

MND Matters: Episode 14: How Campaigning Works

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

Chris: Welcome to MND Matters, brought to you by the MND Association.

Helen: Alongside, members of the MND community, we bring stories, information, and expertise direct to your ears. Remember to subscribe to ensure you don't miss an episode. Hello, I'm Helen and I'm a regional fundraiser at the MND Association.

Chris: And I'm Chris and I'm director of external affairs at the MND Association

In this episode, we're going to be chatting to you all about campaigning with people living and affected by MND. The MND association has a really proud history of campaigning and advocacy. Essentially, it's all about pushing for change to make life better for the MND community, and to ensure that people with MND get what they need when they need it. Over the last year at the Association, the policy and campaigns team, working in collaboration with coalition partners has had brilliant successes including the Scrap 6 Months campaign and the United to End MND campaign. And we can't do this without all the hard work of all our campaign supporters and volunteers who really make a huge difference to those campaigns.

Helen: Campaigning can and does take shape in all different ways, and our guests on the today's podcast are certainly going to highlight this, so I'm delighted to introduce today's podcast guests. Please say hello to Sue Heal, Nicola Waters and Andrew Lewer MBE MP.

Chris: Sue is a tireless campaign volunteer at the MND Association, who has worked on a number of campaigns both locally and nationally for the for the MND Association on behalf of people with MND. And Nicola is a tenacious and fearless campaigner and a member of the Patients United to End MND group and a member of the Coalition to United to End MND. And Andrew is a committed and extremely supportive chair of the All Party Parliamentary Group on MND.

Helen: All three are here to share some insight on campaigning and from their unique perspectives will be able to tell us about how campaigning works, how this work is essential to improving the lives of people living with and affected by MND, and and how you can get involved in campaigning.

Thank you all so much for being here with us today.

Chris: So, we'd just like to start by asking you a few questions to get an idea of your background and experience in campaigning for MND. Sue, Welcome to the podcast. I'm going to start with you. Perhaps you could tell us a bit more about how you got involved in campaigning and why did you become a campaign volunteer for the MND Association?

Sue: Thank you Chris. Yes, after losing my husband to motor neurone disease with frontotemporal dementia I was invited to join the Norfolk, Norwich and Waveney Branch Committee. Jim and I had received really wonderful support and friendship from our two association visitors and others in the branch, so I said yes. I started with the branch newsletter and later the website, but I never thought of myself as a campaigner. I attended a workshop run by the campaigns team and I still wasn't convinced that this was what I really wanted to do, but then came the MND Charter and I read it and it was a statement of the respect, care, and support that I really believed people living with MND and their carers should expect, and it felt so right. It addressed issues that Jim and I had experienced. And

then I knew I had to get involved, so I agreed to write to my Norfolk County councillor and two days later we were sat in my living room discussing bringing a motion to the Council. The motion was put to the adult social care committee. The adoption of the charter was passed unanimously in January 2017. And Alice, who was the campaign manager for the East, came to provide moral support on the day, interviewed me for the post. And I think, You might well say the rest is history.

I was asked to save the date for a training weekend. I think that's when I first met Chris and I met people like Dave Setters and Katie Styles who were just inspirational and really made me feel part of a very close knit team. So I was a newcomer but I was welcomed. And I think that is something I would say to anybody who's thinking of campaigning with the Association. You will find so much help and support from others.

But anyway, they convinced me that I really wanted to arrange a meeting with George Freeman MP, my local MP. And we did. And actually it wasn't so bad and it wasn't long before I was providing regular campaigns updates for the committee speaking at some of our branch open meetings and the role just snowballed from there - meetings with councils. CCGs, MPs across Norfolk and Waveney – it just grew.

Helen: It sounds it like you have made such an incredible difference to so many people's lives affected by MND by starting on that journey and and not just starting just really getting involved in every aspect of campaigning. Thank you so much Sue.

So, Nicola, can you tell us a bit about your experience of MND and how you then also started on your campaigning journey.

