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# MND Matters: Episode 31: Tanya Curry

## **Tanya Arnold**

Welcome to MND Matters brought to you by the MND Association and sponsored by Toyota GB and Toyota Financial Services. I'm Tanya Arnold, patron of the West Yorkshire branch of the MND Association and a freelance presenter and reporter, and I'm delighted to have been asked to guest host this episode of MND Matters. And we are joined by Tanya Curry, who's just marked her first year as the Chief Executive of the Motor Neurone Disease Association. So we've got a Tanya, and a Tanya, not at all confusing, is it? Maybe I should call you gaffa throughout.

## **Tanya Curry**

Whatever works, I've been called worse, so it's fine.

## **Tanya Arnold**

Because I get Tanya a lot.

## **Tanya Curry**

Yeah, all the time, all the time. But it's lovely to have a chat with my namesake. So really good to see you.

## **Tanya Arnold**

So let's just go back to when the job was advertised. When you saw it advertised what made you want to go for the job of CEO?

## **Tanya Curry**

Well, it was actually a friend of mine who sent it to me who I'd worked with years ago. And she sent me a message saying, this one's for you. So you best get applying, it's absolutely up your street. And I think the more I looked and the more I was really thinking about it, it was just the most amazing opportunity. I have a clinical background as a specialist nurse, and I specialised in end of life and palliative care for many, many years. And I love leadership. And I love the charity sector having been in it for such a long time. And it's almost is a bit cliched, but it felt like the stars were aligning. And I'm a great believer in fate. So I thought, I feel like I could really make a difference here. So that's what prompted it for me.

## **Tanya Arnold**

And what a fascinating time to join because suddenly MND had skyrocketed in the consciousness of the money that was coming in, through Doddie Weir, through Rob Burrow and just a fascinating time to come and join an organisation. I'd have thought

## **Tanya Curry**

I know how lucky am I? It's a bit of a gift I have to say. And as you say, Tanya, the profile, is so high at the moment, and it was really kind of coming into that when I joined. I mean, Rob was obviously diagnosed in 2019. And he and with Doddie you know, they really paved the way for what MND is. And they opened up their lives for people to see the impact. So we're kind of all over the place at the moment, which is a lovely place to be, and a really good chance for us to galvanize what the Association does and what we're here to deliver for people with MND.

**Tanya Arnold**

I suppose it's a weird one, isn't it? Because you are a charity, but to a certain extent, you are a business as well, whose turnover's just shot through the roof?

**Tanya Curry**

Yeah, absolutely. And I have to say, I mean, I've been in charity leadership for over 20 years now. And I've always said you have to have a really strong commercial brain. But you have to have a charity heart when you're working in these chief exec roles. And I strongly believe that you are running the business behind the scenes. That's exactly what we are. But you never want people who need our services or have cause to get in touch with us to feel that we are just on a business treadmill. It's not like that at all. We're absolutely here. And it's all about hearts and minds and getting that right.

**Tanya Arnold**

And unlike a business, yes, you want more money coming in, but you know, you've got so many volunteers that work with you, you've got so many families to work with. And also the huge part that caring plays which you can't really put a price tag on. It must be a weird balancing act.

**Tanya Curry**

Yeah, it's always a fine balance. And you will have people that talk to you about you need to put more into research and why aren't you just a research charity, you'll have other people that say, actually, you've got to put more into care because we're here and we're living with this dreadful disease and it impacts our families. So it's a really tight line to walk. I mean, you never get it right for all the people all the time. But I very much believe this is about giving people the choice and control they need now to live with this diagnosis and actually have the best quality through this awful time that people face. But there's also the hope for the future and with research comes better care and better opportunities and they're so interlinked and I honestly feel you can't have one without the other.

**Tanya Arnold**

So in those early days presumably there was an awful lot of getting your head around where the business was at, what you needed to change what needed to change but but also really important for you, I guess to to get out into the MND community and to meet people.

**Tanya Curry**

Yeah, really important and I am incredibly cause driven in the charity world. So, you know, I'll only ever go into roles that I feel really passionately about, and I think with my clinical background as well, you know, everything that I do here has to be for the benefit of the MND community. I have to go to sleep at night knowing I've done the right thing and made the right decisions. And we have to have impact for

people. And so you weigh that up in everything that you're doing, because if we're not getting it right for our community, then we're not doing the right thing.

### **Tanya Arnold**

I interviewed you on the television ahead of the Rob Burrow marathon. I mean, what an incredible day they harnessed there at Headingley and around the streets of Leeds.

