

## MND Matters: Episode 1: Kevin Sinfield

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

**Nick:** Welcome to MND Matters, brought to you by the MND Association, alongside members of the MND community, including people affected by the disease, health and social care professionals, and supporters, we will be bringing stories, information and expertise direct to your ears. Subscribe to ensure you don't miss an episode. I'm Nick and I work in the research team at the MND Association.

**Steph:** And I'm Steph from the fundraising team.

**Nick:** We also have two very special guests with us today – Kevin Sinfield, director of rugby, former play and captain of Leeds Rhinos and all-round superhero for his Seven in Seven challenge, seven marathons in seven days all completed within four hours all to help his friend and legend of league Rob Burrow and his family after Rob was diagnosed with motor neurone disease.

Also joining us is Jonathan Griffiths. Jonathan lives in Leeds with his wife Louise and daughter Chloe. He is a big rugby league fan and supports his local team Hunslet. Jonathan is a member of our West Yorkshire Branch and he oversees the placement of collection tins in his area to raise money for the Association. He was diagnosed with MND in 2018 when he was 44. Jonathan will tell us what it was like to see Kev's 7 in 7 Challenge unfold and Kev about the challenge itself and how the funds raised will be used.

We will also discuss our commitment of an additional £2.2 million for MND research.

**Steph:** So, Kevin, it's been quite a while since you took that first step on your Seven in Seven challenge but let's go back to the beginning of the story and tell us a bit more about how you felt when you found out your friend Rob had been diagnosed with MND.

**Kev:** Yes, I don't actually quite like revisiting that day but I do understand why. I think we'd, sort of, noticed, you know, Rob have some speech difficulties and, you know, to actually get the diagnosis through was just, sort of, a big part of the journey with Rob to understand the specialist he was going to see, the tests he was undertaking. I suppose to be blind-sided a little bit by, by the outcome. It took us all by surprise, certainly rattled everybody and, and I think at that point you start to try and understand what it means, you try to understand, sort of, you know, the prognosis. What, what actually happens, what's gonna effectively, the challenge that Rob is gonna face and the family, what's it gonna look like? You start to process some of that and understand that, and the first thing everybody does is type into Google and, and you start to read a load of horror stories and, you know, at that point I suppose, yeah, we was all rattled, we was all upset, we were all disappointed. All absolutely devastated for Rob and the family, to have three young children and to understand then the two big stats that stick out are a third of people die within the first twelve months and then 50% die within the first two years.

They're just horrendous stats for anybody to, to face and for us as, as former teammates and friends you're, you're just, I suppose selfishly you think about how it would affect your own life and how it would affect your own family, you know, to see a, a good friend having to go through this and face this challenge is, is really, really tough but one that, you know, we're probably really fortunate, because of the friendships we have and that, that network came together and the Batman sign or the Batman call went out, I went out and all those players and those friendships that we've relied on for so many years actually came to the fore, which is wonderful.

**Steph:** Yeah, I think it's been absolutely incredible to see the support that yourself and your teammates have given to Rob and I think Rob has been so inspiring in the way he's been so open and brave in sharing his story, story, particularly in the media. How has it felt to see that growing support for Rob in the community since he started sharing his story?

**Kev:** Yeah. I, I just think the reaction and the response has been wonderful. Rob has had that effect on people all through his rugby career because he was a 5 foot, 5 foot 4 inches tall in a game played by warriors and big blokes, and for Rob to be able to achieve what he did and defy the odds, the odds for all those years was remarkable and he, he, sort of, had a lot of people who absolutely respected him, thought he were wonderful, they loved seeing him play. They might not have been Leeds Rhinos fans but fans of the game, looked at this little guy and saw what he did and, and was so inspired by him. So, for him to then set out on this, this next challenge, if, if that's what we'd call it or this next fight and, and handle it the way he did, to be so open and giving, to be so sharing is so brave and courageous. You're right, the respect and the support people gave him has been incredible. I think Rob has given so many people some hope, he's given them some inspiration and, and Rob has made it okay to be able to say, you know, the people who have either got MND or a member of their family has and people are starting to understand it now, which I think is a huge step forward.

**Steph:** Absolutely. I think definitely, right? You know, anyone sharing their story about how they've been affected by MND it helps other people to not feel so alone and I know Jonathan was watching that coverage and has seen MND placed at the front and centre of the media thanks to Rob, thanks to your Seven in Seven Challenge, thanks to other people sharing their stories. But, Jonathan, how has that felt to see the media around Rob's story?

