

# MND Matters: Episode 22: Sally Light – Reflecting on 10 years as CEO

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## Intro

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

## Steph

Welcome to MND Matters brought to you by the MND Association, and sponsored by Toyota GB and Toyota Financial Services. I'm Steph White from the care team. And I'm joined today by Sally Light, our chief executive at the MND Association. She's going to be leaving us after 10 years here as chief executive. We're all very sad to be seeing her go. She's got a very busy last few weeks, but she has spared some time to chat to us today. So thank you so much for that. And welcome, Sally.

## Sally

Thank you very much. It's really lovely to be here. It feels like such a privilege to be part of this podcast. So yeah, thank you for giving me the chance.

## Steph

No problem. And as you know, we asked the MND community to send over some questions for you. And we've had a really brilliant response. So thank you to everyone that sent in questions for Sally to answer. We will get started on those really soon. But just before we do, let's have a little chat about when you joined the Association back in 2012. Sally, I'd love to know why you wanted to work here and what your plans and ambitions were back then.

## Sally

Yes gosh, it's a while ago now, isn't it? I guess it's a bit of a strange thing to say. But actually, I never had it in my mind to be a chief executive. I'd been a director for about 10 years. But this opportunity came up. And throughout my career, I've always tried to work in places where I felt I could help people that were underserved or not getting what I thought they deserved. And this seemed like such an opportunity to do that. I'd worked at the Royal Hospital for Neurodisability for a couple of years, and we had people living with motor neurone disease in our ventilator unit. So I'd become a little familiar, I suppose with the disease. And it just seemed to me such an important cause that I threw my hat into the ring. And I was fortunate enough to be to be given the opportunity. I guess I joined the organisation at quite a difficult time where we'd had a couple of years of difficult financial results. And things were quite tricky. And so my initial aims really were try it to try to, obviously to get to know the community, but also to try to reassure people and set some kind of strategic direction vision, I suppose. And also to create a senior team to work alongside me. And that really, for the first couple of years was my business, I guess. And I spent the first two years trying to make sure that I met in some way or another

every single branch or group, branch and group so that I could hear from the community what their priorities were.

Steph

It must be quite overwhelming. And yeah, it must just be very unusual to look back on what's happened in the last ten years as well. So amazing, at the same time to think that it has been that length of time and everything that's changed. So yeah, definitely a job well done, Sally. Now, we'll definitely go to some questions from the MND community because I know they're, they've wanted to ask you lots of things. So yeah, great response. And we've got a question first from Olivia.

Olivia

What has it been like working for the MNDA Association? Has it been rewarding, emotional, or both? And what is your connection with motor neurone disease?

Sally

The balance of hard and rewarding is massively in the favour of rewarding. I mean, of course, it's been hard at times you would expect it to be, but it has been hugely rewarding it I mean, without question the job of my life. Just amazing. And I'll you know, I'll never forget it. I don't have a, well, I don't have a personal connection to motor neurone disease, I would never say that I did. Because I would never assume that I knew what that experience was. But now after 10 years, I've definitely got a deep connection to the cause. I've I've got to know so many people over these 10 years. And I've also lost a lot of people too of course. And I say to new staff that there's something about motor neurone disease that gets into your heart and never leaves. And that's how I feel about it. And even though I'm stepping down as the CEO at the end of the year, I'm not going to be leaving the community entirely for sure. And I intend to sign up as a member on the first of January.

Steph

I had a feeling you might say something like that. Well, I'm sure everyone will be happy to keep in touch with you as well. And I know you've made many friends among the 10 years as well that you will be keeping in touch with. We've got question from Ben and he worked at the Association for more than 10 years.

Ben

Hello, Sally. hope this finds you well, as a past employee of the Association. I just wanted to wish you all the very best for the future and every success in any new challenges that you take on. When I left the Association earlier this year after 14 years, there are a few standout achievements that I'll always be proud of. So I just wanted to ask you, what is your standout achievement, or the one thing that you're most proud of, from your time at the Association?

Sally

Thanks for the question, Ben, nice to hear from you. Well, to be honest, when you're the chief executive, most of your achievements are done by other people. So most of what you achieve is that is done by others. I think we've been very successful in growing the organisation. And that was what I really wanted to do to make sure that we could grow the organisation, increase our income, so that we

could put more money into research so that we could help more people, and also that we could expand our services out, particularly to carers and children, and young people. But I wanted to do that that to enable support, facilitate that growth without losing the heart of the organisation. Because that community family feel of the MND Association is such an important part of its success. And sometimes when you grow an organisation, inevitably you lose that sort of personal touch. And so I guess, I try not to say what my greatest achievement is because I don't think it's my greatest achievement. But what I guess I'm very pleased that we've managed to achieve is that we've grown the organisation while still keeping that very local community based feel and service. And I'm really glad that we've been able to do that, because that's the way that we serve the community best in my view.

