MND Matters: Episode 27: Rob Burrow Leeds Marathon

Intro

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

Ally

Welcome to the MND Matters Podcast. I'm Ally Grant, I work at the Association as the press officer. This May I was fortunate enough to spend the weekend in Leeds to help with the inaugural Rob Burrow Leeds marathon. I spent that time meeting lots of wonderful people, and hearing their inspiring and humbling stories. Come along to hear and feel what it was like, if you want to feel uplifted and inspired go nowhere else for the next half hour. We start early on Sunday morning, the day of the marathon as Julia Beales from our fundraising team and I walked down to Headingley stadium. It's half six. It's fairly misty. There's nobody about except us? And obviously one runner getting a coffee. How are you feeling?

Julia

Yeah, I'm just excited for the day. Obviously, it's been a huge build up for this and working towards it for over a year now. And we're just so excited to get the whole MND community together and running to fight Motor Neurone Disease.

Ally

Quiet before the storm, isn't it? This is literally, the road is closed. There's no traffic. Everything's been put in place. All we've got to do now is wait for everybody to turn up. And it's really exciting, isn't it? It gives you goosebumps, doesn't it? It's so many people trying so hard. It's just very humbling. Isn't it?

Julia

Yeah. Last night talking to people at the pasta party. Like you said, there were so many people who are taking on their first marathon tomorrow or today. And they just said it was nice to be with other people and talk about it kind of calms the nerves, isn't it? Yeah. A lot of them are talking about being on the start line this morning.

Ally

And I think there's been a lot of support for people who are first timers. And that's how they've made it this far. Because of all of the Facebook communities, the WhatsApp groups, the calls from back at base, and I think people have felt quite supported. Like they're part of something

Julia

Definitely the community on Facebook, particularly, it's been incredible. Everyone's supporting each other people sharing when they've done a rant, whether it's gone really well or not so well. There's just

so much support there. And yeah, it's just fantastic. It'd be lovely to lots of those people see each other in person today. Yeah, meet each other for the first time.

Ally

That's gonna be great, friendships start don't move from this type of thing. It's lovely.

Julia

Definitely, it's lovely.

Ally

At about 7am runners started gathering in a makeshift village in the grounds of the stadium. Just time to stash the bags dive to the loos and grab a cup of coffee at the MND Association tent. I grabbed a few nervous looking runners this is your first marathon. It's your first rodeo. How are you feeling?

Runner

Okay, yeah, bit nervous, but just want to get started now.

Ally

Why did you sign up for this marathon? What was it about this one that made you want to get involved?

Runner

I think the cause, I'm going to get emotional, someone at work that was recently diagnosed is only 52 is diagnosed with motor neurone disease. So we've done fundraising for MNDA last year through work. So when this came along, and then lots of people for the running club got behind deck because it was local in Leeds and everything. So yeah, just thought well, we're gonna do one do it now. So yeah,

Ally

You're doing it for a great cause somebody close to your heart, how have you found the process of getting to today

Runner

The gang I'm running with they've raised nearly, just over 3000 So yeah, so it's been brilliant. It's just been going up and up and up every week so and yeah, they've done great job

Ally

so in three words, put it in three words how are you feeling?

Runner

Excited, nervous and yeah proud.

Ally

Standing in the in the village, and we're outside the the association tents like little support tent where you can get coffee and tea and snacks and stuff. What do you what's the atmosphere like for you? How are you feeling?

Runner

I think everyone was feeling really nervous, a little bit excited. At the moment, it's just sort of, we've got an hour, an hour and a quarter before our waves set off, it's going to be a long hour. Just want to get it over with.

Ally

You want to get going, Good luck you'll smash it. How are you feeling? Good?

Runner

Better in 3 and a half hours. I'd just like to get round to be honest. Better than it raining. And emotional.

Ally

It is emotional. Are you doing it for anybody in particular?

Runner

No I've had a lot of good memories here. I do like watching Rob and Kevin, that brought a lot of good times to my family watching over the years. So at least I can do really bring someone in, give back for two blokes that really deserve it

Ally

Why did you want to enter this marathon?