**Kev:** When I was diagnosed back in 2018 I didn't know what it was, you know, and like Kev says, he, the first thing you do, Google. You come home and since Rob's diagnosis the awareness of MND has shot up, you know? And living with MND, finding out about the side effects, the medication, all the research that's going on, that's helped in the media because everybody has realised it's not a difficult disease, well, it is a difficult disease but I mean it's understandable, to put it out there in the media when people thought, 'Well, what is it?' And I bet a, like you say, a lot of people have Googled it and getting it out there with Rob telling his story, certainly that documentary it's helped a lot of people understand how, what and various other things.

**Nick:** It is really important that, that awareness that's been raised through the activities that have gone on through Kevin's challenge, you know, it's absolutely vital. There's so many things that we struggle with working with MND, you know, the process of diagnosis is so difficult, finding effective treatments for it are really problematic and, as you say, it devastates families so being able to bring that out into the open in such a way, you know, there's been a real fantastic, positive movement I think on the back of this challenge and other, other things as well. From my point of view working in the Association it's exactly what we need to get it front and centre and there is something that causes motor neurone disease and there is a treatment out there somewhere and we just need to find it, and if we can raise that awareness which leads to raising funds and do that research, and also look after people with MND and their families then that's exactly what we need to do. So, Kev, you're kind of at that position where you, you really wanna help Rob out and you're thinking about doing some events, we're in the midst of COVID and all kinds of things going on in the country, money is tight with people and you've presumably have had to cancel lots of events you were thinking of doing, so somehow you've ended up saying, 'Right, I'm gonna run seven marathons in seven days.' You could have sat in a bath of beans for seven days but how did you end up doing that and how did you end up with other people coming along with you?

**Kev:** Yeah, it was, it's been a, sort of, strange 15, 16 months I think on the back of Rob being diagnosed. What we found was the club, the club has been absolutely wonderful in their response and then that team, that, that group that had such a close bond and had some wonderful friendships came to the fore, as you're aware very quickly. You know, Jamie Jones kindly shared his testimonial game with Rob which meant that old band of brothers put the boots on for one more time and got a few minutes on the pitch, which was a wonderful day with a sell out crowd. It was shown on Sky Sports, just, like, the awareness we generated on the back of that and some, some well needed funds was magnificent. Straight away we had a load of momentum to raise funds which was, you know, huge for us given what Rob was facing and the family but also the awareness, the awareness to generate for the MND Association and for so many other people out there. Then COVID hit, as you said, and the initial one was, 'Right, well I'm gonna run a marathon in, in April and it will be for Rob.' Now, I'd never run Manchester Marathon so I was in for Manchester. I could sense that were about to get cancelled so I very quickly turned my attention, 'Right, well I'm still gonna run a marathon but I'll do it in Saddleworth and I'll do my own, I'll do it on my own,' just before lockdown hit that first time and, and then we all got locked down, didn't we?

We all got stuck and there was all different restrictions and, and that put a stop to many things but I always planned on doing something later in, in the year. I didn't quite think Seven in Seven but it was always gonna be another marathon, if I'm honest, and then I just got really inspired by some of what my other teammates or former teammates did. Jimmy Peacock did a, an ultra marathon as we come out of lockdown that first time. Barrie McDermott, Keith Senior and a number of others did Three Peaks in, in 24 hours and, and I just thought, 'Right, well, I wanna do something special for Rob.' Christmas was a big landmark for us because right the way through when Rob got diagnosed last December or 2019 December we wanted to make sure the following Christmas he woke up that Christmas morning and were just absolutely able to focus on the kids and not have any concerns about what life was gonna look like for the next few months or years but actually know that financially that was taken care of and but we were well short of that target, the plan was to try and raise £77,000, as you know, £777 all around Rob's squad number and it was a challenge that I felt would, I only had a short space of time, you know, I didn't have, nobody could go on holiday and I thought, 'Well, I'll take seven days off and I'll just try and do something with my time.' Very quickly I asked a few mates if you'd be interested, knowing we had to follow the rule of six.