Nicola: Yeah, so I was diagnosed with MND three years ago. It started off with a sort of just sort of tripping up now and then and I'm very fortunate, I'm a slower progressor so unlike many people with MND, I do still have the ability to get involved in things. So I'm very conscious, I really do feel a responsibility to get involved and do what I can to help the MND community. And my particular interest is research and that's when I was sort of had to leave work, I was used to sort of being busy with work and then I busied myself looking into research, reading what was coming up. Really amazed at the developments that there are and really how exciting the research area was.

So I started off putting a few sort of tweets out and through that got in touch with Professor Al Chalabi, who's one of our leading researchers. He reached out to me on Twitter. And then in touch with Lee Millard and Dave Setters, who were the two patients who started the United to End MND campaign. Sue's already mentioned David as inspirational, I certainly agree with that. And then really sort of got involved and I really echo what Sue has said, what a welcoming community it is. And really the MNDA are really you know, wonderfully supportive of patients getting involved, listening to patients. We're not always. I think, particularly, patients can be very impatient, probably quite demanding. We want it done yesterday and all I've ever experience really from the MNDA is a real graciousness and really trying to meet what we ask of them. So it has been a great experience.

Helen: Fabulous to hear because obviously we are really keen that everything is co-designed and co-produced with obviously your lived experience and everything that you bring to what we're trying to do is so important to the Association.

Chris: Yeah, I'd echo that, and I think also Nicola you talk about being impatient. I think as people with MND and people living with them, you make us impatient because we recognise that impatience and that drives us along. So I think that that's really important in our campaigning. So yeah, absolutely.

So Andrew, if I could come to you, and could you, I wonder if you could tell us a little bit about the All Party Parliamentary Group on MND. What it does and how you came to be involved in the group really.

Andrew: Yes, thank you. It's great to be here. All party parliamentary groups are quite a significant part of parliamentary life these days. And there are a huge vast number of them, but there are a much more limited number of them which are active and effective. And those two things aren't always the same either. But obviously really, and I know we would say this, wouldn't we? But it is true, that our All Party Parliamentary Group for MND is one of the most active and most effective groups in Parliament, and extremely well known. So I came into the Westminster from being a member of the European Parliament, where they have things called inter-groups which are very similar topic-based groups. I always found those very interesting so was keen to do something similar here in Westminster and the headquarters of the Motor Neurone Disease Association is in Northampton my constituency is Northampton South. It therefore seemed a very obvious group to be involved with, although at the time I had no particular idea of how in depth the involvement would be just, you know, national charity based in Northampton and therefore made sense to get together.

I joined the all party parliamentary group soon after becoming an MP in 2017, became a vice chairman in 2018, and then there was a, as there often is, changes at the December 2019 general election, which meant that the former chairman Madeleine Moon lost her seat. I was therefore asked in December 19 whether I would step up to become chairman, which I did and it really adds an extra important dimension to my life as an MP. It gives me the opportunity to campaign as we've just heard and and push forward a worthwhile cause and work with colleagues across party, which happens a lot more behind the scene here than you would think from television news and what have you, that actually behind the scenes MPs. Across all parties quite often work together and work well together on issues that they care about. And you know, I feel a responsibility because the all party group is actually 20 years old this year, and so it's great to be the chairman at that time and I hope we can make the most of that anniversary to help raise awareness even more.

Chris: Thanks, Andrew, I think that's really important that that commitment of you as the Chair and the other officers that really drive the APPG along. Because, as you say, that they do vary, that some of them are more active than others, and I think the APPG in my experience with the Association is it's been a massive asset to our campaigning and I'm always so pleased when we get such great attendance from parliamentarians at the meetings which is really encouraging and everybody is really supportive. So I think it makes a big difference to our campaigning and getting the change that we want to see. So thank you for that and it's absolutely brilliant.

Helen: I think, what is really amazing and wonderful is that all three of you have come to campaigning for such different reasons and and from such different backgrounds. And it just kind of shows how varied our campaigning network and our volunteers and our supporters are and it really doesn't matter what experience you have of MND and there's a place and a way for you for you to get involved and have your voice heard.

