with one of your friends, they're supposed to say 'hi Mike'. They're not supposed to say 'who is this?', you understand, and that's where the book comes in because the book is, what 99.9% me, my voice. Even my children identify me 'oh, that's you dad. That's your voice', you know what I mean? So, I'm Afro-caribbean and your voice should sound like where you're from. Everybody needs to be included so it's important that we get it right.

You mentioned Stephen Hawking. Everybody accepted that synthetic voice was Stephen Hawking's voice, but he kept it because it came to be his identity. But I would have liked to hear what he actually sounded like, his true voice. And if you fast forward to the comedian Lost Voice Man, yeah, his voice sounded like a very posh type of voice, but then a couple of weeks ago someone, one of his friends did a recording of his dialect, because he's a Geordie, and they blended it in, and he said that's what his voice would have sounded like. So, voice banking is very, very important.

Beck: Diana, I saw some nods of recognition really resonating with you around what Mike was saying there as well. Is that your experiences of voice banking as well?

Diana: Yeah, definitely. You know, I remember 20 years ago working with children on a word processing application in schools and hearing that posh voice that Mike's just explained and it was called Microsoft Sam. There was one called Mary and there was one called Sam and the children used to select the different voices, and there was a more computerised one, but they were, they did sound quite realistic and a more human voice but this was possibly 20 years ago. And, you know, I can sympathise and understand what Mike was saying about banking voice. Banking voice was just soul destroying, just sitting there and, Nick said it's up to three months, well it took me about two months, and I just lost the will. I just felt 'I've said this sentence before. Why have I got to say it again?'. I completed 150 sentences I'd been told to do and then I expected like a gold medal at the end, only to be told 'yes, well done. You're nearly there. You've just got another 150 to do'.

Another two weeks later for my voice to come back and it didn't sound like my voice. I even played it to the pupils that I tutor. I tutor online for the MND Association, I have a fundraising page, and I played it to the children, and they just laughed. They were like 'that's not you' and I tutor on an audio only platform, so they don't see me, they just hear me, so my voice is even more important that it's recognisable that it's me. Because they can't see that it's me. How do they know that it's me that they're talking to? It's a bit like on the phone, if they can't see that it's you on the phone, how do they know who it is. Yeah, so I can totally understand what everyone else has said about voice banking. To actually have a creative side to banking my voice, it was straightforward, not too techie, even though I am a bit of a techie

myself, easy to use, and it was sociable. I sat there with my husband and banked my voice which was just lovely.

Mike: Yeah. One of the things that I can't really understand, maybe you guys, Stuart, could tell me, why is it that when you make a phone call to someone, the person at the other end can recognise your voice instantly but then all these different voice banking types of whatever are so hard to do. Why is it so different on different platforms if you try to bank your voice but on a phone call, everybody knows it's you at the other end?

Stuart: So, if you think about it Mike, I suppose the old way of doing it was, you know, read all these sentences that didn't make any sense right and what would usually happen, the reason why people don't recognise you is, do you ever answer the phone in a really wooden way 'hello, it's Mike'. You would never do that right? And you'd read these sentences out, the old imagination for how you bank your voice was read out 'red lorry, yellow lorry'. Read out, you know 'the rain in Spain falls on the plain' and that sort of stuff. and that's just not the way people talk. So, when you use the book, and I dare say it's not scientifically proven, but when you use the book, there's much more emotion in this book which I can tell you very openly, we as a group when we were trying to figure this out were petrified about because that's not the way that people do it today. What if it's wrong? What if there's too much emotion in your voice? What if we get too much of what feels like you out? That's exactly what we wanted to do right? And then we find that, as Diane said, when you get the recording back it sounds a lot more like you. Well, maybe, it shouldn't come as a surprise because we don't talk in a wooden way do we? So, hopefully, some of it is, by this change of approach to it, we've not necessarily redefined the science behind how you do it, what we've done is change what we're capturing in the first place and that makes it more like you. But you do have to give that bit of you for it to sound more like you which is why people who've read the book do say it's quite an emotional experience right, but you need that emotion to put emotion in the voice. If you don't have it in, you won't capture it.

Mary: Yeah, that makes so much sense. And I think for us, in terms of the book, I could just see how that could be so much more impactful, not just for yourself as the sufferer but for your family because I feel as though the thing with MND that is different to most other illnesses is that it robs you of so much as an individual but it also robs you as a family of so much. I remember one of the other participants in the video saying that, when they received the diagnosis, a piece of her died that day. It was her husband who received the diagnosis but a piece of her died that day, because actually you don't go through this illness by yourself. If you are fortunate to have a family, everybody's going through it.