We planned to go from Scotland and work our way down and involve Doddie Weir who has been wonderful, involve Steven Derby who, again, has been wonderful for Rob and incorporate, sort of, that MND community and, and try and get people the journey with us, well that got quickly scuppered with the different restrictions and authorities, and we had to get MPs involved, local councillors and we managed to say, 'Right, we'll we're just gonna go in, in Oldham and in Leeds,' and everybody worked so hard in putting it together. We threw it together in six weeks. Why Seven in Seven? Purely because the numbers worked and we thought, 'Right, it's gotta be all around it now.' I'm just glad it wasn't number 33 or number 88 but it just worked for the numbers and we didn't quite think about how it will piece together, whether it was gonna be doable for, for me and the other guys who, who took part but it was absolutely the best thing I've ever done, best thing I've ever been involved in. The awareness we created, the support, the fundraising we got and, and that were, you know, that weren't just down to that team who, who ran, all of the guys who ran who, who provided some wonderful support. That were down to the BBC, it was down to the MND Association and, and just how it got pushed. Do you know, the support we got through the BBC was incredible and Sally Nugent and Dan Walker, and Claire Ryan at the BBC.

Everybody involved just pushed and then Phil Daly, our Rhinos media manager who's played a huge part in, in helping shape where some of this money gets spent. He's a very good, good friend of Rob's too. The way he pushed it, the way he opened media outlets, the way he opened interviews up. We did everything we could just to get that message out there, so the whole thing was brilliant. We set off day one with £40,000 in the bank. We were actually all, I can remember being in that car park at 6:30 that first morning,

sort of, thinking, 'Have we bitten off a bit more than we can chew here? We're not quite sure if we're gonna, gonna hit our target,' and, and that target just meant we were a bit closer to that magic number for Christmas morning for Rob and for it to do what it did was just incredible. And I, I think to be back in a team, to do something for a former teammate who's fallen on some tough times but at the end of it to provide some hope to that full MND community, the messages of support, the emails I've received were just so humbling and, like I said, it's the best thing I've ever done.

**Nick:** Fantastic and, yeah, I'd recommend anybody catches the, the RAM film that was made, the inside story which, yeah, really shows kind of the, the struggle of it actually and, and that camaraderie. You know, everybody that came with you all had their own little stories and their own issues. It's really, it's really phenomenal and the kind of risk I guess that you, anything could have happened with injury, that kind of thing and for it all to come together in the way that it did it was just, it was just amazing. Amazing. Absolutely inspirational story and I think really in terms of yourself and Rob being such great leaders and inspiring people I think that's one of the, sort of, secret formulas for making the thing such a success, it just gathered so much momentum. So, as you were, as you were, kind of, going along I guess you, you thought you, you wanted to hit the £77,000 target. What was it like as you saw the total just going completely crazy in awareness for it? It was, from, from where I was standing I had mates phoning me up messaging me saying, 'This is incredible. Have you seen what this guy is doing?' And the reaction from people.

**Kev:** Yeah, it's, it's mad when you think we, we were just going for a run, do you know? When it, when it all boils down we just had seven runs. So, to think, just think of where it went we were absolutely all bowled over and, do you know, when we get chance that team will celebrate that week because for all of us I think it were pretty, pretty life changing just to go through that, to experience it, to experience the support, the love. So many well wishers out there. Do you know, when actually you're just trying to do your little bit and if you'd have said to me today, you know, 'You'd have hit your target and that's all you would have got,' you know, I wouldn't hesitate to do it again tomorrow because although the money was brilliant actually just the effect it had on that MND community and for Rob and his family was, was far greater than anything else you could have given us and, and, again, I will say it were seven runs and that you look out there there's people doing some magnificent charity events that are far greater and far tougher than what we did but I think Rob's story really resonated with families and, like I said, once again the work the BBC did, the work our media manager did and the fact that probably we're in the middle of COVID, it were leading into Christmas, people were starting to put their Christmas decs up and, and just wanted something to feel good about and hopefully our Seven in Seven showed that sometimes, you know, putting yourself out there and doing something for others can give far greater satisfaction than anything else and we certainly found that.