So Sue, is it possible for you to tell us that maybe a little bit more then about your involvement with the Scrap 6 Months campaign?

Sue: I think having worked within the branch and organising support meetings, I'd heard people talk about their experiences with benefits. I remembered our own experience applying for disability living allowance. The very long forms to fill in. In April 2018 before the campaign was launched. I was asked to meet with Peter Aldous MP for Waveney. And I'd gone along with a branch member who'd been experiencing difficulties getting a DS1500 to use the special rules for terminal illness. And I started to realise talking to him and to Martin just what problems people were facing with the special rules for terminal illness. Which were

supposedly intended to enable people to access benefits more quickly, but they're not having to fill in long forms, undergo face to face assessments or wait weeks for payments. And there were really two major problems with the special rules that we could see. First was the six month eligibility criteria restricting access to people with a limited expectation of death within six months and the second was the three year benefit award duration where I had heard of people who were having to reapply at the end of three years because they've been lucky enough actually to outlive their prognosis. Because, as we know, MND is one of those conditions that is very variable. It's very difficult to predict how your disease will progress.

So when in 21st of June 2018, I think that the campaign was launched, I was standing outside Norwich City Hall, lit in blue and orange with a group of counsellors and other branch members. And I talked a little bit about what I'd read about the campaign, but essentially it had two main aims. Scrap the six month rule. Scrap the three year award period and you asked me, so you know what did I do? Well, there were a number of things over the years. I mean, one was the petition launched in December 2018. And this was to demonstrate to the government that there was strong support for changing the law. The aim was 17,000 signatures - the number of people who died while waiting for a decision on their benefits from 2013 to 2018. I wrote to the local press. I spoke at local U3A meetings. I knocked on doors in Windham, in Norfolk, asking neighbours to sign the petition. My daughter helped with social media because I was very much a novice at that stage, and we put things in the branch newsletter. Put things on the branch website encouraging people to sign and, of course, campaigners across the country were doing the same thing, so when that petition was actually handed in, I forget the figure. What was it? 55,435 signatures handed into Downing St on August 2019. Over the course of the campaign, one of the things I'd tried to do was build relationships with all of the local MPs in Norfolk and Waveney, there are ten of them. And this is where having the e-actions that the campaigns team launch was really helpful because I could extract the email information, personalise it, send it to the MPs and then follow up and one of the things I often did, of course, was invite them to the APPG on MND. And many of them have attended over the years.

But of course, in writing to them they would often come back at me with questions which I had to research and answer. Sometimes with personal experience, sometimes with help from Alison and Lana. But it really is so helpful that you always know that there is backup there to help you out. Then in July 2019 I was invited, along with other campaigners to join the parliamentary drop in. Hosted by the MND Association, Marie Curie and the APPG on terminal illness. And two of my MPs or two of the local MP's I should say turned up. And then in November 2019 I was invited to attend the Conservative Party conference and I had the opportunity to ask questions about all manner of campaigns. But particularly, you know about how to progress the Scrap 6 Months campaign. And so time went on. There were announcements and Northern Ireland scrapped the six month rule. A review, of course had been announced back in July 2019 by then secretary for the Department of Work and Pensions, Amber Rudd. And we waited, and we waited, and we waited, and the MP's asked oral questions, written questions. They wrote on our behalf, and then suddenly it seemed, we had the announcement from Justin Tomlinson on 8th July, yes! There will be a change. Wonderful, we welcomed it and he confirmed that the special rules which led to fast track benefit applications for those with a terminal diagnosis of six months to be replaced with a new 12 month end of life definition.

And I think we all thought yeah, that is really good news. And it is. And we are so happy about it. But this in a sense is just the beginning. Of course we're still waiting and as yet, I don't think we really know, you know what is going to happen to the three year award, so it's still a work in progress and I would say to anyone thinking of getting involved in campaigning. It's not a quick fix. It takes forever. This is three years. But we have a result and there's a wonderful feeling when you have that result. You think yes! It was worth all the time we put in and I think again I would just reinforce you know there's a sense when you

work with the Association of this sheer camaraderie amongst the campaigner and the campaign team, the knowledge there's always somebody there you can turn to for help. I think the strapline was if you can help a little we can help a lot. Well, that is so true.

