

MND Matters: Episode 16: LGBTQ+ Pride Month

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 and sponsored by Toyota GB and Toyota Financial Services

Helen: 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. Hi, I'm Helen and I'm a Regional Fundraiser at the MND Association.

Beck: And I'm Beck and I'm an Area Support Coordinator at the MND Association. And in this episode we're going to be using a few acronyms such as LGBTQIA plus. So we quickly wanted to explain what that might mean. So it stands for Lesbian, Gay, Bisexual, Transgender, Queer, or Questioning, Intersex, asexual, and any of the sexual identities and gender expressions.

But for the purposes of this episode, you may hear a shortening that to LGBTQ plus or LGBT. We just wanted to make sure that we're clear that we're including everyone within that.

June is LGBT Pride Month, and we're so excited to share this month's Pride themed episode.

Helen: Lesbian, Gay, Bisexual and Transgender Pride Month. LGBT Pride Month is celebrated annually in June to honour the 1969 Stonewall Riots.

Pride Month works to achieve equal justice and equal opportunity for LGBTQ plus people.

Beck: Now you might be thinking, what does MND have to do with Pride Month? Well, MND does not discriminate. It can, and it does impact all people, including LGBTQ plus people. MND can affect anybody regardless of their sexuality or gender identity. So with this in mind, it's important that people living with and affected by MND in every community have access to the right health care and support

Helen: Absolutely. And I'm delighted to introduce today's guests who in this episode will be chatting to you all about their experiences with pride and MND. So say hello to Sally, Sam and Angela.

Beck: Sally is the CEO of the MND Association. Sam's living with MND, with his husband and their son, and they've been busy fundraising, raising awareness for MND. Angela is a brilliant volunteer at Opening Doors, a charity providing information and support services specifically for lesbian, gay, bisexual and trans people over 50 in the UK.

Helen: We are so pleased we're all here today. We're looking forward to hearing from your very unique perspectives. So let's dive straight in. Let us. Sally, is it okay to ask you why it's important that we as the MND association are having these conversations?

Sally: Yeah, absolutely. And it's great to be part of this podcast today. So thank you very much for inviting me.

It's just so important that our Association is welcome to absolutely everybody living with and affected by MND and everybody that wants to join our cause. We know that there are probably about 250 people from this community living with MND in any one time in the UK. And we want to make sure that they feel that our Association is absolutely a place to go for support and help and advice, but also that they're able to access the support that they need from statutory services when they need it.

And so this area of work is such an important thing not only for staff in the Association, but also for our volunteers.

Beck: Brilliant. And, we want to make sure that we have equal access to health and care. But we know, Angela, that's not always been the case, has it, in the UK for people from the LGBT community?

Angela: It's well, it's our health, isn't it? It's all to do with our health and wellbeing. But we're so well, 'we' speaking from personal experience are very reluctant to go forward for that health care service. Our lives have been based around fear, fear of being discriminated against, prejudiced. Fear from abuse, whether that's verbal or indeed physical abuse that's shaped our lives and shaped our perception of most things in the public arena.

And the past where we've grown, it's been very hostile environment. So we're just fearful from our life experiences and all the hostilities that we've lived among and through that these things are just not safe for us. And many of us would gladly not go and seek those services that we might otherwise need for our health and mental wellbeing and for our social care.

Even our housing needs, we just might not go for those because of that fear factor. And it's and you're saying to Sally how important it is to have this conversation. It's because we need to break that cycle of fear, not just fear of LGBTQ people among everyone else, but the fear of the world among LGBTQ people. And that fear is all just bred out of ignorance.

So having a conversation breaks down, you know, violence that's there. So that the ignorance doesn't feed into fear. If you break down the fear, you're going to need less health care services anyway. I think particularly in terms of mental health care and, you know, mental health care affects physical health care and so on. So it's a you know, it should be right up there at the top of the health care agenda to be able to break down the fear, improve, improve awareness and break down that fear.

Beck: Yeah, because we've heard examples, haven't we, about people choosing not to access the care and support that they actually need from that fear, from that fear of not being recognized for who they are.

Angela: So it's a very, very real situation. And I, I have some experience. Some positive health care, but one or two experiences of very poor health care, which is in

my experience has only been translated as an attitude shown towards you. You can see when they see on your note I'm a trans woman and they see that that's the case on my medical notes, as it were. And the tone of voice changes, you can almost hear it in their minds go oh its one of you. The sooner they can get you out of that door, the better it is for them. They just they don't really want to deal with you. It's as if you don't have a right. Well that's the impression they give to you.

But I have equally experienced some brilliant health care, people have been so kind and really looked after me.