**Steph:** Definitely. I know I was checking my, you know, the TV, checking Just Giving, just watching for updates on my phone continually and I think it definitely was at a time where you just needed some hope in general, of course. Obviously, you know, working at the association, knowing so many people affected by this disease I'm so passionate about anything that's being done for the Association so I would have been on-board with that anyway but I think across for everyone it was just seeing you doing something for your friend who is in a really difficult time, as you say, and it was just so inspiring. You know, seven marathons in seven days, I've ran a marathon, Seven in seven days makes me feel a little bit sick and I think people who hadn't ran a step could still think that was an incredible challenge, and people who have run loads still think that's an incredible challenge. So, it was, it was just a winning formula really but absolutely incredible to see it unfold and I know, Kev, you've mentioned the support that you had from the MND community throughout and I know that was really important for you but Jonathan, how did it feel for you to see that, that breadth of support for people effected by MND and the donations coming from everywhere really, you know, for people affected by this disease?

**Nick:** I heard on the news that Kevin was doing this Seven in Seven and (audio cuts out 17.58) through the West Yorkshire branch of the MND Association. It was (audio cuts out 18.06). We all talked and, you know, we kept an eye on the total and as it were going up and it were going up, and going up. It, it got to the, to where it's like, 'What? This is unbelievable. Such an inspiration to so many people to do something.' Yeah, it shows, it just shows what an impact you had doing this Seven in Seven and, you know, I encourage everybody to get, get involved somehow, somewhere.

**Steph:** Yeah and it obviously resulted in an incredible £2.2 million coming to the MND Association which we are just so grateful for, Kev, and to absolutely everybody that donated and, you know, the impact that that is going to make is, is just absolutely, you know, it, it, it's just incredible for the association. So, yeah, we can't thank you enough.

**Kev:** No, you don't have to thank me. I absolutely loved it. It, like I said, it, it was the best thing I've ever done and if I could do it again tomorrow I, I absolutely would. I'd have to get some time off work but yeah. I would, I would do so in a heartbeat. It was, it was brilliant and I know Nick asked a question earlier about the money and, and it ticking over. There was two really, sort of, poignant moments and, and the first one was it was day five and, and Rob was viewing the mural that was being opened up, if you like, on, on that day and as we got there and as we ran past Rob and as we had that very small embrace, in fact I nearly got run over by a bus, we hit the £500,000 target and it were just sort of, you couldn't have scripted it any better and then on the final day we was on, sort of, the last couple of ks. I think we had 2.5k to go. I ran past my old high school which both my children were at because schools were back open then but both my children were at, one of them was doing his mock exams. The other one had been brought out of his lesson to, to meet us and as I, sort of, see my youngest son we hit £1 million as well so it was two, sort of, huge moments where you go, 'Someone is looking after us here, someone is making sure we get this done and someone is sending us a couple of special messages,' so, yeah. It was brilliant.

**Nick:** Fantastic. Yeah, amazing that and I think your, your eldest lad, Jack was it? Who he walked round the, the last marathon as well with Dave, was it? One of the chaps.

**Kev:** Yeah, yeah. So, you know, David straight away when I mentioned, you know, 'I'm thinking of doing this?' Just said, 'Can I do it with you?' However his final training run he, he tore his calf and he said, 'Right, I'm gonna walk them every day and I'm gonna walk them in seven hours and I'll just get through,' and, you know, thankfully was able to do the last one but yeah. Me, me eldest son did day five with him, you know, they was, they was up at 4:00am and off they went and they got it done in seven hours, so that were really, it were really great that Dave did what he did and still wanted to be a huge part in it and he was and we all felt a little bit sorry for him because he did I think the first three or four on his own and then after that people started to go with him and, and help him out a little bit and get him, get him over the line but, yeah, it was, it was really special that my eldest went with him one day.

**Nick:** Yeah, great as a dad to have your kid be interested in what you're doing and, you know, proud of you and things. It's, that is a very special thing that, you know, we're very fortunate to have, those of us who do. So, you have been left with a really good problem to have, so where to spend the money and I know that the association, it was very important for us to work with you, Rob and Leeds Rhinos to discuss how the money that you raised should be used. So, we talked with you through a lot of options, so what was the process for that and how did you decide what you wanted the money to fund?