Runner

It is a cause it's really close to our hearts as a as a couple and our family really. It's we're rugby league family. So even though we're not Leeds Rhinos supporters, Rob is somebody that kind of inspires us. You know, just just his story, everything around the support he gets with family, and it just just really does inspire you. So as runners, it's the little bit that we can do. Quite simply, I couldn't not do this marathon. I've been running for the Association now ever since Rob's diagnosis in 2019. I run London marathon last year with the Association. This was an absolute no brainer. If I never run another marathon again, this was the one to do.

Ally

And what is it about the MND association that you want to be involved with? What's your connection to it?

Runner

Rugby League, there's no family connection for us. We are Wigan Warriors fans. And this is something I always say about rugby league. And I've said it once and I'll say it probably another 100 times about the connection with Rob, doesn't matter what team you support in Rugby League, it just was one of ours. It's the Rugby League family, like, you know, I pulled my running shoes on for Rob in 2019. And I'm not stopped running for the Association since. I've done fundraising for different organizations. And I've got to say it's kind of been the easiest, it's the easiest to engage. It's the easiest to come to. You know, if you're looking for specific support, you can just find it. But phone calls and motivational phone

calls have just been fantastic. I'd have two Yeah, I've had two calls. And it's just been fantastic. And you know, the support from the team is just brilliant. And from other runners, you know from the Facebook groups. On other social media, it's just been brilliant. You know, we're we're talking about the purple party, because purple wave is kind of the last wave but it's the I think it's going to be the party wave.

Ally

We're about to start what time you're in the blue wave. So you're going in 20 minutes. How are you feeling?

Runner

Yeah, feeling pretty good. Pretty nervous. But the crowds are wishing us on so it's quite nice. Yeah. But yeah, the all you can eat last night probably. We were thinking carb loaded. We went a bit too far. So it'll be interesting We ate our way around last night, I think maybe wasn't the best way to go.

Ally

And have you got people here during the day going to support you and cheer you on.

Runner

Yeah, so I've got the rest of my my father and my sister and her partner here.

Ally

Why have you chosen to run for motor neurone disease.

Runner

So just over a year, unfortunately, I lost my mother to motor neurone disease. So it's quite close to my heart. So I've never run a marathon before and love the way that Rob Burrow and the charity do so just wanted to run to show support. The team at the MNDA have been really good. They've sent a lot of stuff out. And we've we've managed to raise nearly 6000 pounds which is which is quite good. Because they were the MNDA who we're running for helped our family quite a lot during the difficult times. So I've just hoped that that 6000 pounds can go towards helping families like they did ours.

Ally

How are you feeling just before you set off,

Runner

excited, unprepared and optimistic. I like it.

Ally

The start line was buzzing and crowded with journalists film crews and family members of Rob burrow and Kevin Sinfield. I got to the platform where all the VIPs were speaking. Here is Yorkshire prose, also known as Ben Taylor, who wrote and read a special poem for the day to get all the runners geared up.

Ben Taylor, Yorkshire Prose

Oldham is my town. Leeds is my city. There are words that Kevin Sinfield would say. Well, today the city belongs to you. All 26 points 2 miles ahead. Pounding pavement through parish of poole, and dashing deftly down old Otley run. Through hamlets and high streets and over all hills. Will be folk out in rain or in sun. All city are cheering for you in the same way it always has Rob because like him it was rise to the challenge and this city knows that you're up to the job. Now this might be your very first marathon or you could be a maniac like Kev over there. Either way all hard yards are done, try and enjoy this now that you're here. This is just a bit more through city. It's a festival a party on streets, there's brass bands and bangra and steel pan and so an old fellow runners to meet from the start line just outside stadium across all routes, no matter the weather, all abilities, all shapes, all sizes, through Leeds proudly march on together. Now I'm not saying it's bad to be easy. There will be some ups and some downs you'll go through some emotion some aches and some pains and a blister or two. In that moment. Remember your why. Your reason for getting to end for your family, your friends, a charity for Rob, like Kev on a run with a friend. And what a source of inspiration? The Burrow family are for us all. That South stand will erupt and be bouncing like it did when Rob broke through with ball. With that in mind and some true Yorkshire grit. Just enjoy what's before you today. There can be heartbreak life can be cruel. You don't know what might be taken away. Awareness for motor neuron disease since Rob and his mates champion cause. Well, it's gone well and truly through the roof and that's worthy of endless applause. A Rob Burrow center for MND in Leeds, what a worthy legacy summit like that'd be I know in the strength of that man and his team. It's summit I'm sure we'll see. That's why today is a celebration, celebrating Rob and the city and all you so when you get that finish line feeling you can be proud of what you put yourself through a day of emotion, achievement and aches, a day to remember I'm sure you'll agree a day to add to the culture and history of Leeds. The Rob Burrow Leeds Marathon 2023. Cheers all, good luck.