### **Tanya Curry**

I mean, didn't that show the absolute kind of palpable love from the community? I mean, what Kev and Rob did in all of that was just fabulous. And yes, if you needed a moment to realise why you're doing what you do, and why you need to do more, and get this better for the community. That moment really seized it, didn't it, it was just a great feeling. And you saw everyone coming together. And no longer was MND this kind of hidden disease or this hidden title that no one knew what it was. It was out there but the strength of friendship, love, determination to make this better - you could just feel it everywhere you went in Leeds that day. It was amazing.

### **Tanya Arnold**

And not only have Doddie, Rob, you know, Stephen Darby people like that, you know, opened the doors on their lives, Rob in particular, we now have a character in the biggest soap in the country, Coronation Street with MND. I mean, I go back, I interviewed a rugby league player called Sam Burgess, who was a teenager was looking after his dad who had MND, and I said to him the other day, I was embarrassed, you know, when I look back at it, that I really knew nothing about it. And I didn't really go and look. And he said, I didn't either! I mean, it's just on a different level now, isn't it?

### **Tanya Curry**

Yeah very different. And actually, I was at a support group in Merseyside only last night, actually. And we were talking about the impact of the diagnosis for people. And actually, you're finding now that people with MND don't necessarily have to explain it to other people, you know, the man on the street has often heard of this disease. And I was like you and I mean, even clinically, 10 years ago, the landscape for people with MND was incredibly different, not in a good way, to where it is now. So we are definitely moving forward and things are starting to shift.

### **Tanya Arnold**

So when you came in, what was the first things that you felt needed to change and that you needed to put in place to make that shift and to move forward?

### **Tanya Curry**

Yeah, I mean, I inherited a really strong, stable, solid organisation, and every member of staff I've spoken to, every volunteer I've met is totally driven by the cause of MND and the difference that they can make. As a charity chief exec that's a gift, because you can't teach people that. But actually, from day one, I had really hoped to come in and I had ideas of I was going to travel around the country and go and listen and learn and really kind of work out what people wanted from the charity, and from my role and my team, I have to say, I came in to lots of people saying, Oh, we're very glad you've arrived, we've saved some of these big decisions for you. So I kind of felt like I hit the ground running. I would have loved more time actually to get to know people and to get to know what's going on. But I found an

organisation that was totally harnessed around what it was doing, but had been so busy, because of the profile, we were probably one of the only charities or one of the few charities that grew during COVID. So we were absolute head down working so hard. Income was coming in, we were really trying to deliver in a different way. And actually, when people are in that mindset, you don't get a team then that lift their heads up and look up and out to really think where do the community need me to go next? What do I need to do? Where do we need to invest? And how do we need to work differently for that? So we're doing a little bit of catch up in that sort of respect now, just taking a really good look at the organisation. And we're really listening to our community. We're asking lots of questions about what we need to do and how we need to deliver.

**Tanya Arnold**

One of the things that COVID did, I think, was made people impatient, particularly that they looked at COVID. We came up with a vaccine in a matter of months because a lot of money was thrown at it and people think – expect - now that to happen across medical spheres don't they? How difficult has that been for you to juggle the message that it just doesn't happen like that?

**Tanya Curry**

Yeah, I think that's really hard. And I think that's two pronged and actually, it's, as you say, we're all consumers in life, aren't we, and we all expect things when we want them, and we just expect them to happen. And with the science, with the research, with getting drugs to market, it's actually a long process. And how frustrating is that for people when they have a diagnosis, which means their life is very limited. And I think for the first time in about 20 years, MND is entering a more exciting stage where we've got more trials than ever, more research than ever, and potential opportunities. But potential opportunities don't feel good enough if you need that treatment, and you need an opportunity for your life to be extended. So I think that gets really difficult, but we have a duty of care, you know, we are the patient organisation for MND across three nations, and we absolutely have to share with people how the process is, how long it takes where they are in that process of drug discovery. And, you know, I strongly believe we probably haven't done that very well over the last year. And it's an area that we are really looking to improve over the coming months.

**Tanya Arnold**

One of the huge announcements we made in the last couple of weeks, the Research Nurse Network that you've launched, how important is that in that whole process?

