MND Matters: Episode 38 – Shaped by you: our five-year research goals

Rick
There are more than 5000 people living with MND right now in the UK. I'm one of them. We all know what a brutal disease it is, and because it concerns the human nervous system, the most complex item in the known universe. It is frustratingly complicated and difficult to understand, so there are no effective treatments for the majority of people who have motor neurone disease.

Ali
Hello all. Welcome to MND Matters, a podcast by the MND Association. I'm Ali,

Rick
And I'm Rick

Ali
In March 2025 I lost my wonderful mum, Sheila, to motor neurone disease. So I am throwing myself into supporting the MND Association. I'm trying to share my experience and also support others, including this research strategy, which we're going to come on to shortly.

Rick
I'm a biologist, educator, advocate and artist, living with a slowly progressive motor neurone disease. So I've had symptoms for about 20 years ago. About 18 months ago, my GP confirmed that she was assuming I had about six months to live. However, to misquote Mark Twain, reports of my death are greatly exaggerated.

The MND Association is the largest charity funder of MND research in the UK, and has been around for four decades, but we still don't have the answers that we as a community of people affected by MND need.

Ali
Rick and I have been involved in some well, really honest and robust conversations about all of this with a team from the MND Association and other experts, including researchers and healthcare professionals, we've talked about what we want to know and the questions we think research should be answering and what we'd like to see research focused on. The result is that together, we've come up with a roadmap, a five year strategy, which, if we all work together, really will drive that work that will turn understanding into breakthroughs and breakthroughs into treatments. We're joined by Mike, Mike Rogers, the Association's Director of Research and Innovation, to explain more. Hi Mike.

Mike

Hi Ali, Hi Rick. Thanks very much to both of you. So just to explain a little bit more about our research strategy. We developed this over 2025 and it's building on the overarching Association strategy that was that was released earlier in 2025. We wanted to really identify the things that we wanted to do over the next five years, but we also really wanted to understand the views of the community and place those at the heart of what we what we were going to do. We want to make strategic choices for how we prioritise research activities, and this was a great opportunity to do that. So critical part of developing this strategy was listening to our community, and that includes researchers. It includes healthcare professionals, but importantly, it includes people with MND, their carers and their families. Their experiences have been critical to the development of this strategy. So what we did, we carried out surveys, we spoke to people on our road shows. We had interviews and also focus groups with patients, carers, healthcare professionals and researchers, patients and their families. Developed a list of research questions that they were interested in, and a smaller group of people affected by MND and healthcare professionals actually ranked those. We took a large list of them suggested by the community and had this group rank those for us to give. Give us their top 10, and we're going to publish that on the website in due course. We also did a lot of research into the background, what else was going on elsewhere? Who was funding what? We took all this information and developed a new research strategy, and we're really excited about this new research strategy. It's built around four objectives, to understand, to detect, to discover and to innovate. And we're hoping this is going to change the lives of people affected by MND, both now, but also bring in hope for the future. Our ambition, within five years, we'll spend at least 20 million pounds every year investing in brilliant people, world class research and the most promising innovations. So that's where we are, and I can provide a little bit more detail on each of those strategic objectives as we go.

Ali
Thanks, Mike, it's really interesting. Actually. I mentioned already I lost my mum to motor neurone disease last year. My mum was a really healthy, active lady, until she started experiencing fatigue and loss of strength in her hands. At the time, mum, my mum, put this down to her age. She was, she was 74 she persevered with her usual day to day activities, but she started having some falls. And this wasn't like her. This just didn't seem right. We started to question, actually, if there was something more than just being old. So we, we, we encouraged her to see her GP, she had some blood tests done, as is standard, but Mum was now increasingly house bound, and by September 24 She was then bed bound. She just did not have the strength or the ability to walk or stand. So a visiting GP, a suspected motor neurone disease and referred my mum for an urgent MRI scan. The Scan took four months, and at that point, my mum could only really lift her hands to her face, everything else, she was immobile, so she needed help to sit up to toilet, to wash and all the other usual things that I take for granted. She had a three night stay in a neurological ward at a local hospital, and on the third day, she was diagnosed with motor neurones. It's the news that we feared, but what we suspected, but in, you know, in praise of my mum, she took it as a as the strong woman that she was, which was okay, I've had a great life. Take me home. I want my own bed, and I want a decent cup of tea. And that's what we did. We took her home, and four weeks and six days later, she passed away very, very peacefully, very peacefully in a nursing home, surrounded by all her family. Have to say, the room was absolutely filled with love and nothing but gratitude and and love for her, for how wonderful she was. This really this story is why I'm speaking today and supporting the research strategy, it's to be able to assist in any which way I can to create more conversations, share knowledge and support the work of the Association, to provide support and a future that can be filled with hope potentially, you know, when you're diagnosed, rather than the fear that we all had. Rick, do you want to come in and talk about your experience and why you're here today?

