

MND Matters: Episode 29: Cultural challenges

Emily Richardson

Welcome to MND matters brought to you by the MND Association and sponsored by Toyota GB and Toyota Financial Services. 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. My name is Emily and I support people living with and affected by MND to share their stories to help raise awareness of motor neurone disease and the work of the MND Association. It is my absolute privilege to be joined today by two incredible people. Yvonne Johnson is a mother, a wife and works for a local authority in London. She is also living with motor neurone disease after being diagnosed in May 2021 after months of having some speech difficulties. Since diagnosis, Yvonne has shared her story with the MND Association, been instrumental in the development of I Will Always Be Me - the book that banks your voice, she's worked with Google to test and inform them on one of their newest accessibility products called Relate. And she's now using her own social media channels to raise awareness of MND within her community. If you want to follow Yvonne story on Instagram you can find her handle @this.is.me.not.MND, and there's a full stop between all of those words. Liv Little is an author. In early 2021, after experiencing problems with dexterity for a couple of years, Liv's dad became one of the six people diagnosed with MND every day in the UK. He died from MND in March 2022, just over a year ago. At the time of caring for her dad Liv put on hold her master's degree in black British writing to care for him. Liv is currently in the process of promoting her debut novel Rosewater, which she was writing while her dad was living with MND. We are hugely grateful for your time today. And hello, both of you.

Liv Little

Hey, thank you so much for having us. And Yvonne. It's great to get to actually meet you.

Yvonne Johnson

Yeah, likewise.

Emily Richardson

We are gonna have the opportunity to get to know Yvonne a bit more throughout this episode. But Liv I wondered first, if you would feel comfortable telling us a bit more about your dad as a person.

Liv Little

Oh, I'm probably going to cry at some point. But yeah, my dad was is was a lovely human being he, he came over from Jamaica in in his 30s where he met my mom. And then I was kind of born he was a very sweet and sensitive human being. And he drove the London buses for like 25 or 30 years. So he knew all the streets, all the routes. And he had a really strong community of kind of like black Caribbean black bus drivers who were doing the thing and you know, meeting all the people and seeing the city from a different kind of lens. But yeah, he really always wanted to go back to Jamaica. And so that was like, the kind of like driving force while he was working. And he did manage to go back in his early kind of 50s he built his house and that was a really kind of special moment for him. But me and my dad have

always been close. We've always been friends we've always gotten on you know, he was a very like I said a sweet and sensitive human being and him and my mum maintained like fantastic relationship, you know, even kind of not being together. So we had a really special kind of family unit and he gave me Jamaica and he taught me so much and um really witnessing him going through what what he did and the depth of compassion and like gratitude and just like kindness of spirit that maintained even as he was like facing something really challenging, I think really speaks to who he was as a person.

Emily Richardson

Yvonne, you've done so much to raise awareness of MND since your diagnosis can you tell us a bit about what prompted that for you?

Yvonne Johnson

I think being diagnosed with MND doesn't change who I am. And I maintain that. Culturally, I am challenged. I don't let that put me off even, if you like, my community, my family my friends who are of the same culture as myself, if you like I would like to think I am teaching them, I'm making them understand what it's about. Culturally, my friends and family are from the Caribbean, Barbados, and I don't know if you have same experience Liv, but we're brought up not to share our personal stuff out there. No one needs to know except for yourself and your close circle, and I find that difficult dealing with my family abroad, if I start speaking they're like "okay, okay, don't speak, it's okay" and I'm like "I can speak, it's only that my speech sounds different". Even going into shops abroad in the Caribbean I got mistaken for being intoxicated, you know, and this was in a medical setting so um there's a lot to learn for everyone to learn and culturally I wouldn't expect many people from different backgrounds to feel comfortable talking about what they've gone through because when I look on the MND Association platform when I was first diagnosed, I didn't see anyone that looks like me. That was at a time when I was like "who can I talk to about this?" Apart from my family, who can make me understand about this, who can I relate to? I went on the platform and it's an amazing platform, there's lots of things going on. But I didn't see anyone looking like me and I kind of felt a bit isolated you know so there's a lot to learn for everyone but for me I will never let MND define me at all I'm still me, I'm still who I am. I'm not gonna change.

