

MND Matters: Episode 30: The Love Inside

Helen

Welcome to MND Matters, brought to you by the MND Association and sponsored by Toyota GB and Toyota Financial Services. I'm Helen Mackie, regional fundraiser here at the MND Association. Today we're joined by three brilliant guests. Chris James, the MND Association's Director of External Affairs, Mike Sumner, who is living with MND and his wife Zoe. They're here to talk about the Association's brand new awareness campaign, The Love Inside, which at the time of recording this episode, will launch in less than two weeks. The campaign includes among other media four television adverts, which will air in the ad breaks during the episodes of the world's longest running TV drama, ITV1's Coronation Street. The site is currently featuring a character living with MND called Paul, who is played by the actor Peter Ash. So Chris, this feels like a really good place to start. And a topic that we actually haven't spoken about on MND Matters before. It must have been quite a shock to get that first phone call from the Coronation Street producers to say that there's going to be a character on the cobbles with MND. Can you tell us a little bit more about kind of how that storyline all came about?

Chris

Yes, sure. Thank you. Hi, everyone. Yeah, it was an extraordinary phone call. MND has been featured before on soaps and their various soaps. But clearly Coronation Street, for many and with apologies to EastEnders fans, Coronation Street is kind of the big one, you know, it's got 6 million viewers. So it's a really big opportunity to raise awareness of MND. So we were hugely excited by the opportunity. I think tinged with that is also a slight nervousness as well, because you also realise that Coronation Street as a soap is a drama. It's not real life. And it is a drama. And there's always some like dramatic license in storylines. But it was clear from really the start of the process, that Coronation Street were really keen to get this right. They really wanted to make it a really true and authentic story about MND. And everybody's journey with MND is different, but they wanted to make it a really authentic storyline. So with that in mind, we wanted to seize that opportunity and build on the momentum by creating an awareness campaign, which primarily was to reach and inform Coronation Street viewers and the wider public. The campaign's called the loving side and features, we're very excited to say, television adverts which we played in the breaks of Coronation Street. They'll also be lots of activity on social media, and press coverage to hopefully reach as many people as possible.

Helen

And what an exciting opportunity is it's brought motor neurone disease to a whole new audience. And I think people are now understanding better the impact of the disease on those who are diagnosed, but also all their family, their friends and those who love them. So Chris, how did this opportunity with Coronation Street spark the idea of coming up with the awareness campaign, The Love Inside?

Chris

Yeah, really good question. And I think it's really one of those really challenging things we have seen in the past two, three years a real upsurge in awareness of MND. I think certainly since I've been at the

Association that there's been this real growth in awareness, clearly through diagnosis of people like Rob Burrow and Doddie Weir and and the fundraising activities of Kevin Sinfield. So that's made a massive difference. But this felt like an opportunity to tell the story of MND to a new audience that wouldn't have been aware of MND before, and the and how it progresses and the impact that it has on the family and friends of people that are involved in that in that story. So it was a really good opportunity. And I think, as I said before, everybody's journey is different. But it gives you the opportunity to tell in important information almost about MND to this audience through a dramatic storyline. So we work very closely with the Coronation Street Team over the last few months to make sure that the they're very keen to get it right, we can help them to do that.

Helen

And I'm sure everyone who's watching Coronation Street, all the fans are completely along with those characters and are supporting them and learning along with those actors that are portraying, although dramatized, the realities of MND. And now because of this campaign and the TV ads that we're going to be launching, then they're also going to be learning from people with lived experience.

Chris

Yeah, definitely. And I think it's quite interesting because we haven't done a TV advert for very long time at the MND Association has been a long time I've been with the Association for 10 years, we haven't done one in my time here. And I think we've always been a little bit resistant to it, because we didn't feel that there was that traction of the story and an understanding of MND, that you would be able to really get the most out of a TV advert. However, this felt like an opportunity that it, it couldn't be missed. It was an unrivaled opportunity. We had to take it and that's where the integrated campaign came from. And so, we, we went went into this wanting to develop a really true story about MND. And we were very conscious from the beginning that we didn't want an advert that involved actors. We wanted this to be an advert that involved real people with MND, so that we could tell that story to the Coronation Street audience alongside the dramatic representation of MND that they were seeing.