Helen: I'm so relieved, Angela, that there has been some positive kind of experience when accessing either health and social care services and hopefully by having the conversations on the podcast and all of your volunteering with Opening Doors, you're changing those negative experiences and hopefully changing people's perceptions and understanding. So that in the future that they are few and far between.

Sam, So we've heard from Angela and Sally there their opinions on why visibility is important to them. Can we come to you and ask you what visibility means to you?

Sam: It's so important I feel because my I'm at a stage at the moment where my MND is not visible. It's quite hidden. And when I've shared my diagnosis with others, they almost have to the it's like a double take because it's they can't see it.

It's only perhaps if I'm tired my walking might get a little bit more kind of clumsy and people may notice that I hold things in my left hand rather than my right. Or if I do hold something in my right, I get weakness. So for me, my visibility is speaking about it, raising awareness because there are so many illnesses.

But again, MND is one of those that in early stages, I would say, and most of the time you can't see it, it's not until it starts progressing advancing that it then becomes this, this visible, this and progressive disease that it is. So it's so important for visibility because I've had people say when I've shared my story with them and they think you can walk at the same pace as them, they think that you can run.

I've had people knock me over accidentally, but because I am wobbly on my feet I'm more aware of my surroundings. And sometimes I do want to turn around and say, 'do you realize what I have', and it's I think personally speaking for me, I don't want a label of disease 'you are MND'. I'm still Sam. I'm still the same person. I have a personality. I go and do things. I have hobbies. That's not being taken away from me. And it's that visibility is so important and again, as we know, it's a disease that robs people of their voice or can rob people of their voice. So visibility, say, for me is just by speaking constantly about it.

And for me, my personal experience just by speaking, by sharing, people are shocked, as I'm quite young. And I'm always having to educate people whilst I'm being educated about it, I'm learning about it. I'm having to do that with other people. Because I think from the kind of I suppose main assumption is they go directly to Stephen Hawking, that's, that's the person they see.

Whereas the reality of it is there's many people in various different communities it affects everybody it doesn't discriminate. That's the visibility that it needs. And if just by speaking, by sharing, by publicizing, I don't think there's we can't do anything wrong in that at all. But I don't want to hide behind it. I don't want to for it to feel like it's taking over me. I'm taking charge of it. What I said to someone just the other day there could be ten people with MND. And it will affect those ten people in ten different ways. It's not a, it doesn't replicate in the same way.

I've chatted to somebody with MND who is part of the LGBTQIA community, and I find that really insightful because he's a very different place to what I am, but I'm able to relate to him. And again, he's talks about his boyfriend to me and it's I'm able to feel more comfortable in my skin when talking with him about it.

Beck: Yeah. I mean, that's heavily linked to what we were talking about earlier around like being able to share and show who you are in an open way that again, feels safe and it removes that fear is it's that the more we talk and show who we are, then the more other people are likely to do that as well.

You've mentioned there there's you've linked with somebody else from the LGBTQIA community with MND and it feels natural and comfortable to be able to talk about your experiences, even though they're not the same. But it's a human thing. It's yeah, yeah, yeah.

Sam: You relate to somebody. And, and let's face it, you ask anyone with MND would we really want it. No, none of us do. There's nothing we can do about it. But what we can do is come together and speak about it. And that's where you've got things like The MND Forum, and it's creating those places where if someone doesn't maybe feel confident or open enough to, to share it in such a way, like I have, for instance, they can do it in other ways. They could write a blog. They could appear in the local newspaper, just things like that. There's various kind of ways and means that we can have that visibility and is it's just that it's just relating to somebody else.

And it's, it's knowing that you're not the only one. It makes you feel safe. It kind of feels like people have got your back and I think when you're going through something as we are, that's so out of our control, having that safety, that safety net, that's friendships circle you just you get to know people and that that is the safety that we need.

And so just from sharing my diagnosis and what am I, kind of three months post-diagnosis I've spoken to people I would normally walk past in the street, but now because they've seen or heard about my story, they want to ask you and I will take the time to talk about it because it can only be a positive rather than a negative.

Beck: Absolutely.

Helen: You mentioned there Sam, your blog, can we delve a little bit deeper into your blog, if that's OK? And can you tell us how you're using your blog to kind of document your experiences and why that's important to tell your story?