Marathon starter

As Rob Burrow and Kevin Sinfield make their way down to the start line here, he's a Rhinos legend everybody please welcome to the stage the OBE that is Kevin Sinfield.

Kev Sinfield

I just want to thank everybody on behalf of Rob Lindsey, myself and that whole MND community for doing all the work, the effort, the training, to rock up today, in great shape, bring the sunshine with you, I can only thank you. We have created something incredible in Rob's name. This marathon has been put together. And it's all about friendship. So I asked you for one thing today. If someone's doing it tough next to you, and struggling, get your arm around, give them a smile, help them through, because that's what we're here for. Last thing I want to finish with today is about friendship. It's about raising awareness, and money for people we all love and care about. I'm delighted to tell you so far cumulatively we've raised 3 million pounds for a range of different charities across the UK Thank you very much if you pass us along the route come and give us a smile, come and say hello and lets help each other through.

Ally

Moving around the course the crowds were amazing. Leeds was buzzing. It was three deep in places and people from all ages and walks of life were there to cheer people on one of the MND Association cheer points. I met up with some of the West Yorkshire branch. I spoke with Tanya Arnold. She's a familiar face to BBC Look North viewers. Not only is she a journalist who has followed Rob's story from the very start, but she's also a patron of the West Yorkshire MND Association branch. This is your, your branch here this cheer point. How are you feeling?

Tanya Arnold

It's been absolutely incredible what an amazing, amazing atmosphere. I've been lucky enough to be around since five o'clock this morning down at Headingley and you felt it build and it was quite nervous. Down at the stadium. There's so many people who are doing this for the first time, which is just incredible. But now they're all going it's got this kind of party atmosphere around it. And I I just tip my hat to anybody who's doing it

Ally

The support for them is amazing.

Tanya Arnold

Absolutely. My hands are hurting. Yeah, and I mean, absolutely incredible. And it was really interesting. It was really, really emotional down at the start as well. And Kevin said some words, Yorkshire prose did a beautiful poem and . It's taken such a long time to get to this point, you know, it was it was a dream, quite frankly when that when they had it and the organization that's gone into it and to see Kevin be able to push Rob around this just so so special.

Ally

Also at the cheer point was Gemma Bonner, the England and Liverpool defender who is also involved with the West Yorkshire branch.

Gemma Bonner

So I've previously done the challenges with Kev. Obviously, I've known Rob and Kev since I was probably seven years old. And they've for me been incredibly inspirational from me being such a young kid, and they've always supported me throughout my career. So obviously, to see the effects of this awful disease and how it's affected not just Rob, but I'm close to Stephen Darby too everybody else in the MND community. It's you know, it's been heartbreaking for everybody. But I think the incredible work that's been done. And today's event is honestly, it's just unbelievable.

Ally

The atmosphere is fantastic, isn't it? Can you describe it?

Gemma Bonner

Yeah, it is. I mean, the streets are lined, I think not only the amount of people that are running with MND shirts on, I think that's just incredible in itself. But the amount of people that have come out and supported, you know, the streets are packed out there. So to have something like this in Leeds, and especially on behalf of Rob, I think it shows how much Rob means to the whole community of Leeds, but also how much everyone is behind him, and hopefully trying to get a cure, ultimately for the disease.

Ally

Because a lot of people running today, it's their first ever marathon. And it's no coincidence that today is their first marathon, because they're doing it for Rob and Kevin aren't they.

Gemma Bonner

Oh, 100%. And I think you look at how many people he's inspired, I think, you know, almost puts it into perspective. And, you know, you see how much Rob and everyone close to him or suffering from it. You know, it kind of makes people get up and think, you know, what we're what we have, we're actually very lucky and privileged. And, you know, why not go and do a good thing and raise as much money and awareness as possible. And the amounts raised so far, honestly, they're just incredible. And that's only going to continue to rise. And I think the strength of this community is unbelievable. And you can see the amount of people out here and there's so many support branches across not just Leeds but everywhere. And it's such a special community to be a part of.