**Tanya Curry**

Oh, that is so important. We're hearing from our community all the time about the gaps in the care that happened in the clinic, you know, and people having fantastic care, but often not enough time to talk about potential clinical trials for MND. And actually, researchers and scientists are really busy, and they need people to take part in the trial. And we always know that good care equals good research equals good care, it goes round in a circle. And actually, if you've got a diagnosis such as MND, you want every opportunity to have the right conversations in the right place at the right time. So you know, you are getting the best possible opportunities for your own personal needs. So we were so excited to launch that. And we worked really quickly. I mean, hats off to my team, I came back from conference in December on about the 9th or 10th of December and said we absolutely need to do it. And I want it launched in January. And it was the look around the table that told me everything. So I think we

launched at the beginning of February, but it will be brilliant. And it's what the community absolutely need and deserve. So I feel very galvanised by it's the right thing to do. And we're going to work at pace to make it happen.

**Tanya Arnold**

The team forgiven you yet?

**Tanya Curry**

I kind of think so. I'm gonna buy them Easter eggs, I'm sure it'll be fine.

**Tanya Arnold**

Is that also, it just it's something where you can show people where the money's going, because research and a lot of money goes into it. But people can't see a benefit from it necessarily to the until somewhere down the line, something you know, appears that makes it better.

**Tanya Curry**

Yeah, definitely. And we are putting more money into research and we need to put more money into care. We're working really hard at the moment to think about what's our strategy for the next three years. And we'll be launching that in 2025. But we're doing lots of work now talking to our community about where we need to position ourselves. So it is really important. And we you know, we need to be really transparent about that. And we also need to showcase and talk about the work we're doing and the impact that that investment in more clinical trials, for example, will make. So I think we've always done it, but we need to do more of it. And we probably need to do some of it a little bit more pacey than we have done.

**Tanya Arnold**

So if you look back on this first year, what are the things that you've put a big tick against, what are the things you think you need to do more of?

**Tanya Curry**

I guess, you know, the things that I would really tick, the research nurses are one of them. I feel so proud. And I think the fact that I've been able to meet pockets of our community and I've been so warmly welcomed to every group that I've been to, and people are not shy to tell me how it is. And they're not shy to kind of tell me what they need to see more of, what we do really well already and how they'd like that to be, you know, better for everybody that's got MND. I think the other thing was the integrated campaign with the Coronation Street story. I mean, I kind of I defy anyone to not be moved by that campaign and to not really see the impact that this disease has on people. So to be the chief exec when that launched as our first television advert. I feel incredibly proud of that. And I think the other moment was when I was at the International Symposium in Basel in December and to look how much work the team do and to have 1500 delegates from around the world all committed to MND research, trials, progression of treatment, all under our brand and under our name, you know, that was a massively proud moment. So there's so much to be proud of I guess the bits I'd like us to do more often better. Someone described MND Association to me the other week as a lovely, friendly dinosaur. And I kind of thought I get, I guess I see that, you know, we're very solid, we're very safe, we are absolutely there for people. But I think what we need to do is probably move a bit quicker, we need to

be on the front foot. And if you look at MND as a disease, it waits for no one, you know, people get a diagnosis and their lives change so quickly, we have to be with them, we have to be faster about some of the things we're doing. And we definitely need to make sure that we're championing the patient voice here in everything we're doing. So I'd just love to see more of that. And I guess the other thing we need to do, going back to kind of how the organisation worked over COVID is really lifting our heads up and thinking, what's the strategy for the next three years? How are we really aspirational about that? Because that's what people deserve. And then quite frankly, we need to get on and deliver it.

**Tanya Arnold**

And the research, I know, it's a frustration for you because you have to have, you're waiting, aren't you along with everybody else for those results? I mean, as an organisation, is there more you can do to work with politicians? Or to put the pressure on it? How can that work?

**Tanya Curry**

Yeah, I mean, we really are doing that. And it is so frustrating, because I sometimes sit here and feel I've absolutely got my hands tied, and I'm doing everything I possibly can to get things moving forward. One of the parts of our strategy going forward that needs to be stronger is that whole influencing piece and actually how do we work with regulators, the NHS, or the big stakeholders, our politicians to make sure that actually people understand from us the impact that this disease has, and why we need things done well, done safely, but done, really, you know, with a bit of speed and a bit of urgency. It's not going to be easy, we don't control that space, you know, we can try to influence we can try and give some really good leadership around that. But we are a patient organisation, and it is our job to champion what our people with MND need. So I think more, oomph needs to happen in some of those areas. But I also think we've got to be realistic about what we can do what we can change in a system, which sometimes is very limited. But I always want to come to the table knowing we are absolutely doing our best for the community. That's the bit that's really important for us.

**Tanya Arnold**

So if you and I are speaking in 12 months time, what do you hope to have achieved and then coming 12 months?