**Kev:** Yeah. I, I think this was, it was really difficult yet also really, a really nice problem to have. The, as you, as you rightly pointed out, the vast majority of the money came to the MND Association, do you know, an amount went to Rob as well which was what it was all about and making sure actually we hit that target on Christmas Day, which I'm so thankful for to be able to do that. The first thing we wanted to be able to

support those who had been diagnosed, provide care, to educate people better in understanding this disease so that people could be better at dealing with it and the second one was for research to make sure that existing treatment didn't, and, and trials didn't run out of cash but also the, the big drive in all that research stuff was to try and find a cure, try and find a way of helping people now. We went about it or tried to go about it in a two-pronged way because we felt there was a, a huge need for that care and support, and as Jonathan rightly pointed out like we all were, the first thing you do is Google it so that education is it on hand? Is it concise? Make sure it's not conflicting with any other advice out there, let's make it really simple for families to understand what is happening and then obviously the research is the big one because we want to stop this happening, we want to make everybody, everybody's journey through this as easy as possible too. So, with Rob having a young family, families and children and young people were really important to, to where some of these funds went.

The care centres of which there are 22 across England, Wales and Northern Ireland were really important too because that's the first place that people get signposted to and within that it's a, sort of, a multidisciplinary support network that people get. Now, rather than go and see a dietician, a speech therapist, you know, someone who is gonna work on your muscles, rather than having to go to different places to get all that treatment it was-, it's provided at these care centres so you can get it all in the best that there is but you get it all in one place which makes that journey or that, that patient's day a little bit more easier to handle. Some funding towards the MND Connect which is the helpline, which is so important so people can just pick up the phone and get an answer and be able to talk to someone who understands what is going on. The clinical trials to make sure that some of these care centres, the, the 22 that I've touched upon, are better setup and resourced to be able to do some of the testing, some of the trials that take place and some of them aren't capable of doing it at the minute. We wanted to make sure that that was spread right across England, Wales and Northern Ireland and then I suppose the final one was, was to aid ongoing research but new research as well and, and be able to provide that support and we were really keen on that being a collaborative approach with some of the stuff Doddie, Doddie's Trust does up in Scotland but just making sure everything were joined up.

I have to say the, the MND Association have been absolutely wonderful. The support, the knowledge, being able to educate myself. Phil and Sharma has been really, really helpful and I suppose really helped us put a plan together because you can go into this blind, you know, there's all that money and in effect we were happy to hand it over and say, 'You spend it where it's needed,' but I think it's really important that we understood it and then ultimately Rob, Lindsay, Rob's mum and dad were part of the journey too, although they weren't at the forefront of it where we got to and when that, you know, the, the final proposal was put together. It was really important we got them to, to be happy with it as well because they've lived it, they understand it and if there was anything we'd missed or there were any holes in it I wanted us to make sure that we're covered off and, like I said, the MND Association have done a wonderful job. I'm really proud of how that money will be utilised and hopefully this is just the start of more fundraising, more awareness and, yeah, we can just continue with it.

**Nick:** I think that's absolutely right and, you know, it's good that you've, you've taken a great interest and understanding in the, kind of, depth and breadth of what we do as an Association and what is actually going on and where the money is going to. You know, and we're really greatly appreciative of that and also saying that, you know, this will, this will move things forward as. So, so, so your contribution is making those ripples that will go all the way through the MD research community, all the way through the care side of MND and the campaigning side that we do as an association, so we're extremely grateful for that and yet this is the start of great things to come, you know? We're pushing at the door for research, effective treatments and good things, good things around the corner. We certainly hope so.

**Steph:** Really what those funds can achieve is absolutely incredible and we are really grateful to you and we really appreciate the thought that you've put into it and, you know, the considerations that Rob and his family and, and everyone at the Rhinos as well. It's really important that the money is spent where, where you want it to be and where it will obviously make such a huge impact as well.

**Kev:** Oh, well thank you. Look, we, like, like I said, you know, a couple of minutes ago we were absolutely confident and believed that the MND Association would spend that money where it needed to be spent and so throughout this whole process it's, it's been done where we've been educated along it, and I think that's been really important for us to understand things a little bit more and, yeah, like I said, it, the MND Association is a wonderful charity, it's one that I said during the marathons but I were really proud to wear that number seven on my shirt but I was equally as proud to wear that vest and that snood. So, yeah, it's, it's been,

**Kev:** Yeah. It's, it's been, it's been a really, really refreshing process and I'm, and I'm delighted that, you know, people get to understand where the money they've donated is gonna be spent and used, and to have that transparency to be able to give the clarity to people out there that, you know, this money isn't gonna be wasted. It's, it's gonna be used in the best possible ways to help and provide hope. I think that's really important.