Liv Little

I think it's a really important point that you're making around culturally, the shame or the, or the feelings that you that you should hide. And I think that was definitely something that my dad struggled with, and that he felt like you're gonna be judged. In Jamaica he would try to stand up, even though it was really hot, because he didn't want people, his family to see him and to judge him. Which is, which was a really heartbreaking thing to see him go through to pretend that he was in a position that he wasn't. But I think the work that you're doing even just within your own family in terms of vocalizing it and standing strong is so is so important. And that was such a such a journey for him. And I had to kind of say, No, this can't be a secret between you and I this has to be something that can be shared out more so but you know, I wasn't in his position and I wasn't the one that was going through the change, you know, and it can be very easy from the outside looking in. You know,

Yvonne Johnson

And also you've got to think about his generation. His generation their mindset was very different to our generation and even the generation coming coming up you know everyone is more outspoken, so I do feel there's going to be change, but there's still a lot of work to be done, you know, because even people my age are a little bit ignorant. I come across people who are like "oh, is something wrong with her?" I like when people say "are you a stroke victim or patient?" and they want to know what I'm going through. I like people that ask me questions, I don't like people that think "I won't deal with her, she sounds like that" you can see it all over their face.

Liv Little

It's about them being uncomfortable and that's important. One thing that I did want to say is that I think immediately when my dad found out that he had motor neurone disease, like the reference point was always Stephen Hawking that was like the go to

Yvonne Johnson

Yes, exactly

Liv Little

A very wealthy individual with like, a lot of access to things that my dad didn't have great wealth and all of those things. And I think that was that was quite jarring. And what Yvonne was saying about coming to the platform and not seeing, like representation, it's like, okay, maybe he was able to, I don't know the ins and outs of every extension of lot and all of these things, because of the position that he kind of occupied. And actually, it kind of it was the thing that everyone would say every appointment that we would go to. And I don't know if that was helpful or not.

Emily Richardson

I think that's a really important point. And I think it's also why what you're doing and sharing your story Yvonne is so vital. You've taken the decision upon yourself to go and raise awareness because you didn't see yourself reflected when you were first diagnosed. And now that's going to prevent other people diagnosed with MND from feeling alone when they come to the MND Association as they will see your face and hear your story. And Liv you've assisted Yvonne with that through sharing her story through your newsletter, The Feels.

Liv Little

Yvonne's doing the work. Yvonne's like taking up space in a way, which is bad and speaking about what she needs to speak about. And so it wasn't me providing an opportunity, I felt like she provided an opportunity for me to share that in my platform. And that's really powerful and really deep. And that so thank you very much.

Yvonne Johnson

Thank you for, you know, putting it out there as well because we have to also point out there's nothing to be ashamed of. And when you said, about your dad, I know that feeling, I was so ashamed but what it is, you think back to what you used to do, how you used to be, what you do with your friends. And, and, you know, will you be able to do that now. And it's hard, because I had all these plans, I'd just finished my degree, I was gonna change my career path, and that all changed, but it's all changed, but I

made it work for the good, you know, I'm putting my situation to some good to make it help people understand and help people get through it.

Liv Little

And I think he even realised that impact. Sorry. You know, it's huge. You're amazing.

Yvonne Johnson

Thank you.

Liv Little

I wanted to ask you Yvonne like, where do you draw your strength from?

Yvonne Johnson

Okay. I have faith. And also I'm that kind of person that I'm not gonna sit down in my misery. And I'm not taking it for granted that I'm that person cause at the same time, I appreciate that not everybody is going to be able to deal with it in that way. It's not an easy thing to deal with. It's about making a choice. And for some people it's not that easy. And I get it, it's not. But for me, I made this choice to get on with my life and live every day with my last and just enjoy life. Anything I want to do, and I think, like "can I do it?" I don't care, I'm gonna do it. I'm all about having fun, laughing just enjoying life. and I'm it also makes you appreciate life, life is precious so appreciate it and make the most of it. To me, I haven't got time to sit down and be depressed. I have my days, I do. But, I quickly get back up and I'm alright, I've had my cry, I've had my rant and now it's time to get ready to go out and have some fun or, you know, there's no choice. I have to be this way. And I'm not I'm not showing off or anything. It's like, I can't find any other way to deal with this. And that's the only way I have to deal with this wicked disease is get on with it.

Liv Little

Thank you for sharing.

Emily Richardson

Thank you, Yvonne. Liv I know that you've kind of written about your dad and some of the things you've kind of learned or experienced over the last couple of years, and I think, have you found any, any of what Yvonne has just said, kind of resonating with you, in your own journey with your dad?