Rick
Yeah, yes, for me like Ali, it's personal, starting from a few years back when my only goddaughter developed ALS amyotrophic lateral sclerosis, the commonest motor neurone disease, just after she'd

qualified as a lawyer, and she died a few years later. I think of her every day, and she's part of my motivation. And then there was my own journey through the labyrinth of diagnosis, five years after one of my daughters said, as I was going to see the GP yet again, tell her all your symptoms, dad, not just the one that's troubling you most right now, wise words from one so young, because that was the day my GP said, I think this is motor neurone disease. And then five years wasted, as I was pushed back from neurologist after neurologist who'd read my notes and had already decided it was psychological connected with post traumatic stress disorder, which I did have. And then, in desperation, my GP sent me to A&E, and a young doctor looked at me, the patient before her, and made an initial diagnosis, clearly something neurological. And stuck with that, even after she had read my notes and admitted me to see a very special neurologist, and the next day, the Reverend Professor Alistair Coles Head of Neurology at Addenbrook's Hospital in Cambridge, said, after an hour of looking at my clear signs and symptoms, I'm sorry, Rick, you have a serious neurological condition, but it'll take us a while to work out what. So two years later, having eliminated everything else, I was finally diagnosed in 2017 with PLS, primary lateral sclerosis, a rare motor neurone disease, by then, significantly disabled. Since then, I've reinvented myself as an artist and as an advocate although these days Sue my beautiful wife and primary carer does progressively more of the advocacy. As a biologist, I understand the complexity, the torturous time wasting diagnoses, the difficulty of cutting through that complexity to find therapeutic targets, but I still cry every time one of my new friends with the ALS dies, and there have been so many short, intense friendships because of motor neurone disease, we both know that time is precious limited, and that motivates me every day, and that's why I'm here, hosting this podcast, and why I'm going to let Mike talk about the future direction in more detail.

Mike
Thanks, Rick, thanks Ali, and really grateful for hearing your stories as well, because they've been really important to us in the development of this strategy, and some of the things that you've talked about wanting to understand the causes, but particularly the diagnosis, is something we heard very, very clearly from people we spoke to. And we feel we need to take some of these things forward as best we can over the next five years. So as I said, we've got four strategic objectives, basically things that we're going to do over the next four years. So the first one of those is to understand, and this is about revealing causes and targets. Far too much about MND remains poorly understood. We still don't know what causes most cases of MND, and we know from talking to people like Ali and Rick this is a question people really want the answer to, and there's also significant gaps in our knowledge about the biological mechanisms that lead to the disease. We must improve understanding of how MND develops, especially in what's called sporadic disease. This is the non familial forms of the disease which most MND sufferers have. The more we know, the easier it will be to find new treatments and to develop better ways to diagnose MND and even prevent the disease. The second objective is to detect we want to see better and earlier diagnosis. It can take many months, or even years, as Rick's outlined, to diagnose someone with MND, and even then, they may have no idea how quickly symptoms will progress. Improving diagnosis of MND is essential to our goal of finding more effective treatments. We need tests that can tell people what form of MND they have, but also what their prognosis is likely to be, so their treatment and care can be tailored to what they need. Something that really struck us when we talked to people with MND and their carers was that they all experienced the disease very differently, and people on the calls were saying, Why am I differently experiencing this disease to somebody else on the call. These are things that people really, really want us to look into in a lot of detail. So it feels really, really important that we do that. The third objective is to discover new treatments for everyone. And we know that people with MND urgently need new, effective treatments. There have been some really exciting advantages, actually, towards treatment for people with some inherited types of MND. So we have what looks like a very, very good treatment for people with the SOD1 mutation, which is called tofersen. And there's also a treatment being developed for the for the FUS mutation as well. There's been a lack of similar progress for people with sporadic MND. We think everyone with MND deserves hope for the future, which is why we're going to focus especially on finding treatments for sporadic