Steph

Yeah, absolutely agree with you. And I'm sure Ben saw a lot of that growth in his time working here with you as well.

Sally

Yeah, sure. He did. He created some of that growth, in fact.

Steph

Well, exactly. And now we'll go to a question from Matt Gately.

Mark

Hi, Sally, this is Mark Gately of the North West Kent branch. My question is during your tenure, who and what has inspired you and motivated you to continue the quest for a world free of MND?

Sally

Hi, Mark, great question. What inspires me most and there are many things, of course, people living with the disease are invariably inspirational, and also their families who have to, you know, have to deal with so much over over time. So for sure people living with and affected by MND. But also, I would like to say, our volunteers and supporters, because I think one of the overriding things that I've learned over my last 10 years is that people volunteer and support us as a way of fighting back against the disease that has cost them so much. And rather than being defeated by that, they want to do something to help others. And that is incredibly inspiring, that in spite of being hurt in the worst possible way, by this disease, their intention is to do something to try to make sure that that doesn't happen to other people. And that is, I mean, quite extraordinary. I don't know whether I would have that sort of courage to be able to do that. And so to see people, you know, and I'm thinking perhaps, of our founder members who've been doing that for the last 40 years. It can't help but inspire you and, and in fact, even now, it's making my hair stand on end on my arms. You know, it's just, it is the most amazing thing. And we are so fortunate to having such incredible volunteers and supporters. So they are my inspiration every day.

Steph

I was just about say, I totally agree with you, Sally, completely selfless individuals that just do absolutely everything they can in the fight against this disease. So yeah, they inspire us all every day. They do. And now we've got a question from Katie.

Katie

Hi, my name is Katie. I'm 24 years old from Essex. I sadly lost my nan's motor neurone disease just over a year ago. My question for you is what is your proudest moments from the last 10 years?

Sally

That's a really, really nice question. Thank you. There have been many sort of proud moments, but I guess the standout moments for me because it's happened a few times is, is when I sit on the platform on the stage at the International Research Symposium, and I introduce the symposium on and welcome people on behalf of the MND Association. And there I am sitting on the stage next to in the past it's been Professor Kevin Talbot from the Oxford MND Care and Research Centre, looking out over a sea of faces of the brightest and the best MND researchers and clinicians from around the world. And the thought that our little charity based in Northampton has organised this International Symposium where we've had as many as 1800 delegates for the last 33 years is a huge thing for me. I remember when I applied for the job seeing that we organised this conference and thinking, wow, that is some impressive charity to be able to do that. And I still think that to this day, so I would, I would say that that's my proudest moment, representing the organisation and welcoming people.

Steph

Absolutely. And as you've talked about research, we've also had a few questions about research, which is really understandably, an important topic for the MND community. So we'll go to a question from Elena.

Elena

Hi, Sally. My question is, how near do you think we are to a cure for MND?

Sally

Thank you, Elena, I'm sure you ask that question, you know, on behalf of lots of people who also want to know the same thing, I really wish that I could put a date on it. I can't, I'm afraid. What I can say is that we are so much nearer to it than we were when I first joined the Association. In those days, there wasn't a great deal of optimism that we were getting very close. We were working very hard. But there wasn't the optimism that we were, you know, there were going to be any breakthroughs anytime soon. And what I've seen over the 10 years is that the rate of progress has escalated. I asked Dr. Brian Dickie about this and he reminded me of a measure that he always uses, which is in the old days at the symposium, we'd have very, very few drug companies, drug companies weren't really that interested in motor neurone disease. And now, we have so many drug companies, so many people with drug company badges on at the symposium and I think that interest by the drug companies shows that and they're of course, you know, they're they're in it for profit for their shareholders. So they know that MND is a growth industry for treatments and, and it's not all that far down the track. And that's, you know, that's the origin of their, of their interest. But also, if you talk to researchers, they're so much more optimistic. And I remember somebody telling me that he never thought he would say this, but now he would say that he thinks there will be successful treatments in his career as a researcher. And this year of course, we have seen some glimmers of hope through the first and trial for the SOD1 mutation type of MND. And although the SOD1 mutation is relevant to a relatively small number of people in the MND community, it is a genetic mutation that's blighted families lives for generations. And so it is perhaps the

start of a chink in the armor, where we can start to think that some treatments are possible. And I hope over the next few years, we will see some positive results out of some of the drug, the many drug trials now that are ongoing. So a light at the end of the tunnel. And again, stealing this from Brian, the train is definitely heading in the right direction and picking up speed.