Helen

And we're joined today by two of the stars of one of the adverts that's going to be being broadcast in the advert break of Coronation Street. Mike And Zoe, welcome. Thank you so much for joining MND Matters today. I wonder if we can actually start by asking you to tell us the story of how you met.

Zoe and Mike

Yes. Hello, thank you. Mike's gonna be the Silent Partner with us here today. His voice is certainly not as strong as it used to be. So we've, we've had a little look see at the general type of questions in advance. He's given me some of his thoughts. So I'll do all the talking. I'll share everything for both of us. So it's, like a lot of our life. It's quite interesting in terms of we actually met on the day that Mike had his first symptom of MND. And even that wasn't a normal day because of other reasons. Because we were filming a TV show, we appeared on Channel 4's First Dates, and that is how we met and how our relationship started a strange way to meet someone, but it worked for us. Mike certainly spoke about that in more detail when he last appeared with you on MND Matters, he reliably informed me it was episode nine. So if anyone wants more details straight out Mike's mouth, you can find that on there. But it was a really interesting experience. From my side, lovely and weird being on the show, seen it on TV,

and then you are in the midst of it all. Great meeting Fred and Merlin, the two most well known faces from the show. You you think you'd sit there and go, 'Ah, there's cameras everywhere' but they're so small and hidden out of the way you just, we were just able to enjoy a conversation with each other and just ignore most of what was going on until the end where you go, oh, there was a there was cameras there. And we just yeah, we had a good time getting to know each other on TV.

Helen

It was it was such a lovely episode to watch. And then obviously I've yeah, I've listened to Episode Nine of MND Matters, to hear it all from Mike's perspective. And now you're married, which is, which is wonderful. And then we call you up and say, 'Would you would you be happy to get back on television?' So can you tell us a little bit about how what it was like to be involved in filming this ad for our campaign? The loving side?

Zoe and Mike

Absolutely. So speaking with Mike, he wanted it to be mentioned that, you know, he's been a fan of Coronation Street for over 20 years. So to be asked to be involved in something that had any relation to Coronation Street was a huge honour for him. So immediately it was yes, I am doing this. On the day, it was quite surreal and fascinating. never quite got used to having half a dozen people in what is quite a small flat that we live in. And there was another half a dozen in the carpark watching via monitor, so just people everywhere, but he enjoyed it really fun to see what goes into making any sort of filmed item and the crew were really lovely and respectful of us. And I'd agree with that. Certainly an unusual day. And they kept the crew to a minimum but there has only so few they can do and I cannot emphasise how small this flat is. We've got a very small flat that we live in and a massive lighting rig in the kitchen that basically took up most of the space that we have there. But they made it as easy as possible. We filmed different parts again and again at one point. So you do still get tired. But that's how it goes that bits not even in the first cut, but that's showbiz.

Helen

That's showbiz. I mean, in terms of filming on the day, how much preparation went into it? Or or was it just a case of you living your life in your flat surrounded by these bright lights? And all these camera people? How did you go about actually filming the scenes that we will obviously all end up seeing in the Coronation Street as break.

Zoe and Mike

Like Chris said, it's about real life and real lives real experience. So they very much wanted to keep it as authentic as possible. So outside of a certain element of refilming certain things to get wider shots and close up shots. It was more or less going about different aspects of our normal daily routine, some in the wrong order some at the wrong time, but capturing all the key things that we are affected by every day that make life a bit more difficult to complete. Things that a fully able person can just do in five minutes, ten minutes. So it was they were very good about just selecting things from us things that we told them about to be filmed for that piece, it's just us doing normal us things.

Helen

Completely unscripted and mildly directed by you then feel the directors of the advert as well as the stars!

Zoe and Mike

I suppose you could say that. Yeah, very much informed by by us and what our routine looks like.

Helen

So you have seen the ad. What was it like for you both to watch it back?

Zoe and Mike

So for for Mike's part, it was weird seeing himself and of course, very emotional. He knew we both knew what they had filmed on the day. But when you see it back on a screen in that format, it was like they'd filmed so much more than he thought they had. And he just really hopes it has the same effect in stirring the emotions for everyone else who sees that as well. I agree that it was wonderful to see how well it turned out, like really good quality pictures and with the music in the background. It's just it's something quite special.