Ally

After the runners had started to cross the finish line, I headed to our reception room where I met with Amy Kilpatrick. She's one of our fundraising team at the Association. And she's one of the many who have worked long and hard on the Rob Burrow marathon. And the day had finally come. Tell me, Amy, now your job is to support people in their fundraising. Do you feel they've done you proud today? Because there's been over 2000 people running for us today. How was it? How's it been?

Amy Kilpatrick

It's been incredible. It's just been breathtaking. It's been overly emotional. It's just been fantastic. The runners have really really put their all in this is not an easy route. There are. It's up hills, it's down dale. They've really really pushed themselves. We've had a lot of new runners here. We've had a lot of new supporters come in. But the atmosphere has been amazing. The runners have really really done themselves proud they've done the MND community proud and then done the MND Association proud.

Ally

And it's been a lot, not a lot. There's been a few people who've completed the course who are living with MND. Their faces, they're chuffed aren't they.

Amy Kilpatrick

They're chuffed, and everybody's chuffed for them. They've had a huge reception as they've come up to the hospitality after the marathon itself. It's made us really proud as staff of the Association, but you could just see the love and the pride in the room when they came in. And yeah, I think that's made them really proud. It's such a such a special thing for them to be part of and I think they'll remember it

Ally

This is the moment the world has been talking about ever since. Rob, Kevin and the team enter Headingley stadium. And then Kev carries Rob across the line. You've just finished. How are you feeling?

Runner

Oh, absolutely brilliant. I was just saying I've never smiled too much in a marathon. I've got 100 miler next week. So this was just jogging around. enjoy myself. Obviously, I'm dressed up as a superhero. Loving the crowds. The kids loved it. Lots of high fives grabbing sweets. Yeah, and the crowds were just amazing. It was it was absolutely fantastic.

Ally

There's such a buzz around the places in the streets were busy even yesterday

Runner

walking through town. You just noticed this buzz and yeah, there's just an energy about which carried over into today.

Ally

And why have you run for the Motor Neurone Disease Association?

Runner

So I run I lost my mother in law, unfortunately, in 2019, June 2019. So from the minute she was diagnosed, this had to be my chosen charity. I mean, and it's a brilliant charity as well. So yeah, I've been doing plenty races this year. I've got 10 ultra marathons in 10 days or 200k and 100 miler next week. So I genuinely mean this. I've worked with some other charities and they are just nowhere near the level of MNDA. They honestly aren't. I mean, the communications fantastic. Build up to marathons, the information, the emails, everything is just top notch, can't knock it.

Ally

You've just finished. Yes. How was it?

Runner

It was tough. It was brutally tough with the heat and the hills but the support all the way around. And every time we went past, obviously, the motor neuron disease stands It was the support was amazing out there. But no, it was very tough. But so good. So so so good to support and we saw Kevin and Rob as well at one point. So, you know, with me and my best friend, we've run it, Charlotte, we've I've said, look, it's not about time today. It's what we're running for. And it was my last marathon. So all good.

Ally

Can I ask you why you run for motor neurone disease.

Runner

My friend Charlotte has got someone who she knows quite closely that's got it. And many years ago, I was working in a shop and a lady is coming with motor neurons disease and loved dogs. So she unfortunately passed away. So this is my best friend. We that's what are around for, for her. And just for Rob because my family have begun to rugby as well. So well rugby. We're on a podcast Charlie! I've run this marathon for my friend Sandra. Who has had MND for 20 years, which I think is pretty amazing that she's managed to live with it for that long. But she's such a determined lady that she will not let it beat her. And I thought I want to run this marathon for you. Because I know how much she would have

loved to be able to do something like that. And obviously she can't, but also the Rob Burrow story just breaks my heart. He's same age as me. And obviously he's got young children like I have, and I just thought I have got to do that marathon for him. And for everybody that suffering with MND. I thought I can't think of a better cause to do it for so even though I have to that was my seventh marathan and it was the hardest one but knowing why I was doing it kept me going. And I think that is probably the case for a lot of people out there today. It was worth all the pain because of what they're going through. So yeah, and it's been such an emotional day. Yeah, so sad. I'm just so glad I could do it and raise as much money as I could for the cause. Yeah, and I just hope that all the money that's been raised today and it's really raised awareness hasn't it of MND because of Rob Burrow and that's just amazing itself, isn't it? So, so

Ally

There can't be many people left in Leeds who haven't heard of motor neurone disease

Runner

No, but But it's good that you know is has really raised the profile of MND hasn't it so which is really good.