Liv Little

Oh, its hard I was like listening to some voicemails earlier that he had sent me and one where he was saying, you know, on a day when he was feeling particularly down, and I wasn't with him, and just saying, you know, he doesn't know if he's fighting enough. And so I think to hear you speak about that in a kind of fight and that resolve. Like he had to have that as well. He like he had those moments where he wasn't, where he wasn't certain and where he did just feel sad, and where he was reflecting. And, of course, it's a huge thing to come to terms with this, an impossibly huge thing to come to terms with. But he definitely he went through his journey with like, with humour, and with some joy. And like, even when he couldn't hold his Guinness, like I'd hold a Guinness with a straw so that he could have some Guinness, and we'd sit and we'd have the Guinness in between, you know, you know what I

mean? It was in those little moments were important. I set up a Google Home so that he could say, hey, Google Play this country and western song and that lit up his whole Yes, life, you know? Yes. Oh, my gosh, it was challenging. But even my mom and my auntie and everyone coming and visiting and my uncle and them just busting jokes about all of the times and all of this stuff being young in Brixton and

Yvonne Johnson

From his diagnosis, Liv, from when your dad was diagnosed, how long did he last, if you don't mind me asking?

Liv Little

Of course. So he had been having issues with his hand for like, some years, but we didn't know what it was. And then like, in 2020, we were in and out of appointments, but start of 2021 we kind of had a hint but started 2021 It was the formal diagnosis. And then he died a year and three months later that he'd obviously been had symptoms for quite a long time. We just didn't know what it was because the Jamaican healthcare system, were confused by

Yvonne Johnson

Okay. Jamaica,

Liv Little

In Jamaica, and I bought him that he's like dual citizenship. So I brought him over in the start of the pandemic to do more tests because they weren't understanding what it was. You know? Yeah. Yeah.

Yvonne Johnson

And that's the thing in the Caribbean, they're not very with it about this disease. And, sorry to say, but even out here too I mean thankfully I had a good GP, but I was speaking to someone that their farther did not get diagnosed until he's now on life support I mean and it's like a postcode lottery and I don't know wherever it is because people from culturally or different ethnic background, especially black people, I don't know whether we're misunderstood when we go to the GP, but he was going back and forth. You know, erm, not a lot of GPs are familiar with MND, surprisingly. I mean, they wouldn't think, some of them wouldn't think "oh, it could be this, or it could be that", they just think you're suffering from high blood pressure, I don't know but people are misdiagnosed until it's too late....

Liv Little

I think you made a really important point around like medical bias and who is seemed to be like, there's been a lot of conversation around that with like pregnancy and black women for example. So yeah, of course we know that there are certain groups of people who are less likely to be believed and you don't there's not time to waste in these moments right you need to get to the heart of it and like support people and living the best kind of version and quality of quality of life.

Yvonne Johnson

Exactly.

Liv Little

I was gonna say did you know much about it before because I don't think I did.

Yvonne Johnson

I didn't. I knew about Stephen Hawking and to be honest I knew that he had that but I wasn't interested in it and I just thought this man needs a hand with this and that's really good but as we know, like you say, he was middle class, loads of money, maybe it was the money that kept him going for so long. you know we don't know but I decided to find out more about it. And also you know people of colour were so misrepresented I didn't I had to go and ask my speech therapist that evening, "do black people get this? is it rare?" and she said "yeah, they do". I went on online I tried to research black people and it only come up with associations from America. so I thought I went back on the MND platform and I thought "no, this ain't right" you know, I thought there's people of colour out there with this horrible disease and they probably feel ashamed or feel like they don't see anyone that looks like them, so, you know, we have to make the MND Association has to make people from different backgrounds feel comfortable about coming forward and sharing and making them feel like we understand the cultural barriers and we understand, you know, because I didn't see any of that and you know, we need to do more.

Emily Richardson

Thank you both so much for I think you've made some really important points there. I'm going to come back to one of them but I thought I would mention at this point some of the work that the MND Association has just embarked on. MND affects people from all backgrounds. And that's why one of the five promises that we've made to the MND community is that we will not rest until nobody faces MND alone. We need our services and our support to reach everyone with MND across England, Wales and Northern Ireland, regardless of their background, we want to support everyone. The Association has embarked on a Community Engagement Project, which is working in different areas around the country to try and understand some of the barriers that people face which a couple of these have been talked about today. Barriers to participation, our support and so that we can gain a greater understanding of what different communities need and the cultural differences so that we can start to understand the impact of health and social care inequalities and hopefully this is going to help us design and reengineer our services. There's a saying that there are hard to reach groups but I think it's more beneficial to reframe that into hard to reach services rather than hard to reach people. But I also wanted to come back to something that you both started to kind of touch upon a little bit which was health inequalities for black people and other sort of racially minoritised people and I didn't know if either of you had experienced that Yvonne personally but lived through your data do you kind of have any experience of health and social care inequalities?