MND over the next five years, while also continuing to support some of the great research into the inherited forms of the disease. We've seen great promise through existing investments and large scale programmes. These are things like yeah UK MND Research Institute, the EXPERTS-ALS platform and the MND SMART trial, we want to continue to invest in large scale collaboration to create innovative new treatments and give many more people with MND the opportunity to join clinical trials. Again, something we heard loud and clear from people that they didn't feel like they'd been given the right opportunities to join clinical trials. We want to get as many, as many people from our community on clinical trials as we possibly can. And the fourth objective is about innovation. It's about innovations in healthcare. So we can do all of those things with an eye towards developing new and effective treatments. But people have got MND now, and living with MND is very, very challenging while we wait for new treatments to come through, and obviously, people with MND experience a very wide range of physical symptoms, communication difficulties, emotional challenges and often behavioural and cognitive changes. Through research, we must improve the care people with MND receive to give them the best possible quality of life. It's absolutely essential that we take those developments in healthcare research and make sure that they're implemented in the health and care system. We also want to see people with MND being able to benefit from new technologies that can help maintain their independence. So we're going to play a role in assessing what's available and addressing the gaps. So they're the four strategic objectives. We can only do this by working with people with MND at every step. So those conversations that we had with people with MND are the start point for us, not the end. We're intending to take them with us through the development and implementation of the strategy over the next five years. We also want to continue back in the brightest minds of MND research throughout their careers. We're going to continue to collaborate with people, with institutions and with companies which share our vision, our drive and our ambition in this area, and we also want to make sure that we're harnessing the opportunities that cutting edge technology offers. So that's a flavour of the some of the things that we're going to be doing over the next five years.

Ali
It sounds as though we've cause to be, well, hopeful. I mentioned hoping what I said about, you know, when, when we, we had this fear of my mum being diagnosed with MND. We, we, we hoped it was something that could be cut out. We hoped it was something that could be treated by more simple process, but obviously, obviously, you know, as we learned there, there's, very little for people suffering with MND. So it sounds like from the research strategy that there is cause to be hopeful. There is a there is a reason to be excited for this research strategy, and what this can do for the MND community, is that fair to say?

Mike
I think so. Yes. What we're doing here is building on incredible progress over the last ten or so years. So, you know, Brian Dickie, our Chief Scientist, has done an incredible job in working with the community, the scientific community, you know, we've got a great scientific community, both in the UK and internationally. Our understanding of the disease, you know, has improved massively over the last ten years. Now there are some crucial things that we still don't understand, but we're in a much better place. So what the strategy does is builds on that progress, Ali. There is hope. Researchers hope, the number of, you know, phenomenal brains that we've got working on. MND, their ambition and the things that they've done so far say to me that we can really make some really important developments in the next five years. This won't happen immediately. Research can be slow moving, and it can be difficult. It can be difficult, for example, to get new discoveries into new treatments and get those tested in people, but developing that pipeline and moving these things through quickly, I think, is a really, really important part of what we're hoping that the strategy will achieve.