Steph

Thank you. So we've also had a couple more questions about treatments. We've had those from Linda and Lara, which you'll hear shortly. And we also had a question in from James who's living with MND. So thank you all for sending in your questions. And now we can hear the ones that Linda and Lara have sent in for you to hear.

Linda

Hi, Sally, my name is Linda and my dad was diagnosed with motor neurone disease in August 2021. One of the most heartbreaking things he said to me after his diagnosis was that he felt completely without hope. Do you think there'll ever be a cure or an effective treatment found for motor neurone disease?

Lara

Hi, my name is Lara. I lost my dad in August of this year to MND. 15 months after diagnosis. My question is honestly, how close are we to finding a cure? Or at least an effective treatment?

Sally

So I hope my previous answer was was a little bit helpful. I think what else I would say is that the way we're doing research is improving all the time as well. Also, we've been funding for quite a long time some work on biomarkers. So this is trying to find the sort of physiological marker of motor neurone disease. And that will be helpful in a number of ways. Firstly, we because we'll be able to see whether a drug is working long before the end of a trial, which is obviously helpful, but also because it will be the potential foundation for a diagnostic test. And we think that one of the problems with why drugs hadn't worked in the past drug trials haven't worked in the past is that we've not people have had motor neurone disease for too long before they get the treatment. So if we can get drugs in earlier, then it may be that we'll be more successful with some of these drug trials. So I think there's a number of things coming together, biomarkers, better research, better drug trials, but also a greater understanding of genetics. And for the MND Association that goes back to the ice bucket challenge, because a lot of the money £5 million of the 7.2 that we that were raised through that, by our wonderful community, were put into, into research and a lot of it into something called Project MINE, which was a gene hunting exercise. And through that, we've discovered a number of new genes. And really, genetics is a lock and a key to being able to eventually find some successful treatments. So I think there's a lot of the building blocks now being put in place, which which will be really the launchpad for finding some effective, effective drugs in time. Obviously, it can never come soon enough.

Steph

Absolutely, thank you Sally. Moving away now from research. We've had a couple of other questions in so we've got one from Barbara who wants to know: How do you set boundaries when caring for an MND patient to protect carers health?

Sally

I think this is this is really hard, isn't it? And it's also a very, very personal thing. I think, Barbara as well. We know that the impact on carers, people caring for people living with MND is is huge because of the disease and how quickly it progresses sometimes, but also the fact that it affects so many body systems. And we know that people that are carers spend more time caring for people with motor neurone disease than with any other disease. And in recognition of that over the years, one thing that I'm really pleased that we have been able to do is we've got to be a bigger organisation is that we've expanded our services out to carers actually also to children and young people, but in this instance, to carers, and we've been able to do that because of people's generosity. And we've been able to provide more support centrally through things like carers grants, but very much locally through our wonderful volunteers in branches and groups organising things like sub support groups for carers, and also increasingly support groups for bereaved carers. So I guess setting boundaries is a very personal thing. But I hope that as time goes on, we'll be able to provide more support for carers, practical support, but also campaigning support. So making sure that people get what they're entitled to that carers assessments are done, and that carers allowance is increased to some sort of reasonable amount for people.

Steph

Thank you. I'm sure that answered Barbara's question. And we've got a question from Abby, who wants to know how will you respond to the government likely postponement of the social care cost cap?

Sally

Yes, this is this is a tricky issue, isn't it? I mean, I know from my own family, both my mother and father needed care at the end of their lives. And, you know, we were fortunate to be able to use the money from their house to fund that. And it can be very distressing and difficult for families. And, of course, it's really disappointing that the government has delayed plans to introduce that that cap, I guess, I also understand that there's an immediate need. I'm a governor at the local hospital, actually the local NHS hospital. And I know that at the moment, there are so many people in hospital beds who are needing support to be discharged to, you know, medically fit but needs support to go home or to go into residential care. And I believe the government has diverted the money that would have been used for the cap into those more immediate pressures. And it's a very difficult situation. But I was talking to a lady the other day, who said that her partner, who needs a feeding tube fitted had been canceled twice. Because there just are not enough beds in the hospital for them to be looked after properly. And so we're balancing really two, two very big priorities. And that's very tricky. So I guess what I, what I would say is that we will continue to campaign and press the government for a timeline and a decision on the social care cap. And we'll continue to work with partners to do that, because of course, this affects many communities, not just the MND community.