And what's so lovely about the book is that it's got such an appeal to the family, and I thought to myself I could see how it could be utilised for both the benefit of the participant like reading that book again and again and again for example, the way that you would read sentences again and again and again gives your voice more dimension. Actually, this is something that you would want to read again and again so actually you would get humour from the way that you may read it in parts or, if you're reading it to your grandchild and they decide to do a headstand in the middle of you reading you might laugh through some of the sentence, but actually that could be quite useful for giving your voice more dimensions but, equally, you're broaching tough subjects with your nearest and dearest and it facilitates that so beautifully so it's got such a broad appeal but does so many different aspects of what needs to be done. It's really beautiful.

Nick: I think that's really true actually and it takes me back to when we were making the book and the project and the feedback that we had at the time which was it really helped people to say what they wanted to say but hadn't been able to find the way to say it. It was really important that we got the story right and Jill Twiss, who's the author, she was fantastic in terms of taking that feedback and saying it in a different way. You know, it couldn't offend,

it couldn't be clinically incorrect, it had to tick so many boxes, and so the words and the way that it's produced into this lovely book, it was so important to get that right and I think Alan in the documentary film, he also talks to it as something that his wife had been saying to him 'you need to write things down in terms of a legacy and you need to create something that will be everlasting' I think is the phrase that he uses and this really does allow that in such a nice way. So, yeah, I just thank everybody that was involved in that kind of production of the book and to Mike and Diana for your involvement in that because it's the best example I've seen in the Association, I would say this wouldn't I, but of co-design and working together with people that we're here to support to get a really good end product.

Mike: I must admit that I'm pleased with the book. I had to stop myself from bursting out in tears so to speak but it was the very ending that got me in the end. Up to that point I was doing okay. But, yeah, very emotional.

Mary: And I'd just like to say as well, I think your approach, your turn it on its head approach, is really good because actually, personally, being on this journey with Mike, to me it's really challenging. I think Mike's daughter who's a nurse said it best. She's a nurse, she's dealt with people with all kinds of illnesses and, when she heard the diagnosis, she retreated into herself and was thinking about, because she knew what it meant, from a personal interaction, which none of the rest of us really did. We all had our own approach. Michael went off, digging and finding videos and going down that rabbit hole of finding out as much as possible but equally it just being really heavy on your head. I went through the process of completely ignoring it to a certain extent and just dealing with it day by day because I knew from personal experience previously, I couldn't deal with going down any rabbit holes because it would just be too depressing. Whereas she knew what was coming and she retreated into herself, but she said it best in that, from her perspective, it was one of the worst things that could ever happen, or the worst thing that could happen, having that illness.

But I love your approach because it's the first time that I've had anything that gives me any hope because, actually, you do want that feeling of being able to have access to things that you wouldn't have had access to before. And, actually, from my perspective, because I've cared for my nan and I've had interaction in the medical field for other things, I don't know whether it's my nan's age or her particular diagnosis because it's quite well known, it was easy for me to get the things that she needed. So going into this with Michael I was like well this is a really bad diagnosis. We're going to be able to get loads of stuff, you know, whatever you need, you're going to be well taken care off. It's going to be a strain yes, to look after and help you deal with things and we're going to have to deal with things in a different way but actually your needs are going to be catered for. And I've been really saddened and very frustrated by the fact that it really is the opposite. I don't think I could have experienced anything that requires so much and is given so little, but this is how it should be. Your approach of turning things on its head, being able to qualify for things that you wouldn't qualify for before should be how it is because this is the one thing that needs it. This is the one illness where you are robbed from everything, that you really need to be given everything, or at least some things at the very least, you know. So, I love that and it's the first time that I've felt hopeful so I'm really thankful because actually from what you've done with the book, it really demonstrates what you're going to be able to do.

Beck: Diana, I saw some real strong nods of agreement with what Mary was saying there for you as well.

Diana: Totally. Mary, you know, you just put it so precisely. Things should come automatically when you're given that diagnosis of a terminal illness. You shouldn't then have to fight for a Blue Badge, you know. You jump through hoops to get that Blue Badge and your PIP assessment, your DS1500, it's all hoop jumping. Now why isn't it just given to you? Look, this has happened, this is your diagnosis, this is how we're going to deal with it, and

everything is just one press of a button and it all just comes to you, you know. And having the book there is just nice because it's one less hurdle to do. I mean I'm hoping that now when somebody is given that diagnosis, rather than the neurologist saying 'we'll see you in three months time', they give you something positive. They give you some leaflet or even, better still, a link with everything on it. We don't want bits of paper. We press the link and it all just starts cascading. That would be so much more helpful.