**Nick:** That's right. I mean, we, we understand that people are giving their pocket money, you know, kids, kids at school giving their pocket money to us as well as larger donations and, you know, we do everything we can to make sure that that is used in the best possible ways and that's really important to all of us at the association, for sure. And, and Jonathan, you, you're a, would you like to share some of your experiences of when you became involved in the Association and some of the services you've been able to take advantage of?

**Jonathan:** I think I went to see Professor Dame Cheryl or Dame Professor Cheryl, whichever way you want to put it. Gave various samples to try and do the bit, help with my bit of genetic research but also to try and find out exactly what I've got. Was diagnosed with progressive muscular atrophy, PMA, and from that point onwards the Association was so helpful, you know? Because it's a devastating diagnosis. It took me a couple of days I think at least to understand what I'd been diagnosed with and from, from that I was passed over to the MND Association who put me in touch with the West Yorkshire branch which is a support group, if you like, we meet once a month virtually at the minute with carers, other people living with MND and families and that was a great help for me to meet other people I could talk through the symptoms I'd got, talk my diagnosis with them and understand it a bit more and then you go to the care centres, I went to the one in Seacroft, they were so helpful as well. They got me in touch with the right people and like Kev says, you're, you're there. You see everyone in one place, speech therapist, physiotherapist, wheelchair services. The whole kit and caboodle are there and they put-, they put me with the right wheelchair for support, they put me, I go regularly to test the breathing, you see a speech therapist, you see all sorts of people, like you say, and it's just amazing the camaraderie, I suppose, like you said earlier but going to that MND support meeting once a month, that has, I think that's the biggest thing that's helped.

I've not used the MND Connect. When I first was diagnosed and got in touch with the Association I was told to visit this support group and I don't, I think that helped me get through it rather than going to the MND Connect. That was my experience, you know, dealing with them was the best thing I've had, you know, all my family has been so supportive as well. It's devastating for both Louise, my wife, and Chloe, my daughter. We were all devastated but speaking to the other people it's not less devastating but you feel, like you say, not alone. You, when you're first diagnosed you feel like you're the, you're the one, you're the only one who's got it and certainly, like I said, with not understanding what the disease is it certainly felt even more alone and then education, the awareness brings you into that bubble. You know, you see all them

people, you talk to them and you realise that, 'Okay, I can, I can do this,' you know? And then Rob gets his diagnosis and it's like, 'Oh my God, it, this is a, a fit rugby player, you know?' It just goes to show it can happen to anybody and you realise how devastating it can be to those people or to everybody. What can I say? But support, that's, that's the key word I think.

**Nick:** Yeah. That's right. I mean, it is absolutely devastating and one thing that we, we say is that MND doesn't discriminate, you know? It can affect anybody and we do our best, as we say, with care, campaigning and research. You touched on MND Connect there. We got in touch with over 3,000 people with MND during the pandemic, we answer about 6,000 calls a year and emails, you know, trying to give out that advice and signpost people to, to best care and services as we possibly can. And, again, we're actually trying to crack the disease, understand the biology of it, find effective treatments and get people into clinical trials to, to really get ourselves to a world free from MND and it was interesting you said that that you've, you've taken part of research studies and given samples and one thing that's absolutely certain is this really, really collaborative attitude of people effected and living with MND that they're willing to take part in these research studies which can't happen without that collaboration and the, and the sort of sacrifice and the bravery of the people who take part in them, so we're very, very grateful for that. And, Kev, as a result of your work and the increased awareness that's led to additional fundraising activity and the response of the community during the pandemic, it's actually meant that as an Association we've been able to commit an extra £2 million to MND research on top of our £3 million that we've already committed this year. So, this is gonna be an incredible addition and more research projects, more discoveries and more understanding of the disease leading us down a path towards those effective treatments.

So, I talked earlier about those ripples that go across, you know, from, from one person's piece of work and your Seven in Seven challenge. Can you believe that actually on the back of standing in that car park thinking that you're gonna do this little run you've now been able to leverage and that extra funding is gonna be available to get more research done?