Steph

Absolutely. That's right. And we've also had another question sent in. The question is, is there any update on the United to end MND government money?

Sally

Yes, I think there is. I mean, this is obviously, this is such an important question, isn't it for the MND community and, and, gosh, what a campaign that was, and it was the MND community at its best, wasn't it? The signing of the petition, the letter that went to number 10, just so much public pressure for the government to fund Motor Neurone Disease Research in the way that it should. And, obviously, we've been anxious to make sure that that £50 million was delivered, especially with changes in government since the announcement a year ago. But we have had assurances from very senior people in government that that £50 million is assured. And what we're doing now is we're working with civil servants and politicians on how that money will be distributed the means by which it will be distributed. And of course, our intention has always been that there will be a new way of MND research money being distributed. So instead of individual researchers having to write individual applications, which can take hours and hours of people's time, that there will be a coordinated approach to this. So there'll be a small number of applications made for coordinated grants across a number of different research institutes. And I think what I would say is that we're now cautiously optimistic that that's going to progress in the way that we hope there is a meeting later this month, which is a I suppose an inaugural meeting of what we're now calling the National Institute for MND research, where all of the relevant stakeholders and we hope parliament, there'll be parliamentarians there are getting together to talk about how we can now start this institute. So it's going to be an exciting time, I think.

Steph

Most definitely very exciting times ahead, which I know you'll be keeping up to date with, even after you leave us.

Sally

I definitely will. I heard the announcement that Boris Johnson had committed the £50 million one Saturday afternoon while out with friends. And that's another another memory I'm never going to forget. Because, yes, it was a wonderful surprise.

Steph

I bet. Yeah, I think everyone felt quite the same when they heard that. The United to end MND coalition, that was quite a different approach to a campaign. What was it like to work in that way? So can you give us a bit more information about how it how it worked out?

Sally

Yeah, I'd be pleased to actually because it was a really interesting, it's been a really interesting experience. And it was started, of course, by people living with MND, who got together with a leading researcher and then invited the charities into the coalition. And we formed the coalition called United to end MND. And it's been a brilliant opportunity to put the voice of people living with the disease front and centre at the campaign. And I have to say that the people with MND involved in the coalition, but also the wider community have been phenomenal in getting behind to the campaign for the £50 million from government. So that's been one really interesting and very positive aspect to it. The other very positive thing, I think, and I think this is the way that increasingly we will work as a charity in the future is the partnership that we then had, with people living with MND with the researchers but also with the other charities the Doddie Weir Foundation, MND Scotland and more recently LifeArc. What we know is that the combination of all of our resources and ways of working and approaches, although at times, it was,

you know, it was, it could be a bit tricky. What I would definitely say is that we were able to be so much more successful together than we ever would have been apart. And I think no one of us would ever have been successful in getting the £50 million from government without the help of the others. So that collaborative approach was very definitely successful. And a collaborative approach with the whole MND community behind us. I mean, who could resist that really? The government certainly weren't able to and, and, and there was the success so yeah, it's been it's been fascinating.

Steph

Yeah, totally agree with you and think everyone wants the same thing at the end of the day, so it's really nice to bring everyone together for for the same aim in a campaign like that. And now we've got another question from Olivia.

Olivia

My late granddad John, was included in one of your campaigns which helped us spread awareness. How can we make people aware of what MND is and spread some more awareness so that we can eventually find a cure?