Yvonne Johnson

To be fair, when I first had problems with my speech and I went to my GP and she said, let's rule out a stroke, let's rule it out. She was like "I'm going to send you to the A&E and let them do a head scan. Was it a head scan? or my heart. because they wanted to rule out a stroke so they done that and then that was it. Goodbye. Your heart's fine. And now when I look back you know I think if they cared they'd know what to do but they needed to find out why my speech was like that. I went back to my GP and I said "oh they said I'm fine". She said "and they sent you home?" and I said yeah, and she said "no, no, no. Didn't they ask you about your speech?". And I said no. She said "No, Yvonne, you need to take

the day off work. I will send you to a clinic and then go give you a thorough check". If she wasn't like that, I don't know where I would've ended up. But I think when I went to A&E they just wanted to get me out, like you're a woman, you're healthy, there's nothing wrong with your heart. And I don't know if I was racially profiled, I don't know. But it makes me wonder. I was one of the lucky ones, I had a great GP, you know?

Liv Little

That makes a difference, doesn't it? And I think actually, like, I have to give a massive shout out to all of the nurses and carers and like people who've really supported my dad, and those to be black women, minority women doing the work hard, intense work, people through, really. And that is actually really deep and really powerful. I've got like quite a lot of aunties, who are carers and nurses and things, and some who supported in this. And I just think, you know, that's really to be, I just feel very grateful that he was able to have that comfort and that support and it was a lot of Somali women who were who were caring for him and in the community. And we became close and it felt like really like yeah, when I'm not there, that he's going to be amazing woman called yours, you know, who I just knew. I knew I felt relieved when they were the ones that were there a new package together, it was like, you just know that in all of it, and they were going above and beyond you know what I mean, really important to just say to express my gratitude to them.

Yvonne Johnson

Yeah, and just to add, my GP was an Asian and lady, and I don't know, whether. It's just who she is. I was just lucky. Not everybody's gonna experience that kind of care and other than that, everything's been great, I'm blessed, everybody I've been in contact with are so supportive. Even down to my consultant she's so cool, you know, my nurse is real? And they're like, yeah. I love it. I can have a joke with everyone in there. That's it, all I want to be treated like is a human being not like, that's it, end of the World, your life's over, goodbye. No. We all count for something, you know?

Emily Richardson

Thank you, Yvonne. I think that really feeds into what you said at the beginning of the conversation around that, you know, you don't want to be defined by MND, you are Yvonne first and foremost, you're living with this condition, but it's it's not who you are. So thank you for that. And kind of one of the other things that you were mentioning, both of you that the only person that kept whose name kept cropping up with was Stephen Hawking. And I suppose relating that to some of the conversations around health care if we look at kind of medicine books, historically, they've generally been, you know, body pictures of bodies of white men, which just doesn't kind of, you know, just represent everybody. So I think that's really interesting. One of the other things that we've got going on at the moment is our embrace network group, or people from ethnic minorities and our pride network group, which consists of and are open to people living with and affected by MND volunteers, MND Association staff and allies who come together to connect in a safe, supportive and welcoming environment. I think there's something really important about connecting with other people who are in these communities as well as the MND community, because we can relate to people who are like us, so I wanted to mention that as well. I'm coming to probably one of my last questions now, I think. And it's quite big question, but from both of your perspectives, and I'll come to Yvonne first. What can the MND Association do differently to make things easier for underrepresented communities?

Yvonne Johnson

Just show up. Show up in places like, you know, big organisations and workplaces and offer courses for GPs, as silly as it might sound, re-educate them in that area. You know, teach them to identify what, what um is not emphasized is that MND comes in many different forms, so, like, someone looking like me they think "you're fine" but the minute I open my mouth, they think I've had a stroke, which is fair enough, I would have thought that too but make people understand it comes in many forms and people are affected at different rates some of it's very fast some people have it mild and there's no clear path and just get out there and show up in places where they'd least expect. Everyone needs to be educated about this. So many people that do not know or understand, they've heard it maybe but don't have a clue about how you're affected, show up in GPs and surgeries, show up in organizations and encourage employers to employ people because some people with MND are employable. And make them feel like they're employable. Thank God my employers are great. But, not everyone's is. So just show up, everywhere.