**Kev:** No, no and it's, I, I think we, if I, if I start to think a bit like that I'll end up choking up, so I, I think for all of us, all of us that took part in the Seven in Seven last year it'll be something we continue. I don't quite think it'll be seven marathons in 2021 but who knows yet? We're still throwing ideas together. I think COVID will dictate how big or small our next event will be but, you know, I, I think one of the things we've been proud of is the amount of people that have taken up their own Seven in Seven and they're still taking place, the amount of money that's been raised also by all of those people has been wonderful and if, if we've inspired one person to just get up and go for a walk then, you know, absolutely we've, we've done our job from an exercise perspective but you're right, the funds are mind-blowing. You know, what has-, is gonna be utilised in 2021 towards all the things we've discussed, that care, that education, the campaigning, raising awareness, treatments, support. So, we're, we're absolutely bowled over, all of us and you, you keep saying me and my Seven in Seven. There were so many other people involved and I were just part of the team, and like I said it got to the stage where I just had to get up and run everyday and that were the easy bit, if I'm being honest.

My wife and my kids were all involved as were all of the other five who were involved in it, their wives, their kids and then it, it rippled further than that because people's friends and everybody wanted to help out and, and, you know, I'll give the BBC another rap here, they were wonderful. Jenn Dodd at the MND Association just couldn't have been more helpful and supportive throughout it all as well and, and then we did the daily Zoom which the day after each marathon we met different families who had been effected in different ways by MND and, and for all of us, you know, if we needed reminding what we were doing it for absolutely Rob was at the forefront of that, of all our thoughts but if we needed reminding, which we didn't, then, you know, just to see how brutal this disease can be we got that everyday too. So, I'm, I'm delighted to be involved in the podcast, doing anything I can do going forward for the MND Association going forward I will. I think you



all understand what Rob means to us all at the club and to those friends and players who played alongside him. We love him to bits and I, I think for those who were involved to still feel like Ready Brek man now, to still have that glow and that just the humbling experience of it all, you know, like I said, I'd do it all again tomorrow.

**Steph:** Be careful what you say, Kev. We'll get you signed up but I know you touched on potentially what's next and you're, you're having a think about those things so we'll watch this space for now. I know there are so many people who've, you know, taken your lead and taken on their own Seven in Seven challenges, as you mentioned, so I'm sure whatever you and team decide to do next we'll see another ripple effect off the back of that and we're very grateful but there is still time for people to join their own Seven in Seven challenge. I mean, they don't have to run seven marathons in seven days, maybe more seven cakes in seven hours or it's seven minutes if it's up to me. You know, I think we've seen that really people are taking the Seven in Seven and doing what is suitable to them or what they want to do and I think that's been really inspiring to see but there's definitely still a time to join the team and we would love to welcome anybody to the Seven in Seven challenge for the association. And I know, Kev, you're always interested to see in what people are getting up to as well. So, I think we've had about over 400 people now taking on a Seven in Seven challenge for the Association since you did yours, so pretty incredible. Yeah, thank you.

**Kev:** No problem. It's brilliant. Do you know what? And I, and I will say it now, I got it in the post probably about three weeks ago. You very kindly sent me my own Seven in Seven medal. Do you know, throughout all my playing career, you know, we got given rings when we won grand finals and medals when we won challenge cups, it's the thing that matters the most to me out of all of them which is bizarre considering you've been a professional sportsman for the best part of twenty years but actually it is the thing that I am so proud of and I hope there will be many, many others that receive that medal too.

**Steph:** Definitely. They're on their way out and I'm sure they mean, you know, for different reasons as much to them and I can see, you know, I can hear how much that means to you and the reasons why behind it, you know, it's all about Rob and that's why that medal means so much to you. But, yeah, thank you so much for inspiring so many more to achieve those medals, I definitely need to get mine, I need to get thinking about those cakes.

**Nick:** Yeah, really looking forward to what's next. I'm thinking maybe seven pints in seven pubs once we get out of lockdown, if anybody wants to join me. Answers on a postcard, please.

**Steph:** You could run to the pubs, Nick. You could run to the pubs at least.

**Nick:** Yeah, yeah. Sure. So, if you've been affected by anything you've heard today please get in touch with us at the MND Association. Massive thank you to you, Kev for your inspiration, drive, leadership and making such a difference to the MND community, getting MND heard in a world of noise is not an easy thing and you've absolutely smashed that and we will be always grateful to you and we really look forward to seeing what's next. Thank you also to you Jonathan for joining us today and for all that you're doing on behalf of the Association to raise awareness and funds in your local area. And thanks to Rob and his family for their bravery in sharing their MND journey and raising awareness and inspiring so many of us. Thank you very much.

**Outro:** You've been listening to MND Matters, a podcast from the MND Association. Find more information at [MNDAssociation.org](http://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](mailto:mndconnect@mndassociation.org).