Sally

Thank you, Olivia. I'm really sorry that your family's had to deal with motor neurone disease as well. And I know that awareness is such an important issue for people with MND and their families. I remember really early on somebody with MND saying to me, Sally, what you need to do is you need to raise awareness that's the most important thing and you know, it's been a key a key plank of our of our work for this last decade and it awareness is never going to be as high as we would want it to be. But it really has transformed in the last 10 years. And I was in a couple of the places where Kevin Sinfield started and stopped on his epic, seven ultra marathons in seven days. And I was completely blown away by the amount of public support. I live in York and I walked up to the minster where Kevin was due to come in, and I thought there might be a handful of people at the front of the Minster and the streets were packed. I couldn't, I really couldn't believe it. And I spoke to a few people and they said, We can't believe that as the MND community. We're standing here shoulder to shoulder with people from the rugby community, but also the general public. It's never been like that in MND. And I think we all found it quite overwhelming that public awareness is is a very difficult thing to achieve. And really, the breakthrough has been made since people like Rob Burrow, Doddie Weir and and more recently, Stephen Darby Ed Slater have been willing to share their their stories very publicly. And, of course, it's it's been enhanced, then by Kevin his three years of completely crazy, crazy challenges. And the support of the BBC has been instrumental, of course, in that we've recently done a survey, commissioned a survey, where 4000 people were surveyed and 70% of them had seen motor neurone disease, the MND Association on television. And if we go back 10 years, there's no way that that would have been 70%, it would have been a tiny proportion of people. So things really have changed. And I guess the challenge for the MND Association now is how do we keep that momentum going? How do we keep awareness high? How do we continue to build on what has already been achieved? And you'll be pleased to know that we've got some plans to do that, of course. So yes, Olivia, never high enough, but so much, so much better than it ever has been.

Steph



Absolutely. I think even thinking back to seven years I've been here when you explain where you work and you say Motor Neurone Disease, people would just look at you blankly but now it really does need no explanation in most circumstances that people have an understanding of what it is or who's affected by it. And I think that has definitely been a big change in terms of the awareness that's been raised over the years.

Sally

Yes, definitely. And I think I was obviously been thinking about this quite a lot lately. And if we go back to the ice bucket challenge, you know, raised £7.2 million pounds for the MND Association. But apart from very briefly, I don't think it did very much in relation to helping people understand what motor neurone disease was. People raise the money, it was fun, but it didn't really improve people's understanding of MND. Whereas what's happened in the last couple of years, two or three years, I think really has increased people's knowledge and understanding and motor neurone disease. And that's really, that's the point of awareness, isn't it?

Steph

Absolutely. And it's all down like you say to people like Rob, who will who have been very bravely sharing their personal story, but also so many people from the MND community who bravely share those in their own circles and their own local press and, and everywhere they can really raising that awareness. So I'm sure Olivia is doing the same. And thank you to all of you for continuing to raise the awareness. And that leads on quite nicely to our question from Maria.

Maria

Is there anything that we could do to help?

Sally

I guess my answer to that is something that I always tried to say, which is that the MND Association could not be the MND Association without its volunteers and supporters. So we are, you know, we're about 200 staff. And yet we have such a breadth of work now, and, and support and services. And the only way we can do that is because so many people do help. And they help with their time with their skills, with their fundraising with their campaigning, with their volunteering by getting involved in local branches and groups, by spreading the word as Steph just said, by creating and generating awareness. So, Maria, if you're interested in helping, we've got lots and lots of ways for you to help and we'd be tremendously grateful. If you if you did want to help us. Please just get in touch and we can find a way to help which you know, works for you.

Steph

Definitely. Yeah, we look forward to hopefully hearing from Maria soon. So that comes to the end of our questions, but just want to say a massive thank you to absolutely everyone who submitted questions. It's been really lovely to hear you or thoughts, Sally, and it's been brilliant to work with you. And massive good luck. I know from myself, everyone here and I'm sure the community as well for the next chapter. But as you've already said, we know that you're going to continue supporting the association and that you're very much be keeping in touch with us here. So we're looking forward to that as well. But I don't know if there was anything that you wanted to say in in close, of course, it's coming very

close now to you, officially leaving us but and if you had any final thoughts that you wanted to share with the community,

Sally

I think really only just to say thank you. Thank you for giving me this opportunity. As I mentioned at the start, it's been the job of my life, I never imagined that I would do a job like this. I've loved it. I've had so many different experiences, I've met so many wonderful people. And if I've done a small amount to help make things better for people in difficult circumstances, then I've been so glad to be able to do that. And of course, I wish the community well. And I will be cheering, at least on the sidelines of the marathon in Leeds next next year, and doing whatever else I can to continue to support the community. Thank you.

Steph

No problem. We look forward to seeing you there, Sally. And I note that you did say at least on the sidelines, so maybe we do have some scope to get your running kit on for that day. I'll speak to you about that a bit later. But yeah, there'll be lovely to see you at lots of different events, no doubt. Lovely to chat to you today. Thank you so much again for joining us and for answering the questions.

Sally

Yes, thank you. It's really lovely to have your questions.

Steph

Thanks again to the community for sending those in.

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