Sam: Yeah, of course. So we started the Daddy Dad and Me blog when we adopted our son and right at the very start of our journey almost. And it was it was a very kind of educational. I wanted it to be about an awareness because when we were in that the first stages of the adoption process, other than searching Google, as we all do. I couldn't really find much material around same sex couples and the process because it all seemed to vary kind of where you went, who you went with and just by obviously we keep his identity confidential, but we speak openly enough about it, the challenges. And I think people it I get more reaction and more messages when people can relate to it. Some especially where I've said like 'I think I had post-adoption depression' because yes, there were I went for a period of time. It was I didn't feel like myself and it's as soon as people can relate to, oh, it's you're not just sharing the good bits, you're sharing the kind of not so nice bits and moving on to diagnosis and talking about sharing my experiences, there I wasn't going to do it at first. I thought I wanted to kind of keep it separate. But we've created this place where we kind of got known really. And just people we'd had subscribers, we've got Instagram, things like that that we share little snippets of our life on. And when it came to and I honestly thought about it and it was James who turned around to me and said, But why don't you do a vlog about it?

And that's where it really came from because it was such a, I could be myself as I I've I was no longer awkward behind a camera and I was able to really share this is what's happened in my life. This is kind of what I'm going through. And it just again, created a space for people. If you wanted to read about it and I'm soon to be writing a blog about MND and my diagnosis. I've only really touched on my bucket list, kind of the what happened with like the tests and things like that.

But like a lot of people ask me like, does it hurt? What does it do? How did you notice it? And I really wanted to put something there to, so people can go to it if they want to and read about it. And that's really where it came from. And again, especially from a same sex point of view, we've had lots of people come forward to us saying, Oh, thanks very much, your blog has been really helpful and and I kind of wanted to encompass that with MND too.

And even just this morning I've had someone messaged me on Instagram saying I've recently been diagnosed just about start clinical trials. Found your blog really helpful. Yeah, it just creates an avenue for people if they want to approach you to do it. And I find it quite cathartic documenting it. Sometimes I'm in that mood. I mean that writing space and I think, you know what? I'm going to write down what I feel and sometimes I won't publish it for a few days. I'll go back in and neaten and tidy it up. But especially in the bucket list, I sat there, it was after James said to me and I sat there probably over two or three evenings, and that's just where I just started thinking, Right, I've got this, what do I want to do?

Beck: Yeah, and that's led to you doing lots of awareness raising, hasn't it? And you're doing a fundraising gala and yeah, you've mentioned your bucket list as well, so how has that been and how's the, how do you feel the LGBTQ community has come together to, to support you in that?

Sam: That for me, it was literally from day one, I kind of did the crying for days and all of that. And then I've always been one of those people, you turn a negative

situation into a positive, and I didn't want to kind of rest on my laurels. I didn't want to kind of, I could, I had the option to sit there and think about it and, and for that to be the way in which I dealt with it.

But I thought for something that's out of my control and I was regaining something, I needed something, something back. So that's really where the fundraising started. Almost immediately, I've had friends that are saying they're we're going to run half marathons for you and we're going to raise money for the MNDA. I've got one of my friends doing the burpee challenge in May. And so that straight away I was like, Oh, that's really nice. Thanks. You feel supported by people. They want to do something to help you and to, to move you through this, whatever you feel. And yes, so with this gala in August has really been taking up most of my time and it's keeping me busy, but it's something I kind of do something in some capacity once a day with it, whether that's booking something for the event or we're getting raffle and auction prizes.

Yes, I had an article in the local newspaper. Then one of the streets that is probably about 2 or 300 yards down from me, I had an email saying we'd never knew this was on our doorstep. Because I live in quite a small village, and the lady said, that we're doing at Jubilee Street Party and we want to raise money for you. So never met her, don't know who she is. And it's, it's just that generosity from people and strangers.

I'm not, I'm going down fighting. I'm not going to be quiet about it, wherever I can get whatever I can do, I will do. Because again, it goes back to a control thing. I want to feel like I'm doing something and for it to be a legacy, I want people to turn around and say, oh yeah Sam did that and it's. Yeah. Whilst I can do something I want to do something and there's still so much to do.

Helen: There's so much positivity in what you've just said and you are smashing it, in bringing your community together. And that's your LGBTQ plus community, but also your village community, the community that you've created because of your blog. You're bringing them all together and you're raising that awareness.

And with that, you're raising the funds that are genuinely going to help us get closer to our vision of a world free from MND. And I'll just take this opportunity to say a huge thank you to you and all of your community for getting out there, increasing that visibility and making such a difference.

Sally, we know why this is important that we're having these conversations. What is the MND Association doing to help improve life for LGBTQ plus people living with or affected by MND?

Sally: Know, that's a really interesting question. I'm very interested to hear Angela's experience of services, because I think it's. Within the Association, it's some of it is about improving people's understanding. Staff always try to do their best, but sometimes they don't know in certain circumstances how to do the the best.