Ali

I think it's also important to to recognise, from the research strategies, that this is very much, although this is a five year strategy, this is very much a long term structure, isn't it, I suppose, for for MND Association in terms of research. So this is a very much part of a longer term plan, because there isn't, there isn't going to be a cure, necessarily, within a matter of a couple of years. It's something I think we'd all pray for, we'd all wish for. But being realistic, I think the five year strategy is giving us, is giving us, like I say, the hope and the excitement that there are a multitude of options in terms of treatment and management and research and fresh expertise coming into the field, where things will potentially start changing, you know, and I hope to see that as soon as possible. But I think five years is a, is a, is a realistic template of which to start with and then to reassess at the end of the five years.

Mike
Yes, I think so. It's a platform to get going with. One of the things we really need to make sure that we do is maintain the developments that actually the Association has been the main player, and in terms of making sure that there's a workforce working on MND in the UK, the Association is largely responsible for much of the progress in that area. We have to maintain that so some of the younger scientists, with the early career researchers that are coming through now and who will support in the next few years, it's about developing their careers as well, so they're still there in the next five or ten years. So that's an example of an impact that might be a bit further into the future. But, yeah, a lot of this is making sure there's a platform for us to build on. And I think that platform, to an extent, is already there. It's just building on it further, yeah.

Rick
And I think, you know, I think that building things, building this, the therapeutic targets, knowing what to make, the drugs, the chemicals to act on, comes from understanding the condition, but also continuing to work on delivery systems. There's a barrier between blood and brain which protects the brain. It's a it's a great protective system, but it makes it extremely difficult to get drugs from the blood into the brain, and so that the work that has been done by MND Association funded researchers on how to get drugs into the brain, the. That work needs to continue and develop so that those delivery systems become better. And for example, tofersen - qualsody - has to be given through a lumbar puncture. And so that's a that's a fairly invasive drug delivery system. It works. It's brilliant. It's the first drug we have for any patients with MND that actually stops the disease. So it proves that, in principle, motor neurone disease can be stopped, which is very exciting. But we need better delivery systems. The other thing that we need in terms of convincing both us that we have a drug that works, and also the regulatory authorities, is, is biomarkers, something that's in the blood that can be detected, that we can see it going down when the drug works, and and that that actually, you know, that's another thing which some MND Association has funded, and which is being worked on across the world, and which is what gives this excitement that we're edging towards a breakthrough.

Mike
Yeah, and you draw on a number of things actually there, Rick, I think that are really, really important that you know that taking discoveries in that early phase in the laboratory, this looks like something that might work, and then moving through into an actual treatment is incredibly challenging, particularly for neurodegenerative disease, for some of the reasons, some of the reasons you outline Rick and so when we're aware, we don't just need to support that discovery science in the first stages, we need to be thinking about the entire pipeline here, how those discoveries get turned into treatments, how those treatments can be tested as quickly as possible so we can get them into humans. And then how do we get regulatory authorities on board the sorts of information that they will need to approve these drugs so Rick's right with things like biomarkers. Biomarkers are really important for a whole range of reasons. So biomarkers are biological signal that we can measure that tells us about the state of a disease and in the body, and they're often used to assess the impact of treatments. Lots of different types of

biomarkers. So there's diagnostic ones that can help us diagnose diseases, prognostic ones that can help us tell us how the disease is going to proceed in someone, all of these things we think we need to develop over the next few years, and that will come from a better longitudinal understanding of the disease from its very earliest stages, when it might not be somebody might not be experiencing symptoms, but they have it all the way through. So there's a number of things here that speak to the to the strategy that Rick's just talked about, that we're determined to make progress on, and we're going to have to make progress on if we're going to make progress in ultimately treating this disease.

Rick
Yeah, and that's important as well, because as we develop treatments people will be living longer with motor neurone disease that that's that's the target. And I mean, I've been living with motor neurone disease for 20 years, and part of the reason why I'm sitting here looking as though I'm sort of encased in things is because I am. I There is no satisfactory neck brace. My head's a heavy object. The muscles that hold it up don't work very well, so I've got two scarves wrapped tightly around my neck just simply to take the weight of my head. There has to be a better way of supporting people's heads than that, agreed. Those kind of innovations, which I think also the strategy points out innovations in making life better for those who currently living with the disease.