**Tanya Curry**

Well I definitely hope these research nurses are going to be already making an impact. We're hoping to have our first ones in place by the very end of the summer, in the autumn, this year. We will be ready to launch a new strategy. So we'll be talking to people about what we are doing, we'll have the results of our first survey asking the MND community so thousands of people what their MND journey is like and what they need from us. So how do we make that better and different, a good different for them. And I've been recruiting, you know, new people in my team that will actually bring new ideas and new experience to the charity. And I hope to be kind of looking at that and seeing some great impact from those leaders across the whole organisation. And I hope to be out and about into the community and kind of less in the weeds back in the head office. I want to be out there meeting people, and kind of really learning and listening about what it's like and what I can do in my job to influence and make that better.

**Tanya Arnold**

And it's an odd one, isn't it? Because the ultimate aim of your organisation is not to exist, because it means we've found a cure. Where are we at do you think with all of that? I mean, that's what everybody is dreaming of?

**Tanya Curry**

I know and that's the million dollar question, isn't it? And I mean, that's the vision for us. That's what we want to be, we don't want to exist anymore because we want to have found a cure. I think things are shifting, you know, things are moving forward. It must feel incredibly slow if you have got the disease or you've been looking at this for a long time, but actually we're investing more, we're seeing more research coming down the line. There is always hope you know, and when I meet some of the early career researchers and see their enthusiasm and their energy and all the things that they're trying, you know, you've really got to be in this to crack that nut so I have no timeframe here. I wish I had the crystal ball for every time someone asked me that question, but we're definitely moving in the right direction.

**Tanya Arnold**

Do you feel that everybody's sort of joined up now, it's not a competition from one place to try to get there before another? Because I know that's one thing that Doddie Weir found so frustrating that there wasn't this link up and the communication and the feeling that everybody is pooling their resources and information.

**Tanya Curry**

Yeah, I really think we're getting there. I mean, we work closely with the Doddie Foundation and MND Scotland. So we've got various teams across the organisation that work together, as three chief execs we come together, and we meet every other month. So we're talking about what we're doing. If any of us have got questions or queries, we jump on a call. So you know, I'm a great believer that no one can or should be doing this on their own. And actually, with all of us going for the same goal, you've got to have a better chance of getting there. But you need to work together, you need to openly communicate, you need to trust each other, you know, you need to have that really healthy collaboration. And that takes time to build, you know, we're all some of us are really new around the table. So we're building those relationships, but definitely going in the right direction.

**Tanya Arnold**

And it's a strange one, isn't it? You sit interviews for jobs, and they say, where do you see yourself in five years' time, and as you've said you ultimately you hope you're not in a job, because that means it's all solved and the box is ticked. But if it's not all solved by there, what do you hope to look back on and be proudest of, do you think?

**Tanya Curry**

I guess I joined this organisation thinking it has the most enormous potential to do more, to really capitalise on what the community are telling us and to see that growth. So I honestly see the organisation being bigger, but I see it having more impact across those three areas of work that I talked to you about. And actually, I'd like us to be much more joined up across the whole health and social and charity system, you know, we're all needing to pull together and work in partnership. And actually, for people to have choice about their treatments, and to have great conversations about opportunities

for their care with an MND diagnosis feels like that's where I want us to be, I want to look back and really know, actually, I've made a difference. And that's what this is all about.

**Tanya Arnold**

And just a final one. As you meet more and more people in the MND community, do you feel yourself changing as a person?

**Tanya Curry**

Yes, I think so. It's really strange, because, you know, I have a clinical background, as I've said, I've been trained in working with people who face life limiting illnesses for years. But the enormity of that never leaves you and actually when you work with people in the community, and you really put yourself in their shoes, and I think as you get older and you realise how complex life is and complex relationships are, and how important you know, these amazing connections around you are, it does, it makes you stop, it makes you think in a very different way. I feel incredibly humbled when I go out. And it hits me hard when I hear, I was talking to my team earlier, and I said I don't want to say when I hear the stories of people with MND, because they're not stories, they're people's real lives, and actually, I feel incredibly privileged when people share them. And you take that really seriously as a leader, you know, people are being vulnerable with you to tell you what's going on in their life. And I feel a huge responsibility to try and make some of that better. So yes, it does change you it can't help but change you. And the day I know it isn't, is probably a day I know I shouldn't be doing the job I'm doing.

**Tanya Arnold**

Tanya, thank you so much for your time. We wish you all the luck with everything that you're doing and fingers crossed you don't have a job in five years' time because we found the cure. Thanks so much for your time.

**Tanya Curry**

Let's hope so. Thank you. Thank you