Stuart: I'd have to agree with Diana and Mary in that my experience was exactly the same with what happened with my father. This is what you would want but the real-life experience isn't the same. So that's why, in a warped way, it made sense to me that if the IT industry goes and does this, you don't need a diagnosis to go and bank your voice from the IT industry. It's a bit like buying a memory stick. If you want to buy a memory stick, you go into PC World and get one. As soon as we took this into an IT world, you know to Diane's point, if you can get to the website now, in theory, once you knew about it you could go and do this self-service which is a very different way. It's very empowering in a way that you can go and do this.

If I went back to a time when back in 2014 this stuff was so far out of reach, it did exist then, but it was so far out of reach that it wasn't something that my dad could use. To Mike's points about, you know, your character and stuff, I wanted to hear his voice. I wanted him to be able to speak to me about stuff because one of the things with MND is that you spend a lot of your time, Mary's already touched on this as well, you spend a lot of your time fighting stuff. And, actually, I'm going to be purely selfish for a minute, for me as his son there's a load of things I wanted his opinion on because I held my dad's opinion as sacrosanct, you know. He was the guiding light, he's my compass if you like, and I want to know his opinion and so, a lot of the essence of 'I Will Always Be Me' is because I set up a system for him where I could text him. Now, it would take a long time for him with his eye tracker to type an answer if during the day I was talking to him through text messages. Because it's asymmetric, what I mean by that is, if I send a text I don't expect it to come back instantly like in a conversation. Face to face, I expect you to answer. If you don't answer within a couple of seconds it feels a bit icky and a bit socially awkward. If I send you a text and you don't respond for 10 minutes, it doesn't matter. But when I got the text back which he'd laboured over for 10 minutes, it would have exactly what he wanted to say and he's still there, it's still him and that's what I wanted us to cherish in this book was, you know, don't see the illness, see the person. And that's the bit that I'm really, really proud of this because of that point of view. It's the very first beacon of that piece which is focussing on you, the individual. Let's stop focussing on kind of the MND bit, let's see how we can circumvent or go round or go over, I'm not bothered right. Naivety again. However, we get round it, however we accommodate it, whatever we can do, lets try and do that but try and keep our eyes focussed on the person that's there in front of us.

Nick: Yeah. From my perspective, this is really interesting to hear and I'm really pleased to hear everybody's comments. I think, Mary, you talked about hope – such a big part of what we tried to achieve here – and improving quality of life for people using technology and making life just a bit easier is kind of at the heart of our new Promises as the Association's strategy, and technology plays a big role in that, and we've committed to it. So, to hear that something like this which is a project we've looked at in a different way and come up with a solution to something which is so much better than what it was I think, it's great to hear. And the next thing for me is, you know, until we find a cure there's care and there's technology and there's better quality of life and it just cements in my mind that the route we've gone down with the Association and the Think Tank and everybody's involvement is the right one.

Beck: It's really exciting to hear all of this, you know, like what's on the horizon and how we got to where we are with the storybook. Thank you so much for Mike and Diana and Mary and all the families that were involved in testing the book and getting it out there and being

part of the documentary and coming along to a thing like this, you know, the podcast, and letting other people know that the process has been improved dramatically and it's tactile and a beautiful way of banking your voice so thank you so much. And thank you Stuart and Nick for driving that forward and the others as part of the Think Tank. I'm excited to see what's next.

Nick: Can I just say two really quick ones otherwise I will regret not saying it. Voice banking is now so easy, just get it done. It's such an easy thing to do now with the book. 20 minutes, 30 minutes of your time and that is achieved so I think it's really important to do that. And, secondly, go to the website iwillalwaysbeme.com. You can access it through the MND Association website as well, otherwise go directly there and have a look. There's some lovely stuff. And if you want to see a wonderful cast of Hollywood superstars like Mike and Diana, they're all on the video so do go and have a look. That's on the website as well.

Mike: I just wanted to ask Diana quickly what has helped you?

Diana: What has helped me? Humour. Humour and carrying on with whatever I possibly can do, not just sit there, do something.

Mike: Absolutely. That's the same mindset I've got.

Diana: Brilliant.

Beck: What a perfect place to wrap up this episode of the podcast. So, thank you again everybody for joining us and if anyone would like to access the storybook then you can go to iwillalwaysbeme.com. It's completely free for anyone living with MND in the UK and it only takes 20 minutes to read the story aloud and bank your voice. Details on how to access it are included in the description of this episode and, as always, you can contact our MND Connect helpline for support if you have been affected by any of the discussions we've had today.

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