Ali
I am fairly new to the MND community, only in the last, well, 12 months, but it does feel like there is that we've come to a turning point. I think we're at a turning point in in understanding motor neurone disease, and I feel that the time is now that things are going to accelerate somewhat in terms of our research and our understanding and our ability to assist with MND sufferers and everything that comes with that. So I feel like we are at a turning point at the moment, and that is exciting. I must admit, that is exciting.

Mike
Yeah, definitely. I think, as I said, there's been an upsurge in MND research worldwide over the last 10 or 15 years. You can actually see it in the number of journal articles that have been published that will start to translate into intellectual benefits for patients over time, we're also seeing technology companies becoming very interested in MND and to help develop solutions. And Rick's made an interesting point as well as we do start to develop disease modifying. And treatments the first wave of those probably, you know, it's not going to be they're not going to be cures for the disease. They're just going to help people live longer, or help live a bit better. But we need to think, then about how we support those people as they experience the disease differently. So I think there's a number of things here that connect through the strategy that we need to keep fires burning in several different places, to make sure that we are, I suppose, providing an integrated research environment that will benefit patients.

Ali
Is there anything from from the rest of the community that they can do, other than, obviously, to continue to learn. And what's been been put out by the MND Association, there is a, I'm sure, a whole army of people that would be listening to the podcast and wanting to do their bit, as it were, is there anything else that that that people can do?

Mike
Yeah, we're really, really keen that the way that we've engaged the community as part of this, part of developing this strategy, is the start, not the end. So involving people with MND is a critical enabler for this strategy, and it's something we really want to lean into over the next five years. So we want to make sure that we're engaging with people in MND through the implementation of this strategy, getting

them involved across everything we do in research. That's a really, really important part of the next, the next few years. So that's things like shaping decisions related to our research activities, understanding people's needs, how they might be addressed through research, similar to how we've done in terms of the strategy, but also shaping new ideas for research projects, advising on what we should and shouldn't fund, and also maybe advising scientists who are developing research and undertaking research, actually having them at the centre of that as well. So these are things that we're really, really interested in developing over the next few years. So people watch this space, there'll be opportunities to continue to get involved in what we do on the research side over the next few years. And we're really excited by that, because that's really the spirit that the strategy was developed in, and we want to continue that as we implement it. Rick and Ali, can I just ask you a question? It would be great to hear your reflections about being part of part of the development of the strategy. Did you feel heard? How did you find interacting with others in your group? What was, what was your experience like in being involved?

Rick
Yes, I enjoyed it. I enjoyed it, because I knew that out there somewhere there were groups of researchers doing the same thing, and there were groups of clinicians and allied professionals doing the same thing. And so I felt as though there were a lot of us pulling together in the same direction. And I also liked I liked it because the questions that we were working with had originally been come up with and devised by by by asking the community, by asking people, people like us. And so actually, we were working with words that had come from within the community, and then working out what the priorities were within those those variety of things. Does that make sense?

Ali
Absolutely, I was powered to do it for my mum, and I felt that it was such a shock to us that somebody in our family had motor neurone disease. We've we we hadn't had any known cases of motor neurone disease in our family. So I felt absolutely compelled to assist in any way I could. So when I contacted and followed Motor Neurone Disease Association on social media, and I saw this, I thought, that's one way I can get involved. So being involved in the strategy was an eye opener. I learned a lot listening to other people, listening to carers. And meeting people such as Rick, who are pretty darn incredible, to be fair. You know, this is a this is a chap that's that's clearly highly intelligent, highly capable, and yet still here powering through and assisting the charity to help others, which I think is incredible. And really, that is what the MND community has shown me is, is absolute resilience and strength.

Mike
And we, I have to say, we were, I mean, we knew it would be a great experience working with the community, but we were just blown away by by what we got from it. And on behalf of the Association, we're just so grateful for everybody's efforts and time. And you know, the amount of thought that people put into this was was fantastic. And I hope that as much of what they wanted us to include has been in the strategies we could get in, because it was a really, really valuable experience for all of us in a very important part of the process.

Rick
How does this strategy build, build on the past, and in what ways is it new? What's different? What takes us forward, Mike?