Ally

Tell me, tell me about what you've just, you've just done something amazing.

Runner

Ever since I guess, I saw Kevin Sinfield doing his first seven in seven. Just running for his mate that I felt well that's, that's the cool thing to do. No alter motive, no bigger reason just running for his friend. And I, I can see myself doing that. So then when this marathon came, came out, and the whole thing about number seven, I thought well, maybe I should give it a try to run seven marathons in seven days as well finishing with the Leeds marathon. In a way I did it as a personal challenge. But what Kevin Sinfield has been doing to just raise awareness for his mate. I think that nowadays I understand it became a bigger thing. And he's trying to go with it. Really, he's just doing this for his friend. And if everyone has a friend like Kev, I think the world will be a better place.

Ally

This is your first marathon? Yes. How are you feeling? Now you finished?

Runner

I'm not sure. Slightly shocked to be honest. I set personal time, four and a half hours and I've beaten that the support from the sort of crowds in Leeds has been the best of any event I've ever taken part in. And sort of did the Great North Run a couple of years ago. And I thought that was good. But I think this has surpassed it.

Ally

Well. Well done. Thank you very much for your efforts. Amazing.

Runner

Okay. Thank you. Thank you. All right. Thank you. And the money keeps rolling in.

Ally

Time to meet an amazing couple. David and Helen Wilson. David was diagnosed with MND in 2021 He used to run mountain marathons with his wife, Helen, he swore he would never run a road marathon. David has lost the use of his arms and legs now. He can still speak. He came to our reception room after crossing the line with his wife, Helen, who had pushed him the 26 miles around the course so that they could do one more marathon together. Well, it's been you've conquered. You've seen you've conquered How you feeling?

David

Feeling great. Now it was so much fun all the way around. So many people out there cheering or waving shouting and it was great. Never stopped smiling. Five hours. Yeah. Me jaws ache now.

Ally

How are you feeling? You've you've done the pushing. It was a big ask how you how you feeling?

Helen

I couldn't have done it without Simon from Todd Harriers. And Chris who's just gone to the bar, my brother in law. They were amazing. It was tough. It was really tough. Very emotional. I just felt brilliant.

Ally

You said you were going to do it together. You said you were going to make him do it a road marathon whether he liked it or not. And you've made him do it haven't you!

Helen

Absolutely. Yeah. We've done a marathon together again. We're used to doing mountain marathons that first ever road marathon. So yeah, absolutely brilliant. We've always raced together David and me. So this is very special.

David

Yeah, exactly the same, I really proud of all the team that's been around me. Happy that I've done it. And yeah, very emotional.

Ally

You've got some good mates haven't you.

Helen

Gorgeous elder daughter and my sister cheering is on the way.

Ally

There's been a good crowd hasn't there.

Helen

Absolutely fantastic. Brilliant. As we came out of Otley there was a huge crowd there. And that was when the emotion really hit me. You know, I'm just seeing so many MNDA T shirts out there. And, you know, as we run out of the stadium at the start of the cheer just followed us up the road into it. It was just lovely. They were just yeah, very, very special. It's a good memory today. It's been a good day. A really good day.

Ally

A massive thank you to all of our runners, supporters, podcast guests, and the team behind the scenes. As it stands as of the end of May. You have helped us to raise over 1.5 million pounds for the Motor Neurone Disease Association. Wow, just wow. You are all amazing. If you want to take part in the Rob Burrow leads marathon in 2024 why not contact our fundraising team. You can email them on fundraising@mndassociation.org Or you can give them a call and they would love to speak to you. They're a friendly bunch I promise 01604611860 is the number. So, we'd love to see you there.

Outro

You've been listening to MND matters, a podcast from the MND Association. Find more information at MND association.org If you've been affected by any of the issues raised in this episode, contact our helpline MND connect on 08088026 to six to four email nnd connect at MND association.org