You know, it may be that they've not had very much exposure to the LGBT community, and it may be that often people are afraid of saying the wrong thing or, you know, just appearing to be stupid or ignorant. And so as a result, they may be

back off perhaps from from having these conversations. So I think at the Association what we're trying to do with this work is to really just open up that conversation, to say we really just want people to engage in the conversation. We're going to provide some training and we're working with Opening Doors to provide access to training for people. And I've had such great feedback about about that training and how much people have appreciated, appreciated it. Emotional as it is, I think. So we're providing support to people so that they feel more confident to engage with the community.

But we're also reaching out to people so that we can provide support and people can come together that identify in that community with that community. And we formed what is quite a successful LGBTQ plus group now that I feel very privileged to be the sponsor of and I think is providing a lovely space for people to come together and share their experiences. And this is part of all wider diversity work, which is also about making sure that we reach out to people in all communities so that everybody feels welcome at the MND Association.

And we fulfil our promise that no one, nobody experiences MND alone. So it's, you know, it's part of a wider piece of work, but a really important focus piece of work for this community.

Beck: It's all intersectional, isn't it, because you can be living with them. And so therefore you have like this terminal illness and you're experiencing that. And then the challenges accessing care that come with that. And then you could be from the LGBTQ community, you could also have other things that disadvantage you. And then so it's all linked, that we're working together to do this inclusion work.

And I think it's it's great that we're, we're talking about this today on this podcast, but wonder if we could roll back a little bit, Angela, and ask you, from your experience being a volunteer at Opening Doors, what are some of the ways in which the LGBT older community interact with health and social care services?

Angela: Yeah, I mean, what I was saying before about the awareness building is what we've all got to do. So the Opening Doors training is building that awareness and then putting some structure in putting some practice and processes in that establish the awareness into something real. It becomes part of habit and behaviour. And so a lot of that is required, a lot of being prepared to stand up and talk about it very openly and sometimes bravely is vital and not always easy. Particularly if you've got families as well. Because sometimes if there is hostility out there that can sometimes target the ones you love as well just by some association with your name even.

And yeah, I think we just need to build familiarity with LGBTQ people, their lives, their experiences and break down any, any ignorance which otherwise breed fear. I mean, we do not we know of course, there are some people who will deliberately feed on people's fear. And they'll stir it in even more and try and promote it even more. We just have to keep keep on being visible and normalize these things in people's mind so that they don't, they don't even know why you should be talking about it, because it's kind of irrelevant. It's just part of life. It's who we all are. That's, that's really what we've got to do. And that's why we've come quite a long way since

the last 30 years, I guess. Within the LGBT community we're far more readily accepted and younger people.

Helen: There's this huge power in people being open about their stories and their truth and that story of a young person feeling really empowered to be who they are is testament to being able to see people like yourselves.

And you can only be what you can see. And and I think we've come so far in society, there's still so much more to do. But it just shows you how vital it is that talking and being open can genuinely make a positive and really tangible impact for the younger generations.

Sally: I think one of the things, perhaps at least for people in same sex relationships that made a difference was when civil partnership. And then marriage became possible because I think that sent a very clear message out that your relationship is now, you know, legally possible. And that was an enormous place of celebration that society had recognized the equality of a same sex relationship. So it's, and that, of course, wouldn't have come about without massive amounts of campaigning by the by the community itself.

And I suppose that's just another point to make in this conversation is that there are problems to be solved. But the community itself is incredibly powerful incredibly resourceful and has over the decades changed many things for the good. And we we just need to celebrate that in Pride Month, don't we?

Helen: And all year round.

Sally: All year round, of course. Of course. But it's the kind of focus, I guess, isn't it, for Celebration, Pride Marches and Pride Month gives us an opportunity to do that.

Beck: And it's really important that we do that as an MND Association to show our community and our supporters that you mentioned earlier, Sally, that we are proud of our community and MND does not discriminate and it can affect absolutely anyone. And there are members of the LGBT community in our community, we're here, we're being visible, and that shows that we are inclusive for everybody.

Angela: I was just because it's important because within within the MND Association is just showing that we're all humans, we're all the same, and all the diseases all the illnesses all the stresses and strains of life, they they affect us all no differently.

Yes. Some some are going to be more prone to some of these conditions and illnesses and disabilities and so on. And some of our life experiences will exacerbate those to some extent. But but fundamentally, we're all as prone to them as anyone else. And so it in a way, you know, in a horrible way, it's a quite a big leveler, isn't it?