Mike
That's a really good question. I think there's a I think there's a number of answers to that. So our previous research strategies have actually been very strong, and you know, they've identified key areas, some of which are similar to the things that we've identified here. It's really about building on

progress and those previous research strategies and moving things further along the pipeline so we can get more promising treatments for people for example. We're a bigger charity than we were when previous research strategies were written. So I think some of the things that we're saying in the strategy aren't necessarily new. It's just around, particularly with things like working at scale, we're going to work be able now to work at much bigger scale than we've done before. Previously, it's been about bringing together consortia and things like that. Now we're going to be able to do things on our own by working at greater scale. And that's a really, really important part of part of their strategy. I think the other, the other part, is the way in which we've involved patients in the beginning and the way in which we want to continue their involvement as we as we move from development to implementation of the strategy. So really, really explicit commitment to doing that is, is, I suppose, a relatively new thing for us in terms of the strategy. And also been very specific about sporadic MND, which is something that a number of scientists actually were very keen on us doing. We've always funded research into sporadic MND. That's not a new thing, but it was this idea of being much more explicit about that in the I suppose, in our public communications around what we want to achieve, that was a really interesting part of the discussions with the with the scientific community, that I expected at all. So that's, that's another thing, I think that's that's a little bit different here. This, this very obvious state of commitment to dealing with sporadic MND.

Rick
I think that's a very good thing. I think if you look at the if you look at the journals, if you look at the scientific papers, there are so many papers about some of the genetic forms of MND, a disproportionate number because it's actually much easier to design the research, because it's much more constrained by the fact that the genetic MND has an identifiable cause. Sporadic MND is much more diverse, and so it's much more difficult to do the research. And as a result, a lot less has been done globally. And as Mike said, the MND Association has been funding work on sporadic MND. Of course, it has, but actually focusing on that, yeah, that's that's a good a good new departure. It's a good move forward. It's good to hear.

Ali
I think, from, from my point of view, when, for the research strategy, for the questions that were being asked, I found I found myself quite surprised, actually, that some of the questions were involving not just the science of motor neurone disease, but also dealing with how families and carers and professionals can be supported. So I was quite surprised actually some of the questions that were being asked because it was, it really was being looked at holistically.

Mike
Yeah, one of the community were very, very keen in terms of research about quality of life, extremely keen that we did something around carers and family members and how to support them, which requires research. This is healthcare research. And again, the Association is always well funded the healthcare research for a long time, a lot of a lot of medical research charities don't do that. So we fund the biomedical side, but we also fund the healthcare side, and we'll continue to do that because of the importance that that it has. And yeah, some of those questions that people wanted us to focus on, really interesting, and we will be focusing on them. They will, they will be specific ask for the research community to do research in those areas on healthcare. So really excited by that. We will start to be more specific about what we want on the basis of what patients and their families and carers have told us.

Rick
I think that's very helpful, and I'm conscious of that every day I apart from Sue, who's my primary carer, and spends a lot of time helping me do all sorts of things. Twice a day, somebody comes in for an hour

and a quarter to give me a shower, to brush my teeth, to help me with the toilet and all that stuff. And they've just come from another patient, and they're just going to another patient, and they work long days, and some of them say, see two or three different people with motor neurone disease in a day, and by the time they get to me, they're already tired and emotional. And you know that it's, it's, it's really tough for the professionals, as well as it is for for the carers who are working behind front doors unknown to anybody, just, you know, living with somebody on a day to day basis. So, yeah, it's great. It's great that that's been a focus for the research in the future. Thank you.

Ali
Yeah, I agree. I agree. Okay, well, where can people who are listening to the podcast or following on socials, where can they read the full strategy to find out more information about this, Mike?

Mike
You can find the full strategy to read on our website and loads of information and find out more through our social media channels.

Ali
Perfect, so usual route Motor Neurone Disease Association website and on the socials as well, perfect. Thank you. Mike, thank you.

Rick
Rick, thank you. Thank you. Yeah, thank you. Bye.