Helen

It is really special. It's incredibly emotive powerful that that music that you've referred to, is a song sung by Roberta Flack, who people may or may not know is actually currently living with MND. So really the perfect soundtrack to the beautiful scenes that that we see, Chris, and I kind of kind of bring you back and just ask what are you and what we as an Association hoping that we can achieve with this this campaign and with these TV adverts?

Chris

I think we're hoping that it will raise awareness of MND. But we wanted to go further than that. And we want to show the impact of MND on people's lives. Also, we want to ask people to support us and support the MND Association because it's, it's through our work that hopefully we can have a real impact on the lives of people with MND. Whether that's providing support for them, ensuring they get the best possible care by campaigning with them, or of course, raising funds or getting research into this disease. So of course, ultimately, we can find treatments and a cure for MND. So I think all of those things are really hope that this will be triggered through those adverse and so I think it's really important for us as an Association and for the MND community. We're very grateful to Mike and Zoe, to Rob and Louise and of course, the other Mike for coming through and you know being filmed because yeah, it's raw. It's not the easiest experience to watch it and we're really grateful for them doing that.

Helen

There is a bravery in my opinion, and I'm sure in a lot of people listening to this podcast in showing the realities of MND. So, back to you Mike and Zoe how, how do you think you're gonna feel when you're sat down watching Coronation Street because you're a fan so I know you won't be missing that episode. And now there's a special reason to stay tuned during the adverts. How are you going to feel knowing that up to six million people who watch Coronation Street are going to be watching your advert?

Zoe and Mike

I'm personally very excited. Mike got over the idea of millions of people watching him on TV a few years ago when First Dates happened, it's almost normal to see himself on screen. The hope is just that when people see it, they'll maybe Google the MND Association. Learn more about the awful condition that is MND, or maybe we'll get some volunteers for the Association because we know that we need more volunteers for visits and other things. But yeah, I'm very excited that we're going to be part of an integral part of something that's not just a new milestone for the Association. But this whole Coronation Street presents, which sounds like it could be a much bigger thing that they're launching into. Just have an opportunity to hopefully make such a difference by raising awareness for me to be involved in personally is quite amazing.

Helen

I personally think that the the adverts are going to achieve all of that when people people see it. And thank you so much for for being being involved for giving us an insight, not only through the adverts, but also through today's podcast into your relationship and your love The Love Inside which I know this is a podcast so the listeners can only hear it, but we get to see it because we're with you today. It is beautiful. And and for sharing that awareness. It's it is going to make a massive difference. Chris, any any last things you want to say about the love inside and the campaign?

Chris

Yeah, thank you. Well, it launches at the end of January 29 of January. As Zoe said it's going to be a special launch presentation as part of the that particular episode of Coronation Street, which is really exciting. Obviously part of a digital campaign as well. So all the three films will be used as part of a big digital campaign as well. The TV ad will be shown other times on ITV as well. So yeah, we're really really excited about it massively grateful to Mike and Zoe, Louise and Rob and Mike, for giving their time and their bravery as you said, Helen in doing that. Really sadly, Louise died over the Christmas period, which was really, really sad, and I think brought home to us the reality of MND as well and obviously sort of very pleased to dedicate this campaign and the films to Louise, and very grateful to Rob and the Louise's family for saying, yeah, please go ahead with the film so that's, that's really good of them. But yeah, we're, we're really excited about it. I think it will feel really strongly part of it. And I just, yeah, really, really positive. It's going to be a great success.

Helen

Amazing. So that wraps up our episode today. Please please, please do go back if you haven't already listened to it to Episode Nine, as Mike said, which is his his episode talking around relationships with MND but going into definitely more depth about what it's like to be on the First Dates. And please do do look out for our campaign The Love Inside It is so special. If you see it on your socials, please do share it. And please tell everyone to start watching Coronation Street if they're not already because they'll definitely have a chance to then see these incredibly precious TV ads as they go out. So no going and making any cups of tea, sit through the adverts, and it will be great to hear everybody's feedback what they think of it. Thank you.

Outro

You've been listening to MND matters, a podcast from the MND Association. Find more information at MNDassociation.org And if you've been affected by any of the issues raised in this episode, contact our helpline MND connect on 08088026262 or email MNDconnect@MNDassociation.org