Emily Richardson

Liv you were writing *Rosewater* while your dad was living with MND, I wondered if any of the, the story isn't about MND, or your journey with sort of your dad's journey through that. But I wondered if any of the emotions and feelings that you were going through at that time have found their way into the book?

Liv Little

Ahh definitely I think, as a writer you draw on the experiences that you have. And this has been not the most challenging thing that I've ever been doing. It wasn't me physically embodying what that experience was, but to lose a parent, to lose a dad to go through all of that. So I think there are moments in the book where there are those kinds of themes not tied to illness or anything like that, but just tied to loss of place, or people or things, you know, I think those are definitely things that I was drawing on. And I really, I have a two book deal. And the next book that I want to write, I want to write more specifically about that it will be fiction, but that kind of father daughter relationship, and what does it look like when you're navigating something that feels so huge, and I really want that to be me honoring him, you know. And in the back of this book, the first the first bit in the acknowledgments is to my dad, and to him. He probably wouldn't have read my book anyway, it's a queer love story, he would have been cringing, but but but he was very, he was very proud. And, like I, I can only hope that I'll be able to, you know, just find ways to continue to honor him and to like, tell his story in different kinds of formats and ways and just allow that love that he showed me like to continue to find his way into the world. You know.

Emily Richardson

Thank you that was really powerful. There's one thing that I actually wanted to come back to if you're both comfortable talking about this, because we've talked we've talked about some of the challenges around culture and MND but I wondered if there were a couple of things that from your cultures or your heritages that you really love and that make you who you are.

Liv Little

Food?

Yvonne Johnson

Food is number one.

Liv Little

Vibrant people, like Caribbean people, we've been through things historically, generationally and we've had to really like fight to have our joy and to have the things that we need that's why Yvonne is able to show up in the way that she does like it's there you know it's real.

Yvonne Johnson

We're outspoken people, we like to be and you asked about Jamaica and Barbados, you know what, we're all the same. We're Caribbean people, my island is smaller than Jamaica, Jamiaca's a big island. We both eat lovely food, the weather is hot the same way. What else is there to say? I mean the only difference is that I'm from a smaller island, that's all. We all have the same kind of mindset. If you like.

Emily Richardson

Thank you. Is there anything else that I haven't asked you about that you kind of wanted to get across throughout this conversation or that you've not had a chance to say.

Yvonne Johnson

Only that the MND Association keep plugging, and keep encouraging more people, from minority backgrounds. I love what you're doing MND association, it's amazing what I see on the platform. I just would like to see more people of colour and from different ethnic backgrounds, I would love to see it, because it hurts me to know, there are people out there, that don't wanna come forward and don't want to talk about what they're going through and I would hate to know that they're suffering or in depression alone with this, it's so sad.

Emily Richardson

Yvonne you really are bringing about change all of these things that we've touched upon by you sharing your story, with the Association with the world with Liv's newsletter, you're really helping us to try and bring that change around, but you're really doing all of that yourself as well. So we are hugely, hugely grateful to you. And you've also informed some huge tech giants on their products as well. And I wondered, while we've got a little bit of time, I wondered what that kind of means to you as a person of color, but also just a person with MND to inform those huge tech giants on their work?

Yvonne Johnson

That is something that I feel good about, because those huge tech giants that you're talking about, huge organisations use them so they too will be educated. When I talk about not seeing people of colour, um I'm not concerned about anyone out there that is suffering alone, I'm not just saying people of colour, anyone, because everyone who has this disease is going through something painful. So I just wanted to point that I don't see people that look like me coming forward. And I wouldn't want anyone not of colour to feel like they can't approach me, because they can, because we're all in this together. No matter what colour we are, we're all experiencing the same kind of experience.

Emily Richardson

Thank you. And I want to mention at this point, this episode has shared the experience of two black women of Caribbean heritage. But we would love to hear the stories of people from all backgrounds, all communities, that's including the challenges that you've faced. And we really want to find out how the Association can do more to support you. So if you're listening to this episode, and you want to share your story with us, please do on communications@MNDassociation.org. I think that might bring me to the end of this conversation unless you either of you have anything else that you want to add. If not, it's been hugely, hugely important conversation to have really interesting. And thank you both so much for your time and openness and starting up this conversation is a conversation that I really hope is going to continue now. And yeah, thank you both for putting yourselves out there for coming forward to share your stories with the association with the world. As I say it's very, very important. So thank you so much for your time. Thank you.

Outro

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