Sally: Just building on that. I was I was going to reflect on something that you said earlier back about people's experiences. And I think what's really vital in this work for me is it's just that encouragement, that support for us all to approach people, that we serve people in the MND community as an individual and to understand where they come from and the kaleidoscope of things have impacted on their lives, the

experience that they've had and that make up who they are and whether they're gay or straight or trans, whether they come from a community in the north of England or they live in London or they're you know, they come from a BAME community. Whatever the kaleidoscope of things that make them who they are, that that's how we should approach somebody. We shouldn't use these things as labels with which to make assumptions about somebody. We should get to know what makes them as it makes them as an individual and what's important to them. And and I see this work very much as helping people to have those conversations and sort of assimilate that into the way that they that we offer our services as an Association

Beck: I agree.

Sally: Yeah. I think that's a danger is that if somebody has got a you know, you've attached a label to somebody that you make all sorts of assumptions about you know, what that person therefore is and what they think and what they want. And, you know, sometimes those things are just not true are they. We're all individuals.

Beck: Yeah. Yeah. And that all comes with that. I guess that opportunity to feel safe to be you and show people who you are and remove that fear and having conversations like this definitely do that and shift the shift the can along the road a little bit further, don't they? The more we do it, the more it happens. So yeah.

Sally: And I think approaching people you meet with a with a kind but inquiring and open mind. I think that's what we, you know, we want we want to hear how people would like us to provide support, provide care or services, don't we?

We want to hear from them rather than have our own assumptions about how that should be.

Angela: And we have to be very careful about those people, I almost use the word those 'forces' that are trying to drag us backwards. But if you call them 'forces' that gives them some sort of authority just now. I don't want to give them any authority. They're just individuals who've got some weird sick sort of idea ideology about the way the world should be and how humans should be. But that they're still there and some of them are in influential places in media and politics and so on. We just have to be mindful that they are there and we still have to keep going when we're not there at all yet. We've got a long way to go, but these things celebrating pride and having pride in our selves as individuals, whoever we are. That's got to be the way forward. And and that's how we will defeat those who have got different view in the world.

Sally: I think that's lovely. I think we must always be alert to, you know, any kind of desire to go backwards, which we must not do. But the idea that we should celebrate pride and be proud is is a really lovely one.

Sam: I think for me, my kind of like final words would be if anyone I know what pre diagnosis when I had an incident basically the medical professional, not, they were qualified, but not qualified to give a diagnosis. And that led to me going in very kind of dark hole. That's all I can really kind of say on it.

And I did lots and lots of research and it's I became consumed by it all. Post diagnosis, I don't want to know about it. But I remember feeling what I felt at the time is I felt very alone, like I was the only one. I didn't really want to reach out to anybody. So just wanted to say if anyone is in that position where you're not sure of what to think, what happens next? Deal with it on a day by day basis. My head was racing right towards the end. I think for me, that didn't help me at all. What does help me and again, may go back to control the thing is just by taking each day at a time. Hmm. As they say, Rome wasn't built in a day. You're still living your life. You're still able to go and do things and I take quite a lot of comfort in knowing that my family and friends have already said to me, my friends, we're still going to be taking you around even when you're in a wheelchair. We're still going back and causing havoc and all of that. And it's just knowing MND doesn't take your identity away, but it becomes part of you. It's just a part of you. But it is not you. To be yourself. But just know that you can speak up and out. That there are places like the MNDA to go to. Go the forums try and engage with people that maybe have been diagnosed with it, and I've just found that super helpful. And it's just by taking it a day at a time and you just kind of deal with it as you go. And that's why I found kind of it has helped me through a dark time. And I'm able to look at things in quite a positive way now. I am not MND I am just I'm living with it. It's just a part of who I am. It's not Sam I am still me

Helen: Thank you so much, Sam. That's such a powerful message to end on.

Beck: Thank you all so much for coming on the podcast today and sharing experiences it's been really eye opening for us and thank you for highlighting everything that we've talked about. It's great that our staff and volunteers have access to incredible training that Opening Doors are providing to us, and we can't wait to see what other opportunities arise from the inclusion work that's going on behind the scenes.

And that's all done to make sure that people living with or affected by MND have access to the care and support that they need. So if anyone's got any questions, feel free to reach out to our LGBTQIA Plus network. Ask us anything that will include the email address in the link for this podcast episode.

Helen: And if Sam has inspired you today to get involved in fundraising and galvanize your own communities, please check out the MND Association website, which has fundraising ideas and events which suit all ages and all abilities.

Thank you once again to our brilliant guests, and thank you all for listening.

Outro: You've been listening to MND Matters, a podcast from the MND Association. Find more information at www.mndassociation.org. If you've been affected by any of the issues raised in this episode, contact our helpline MND Connect on 08088026262 or email mndconnect@mndassociation.org.