Helen: That is, that is a lovely strapline, isn't it? That is, well, I think. I mean you say it, you know it's taken a long time and the dedication of all those involved in in the campaign must be applauded. And it's taken all time, but you've come so far and I think it is right to celebrate and take stock of the Scrap 6 Months campaign today. As of today its included over 75,000 people and that collective voice, that louder voice has made a difference. And yes there's still more work to be done as there always will be, but its yeah, thank you Sue for everything that you've done in kind of shouting about the need and the importance of the campaign.

Chris: Excellent thanks Sue. And Sue mentioned the APPG a few times there. Andrew, when she was talking about the campaign and how do you think the APPG helped the Scrap 6 Months campaign? What kind of did you see was its role in order to to achieve this?

Andrew: Well, it played a vital role really in terms of a drawing the threads together, drawing the things that people want to achieve into some sort of coherent and coordinated campaign. Using the experience of parliamentarians, but also using the experience of the Motor Neurone Disease Association, which has always been very good at knowing how to how to pull the levers and how to to actually get the change achieved at that technical level that we want at that sort of headline level, that Sue has outlined. And that comes through expertise in carefully drafting both the written and oral questions that Sue spoke about. The oral questions being when an MP stands up in the Chamber of the House of Commons and says to administer. 'When is this going to be sorted out' or 'I have a constituent with this problem and it illustrates this wider point that the government needs to get to grips with'.

Luck of the draw with that though, of course, because there are only about 20 oral questions per departmental Question Time. A large number of people putting in to ask those questions, but of course, even more than the oral questions for departments, there's the, ultimate lucky dip of prime ministers questions where even more huge numbers of MP's put in, so you know you only maybe get drawn for Prime Minister questions once a year or once every 15 or 18 months or so on.

And so it was particularly, delightful that I got drawn to ask the very first Prime Minister question of the decade, and indeed of the new administration in January 2020, just a couple of weeks after the general election. So, question number one of Prime Minister's Questions number one. It was me and I therefore I'll say, of course, but you know it was seemed to me to be the thing to do. Was to ask that very first PMQ about Scrap 6 Months and of course the benefit there is that you don't just have the relevant minister in attendance or a useful sprinkling of MP's. You've got virtually every MP either in the Chamber or listening in, so it gives you a huge platform and you get on the television. And you then get the sort of concomitant media interest in interviews that follow on from that. So I asked the Prime Minister about Scrap 6 Months and then just to underline that cross-party work as well and Drew Hendry, who's chairman of the All Party Group on Terminal Illness. You know, this is about as far away from me, ideologically and almost every respect as you can imagine as an SNP MP. But we did write a letter together to DWP on this and again this is where the all party group and the Association work out our tactics because sometimes speaking to ministers behind the scenes. Having a private interview, I've had two or three now with both Secretary of State and Minister of State privately to talk about MND's campaigning and various aspects, but including Scrap 6 Months.

But every now and then, even though ministers would probably prefer that all of your meetings were in private every now and then, a public letter or a public question works. I

have to say sometimes it doesn't because it can sometimes entrench a position. You don't want to be entrenched into, but you just have to pick your moments and this is what I'm saying about campaigning. That it isn't just sort of banners and marches, and we demand this. There's a lot of sort of tactical thinking that needs to go behind it as well.

And that may seem very sort of house of cards and what have you, but it's about getting the result and sometimes you have to box a bit clever to get the result you want. We pushed DWP, but as Sue was saying that in government, there's often a temptation to make a big announcement, and then think that you've done the job. You know, we've announced that we're scrapping six months great. And that's why. As well as United to End MND and Act to Adapt and all the other work that we're doing, we still need to keep on with this because the boring stuff in a way, but the vital stuff at the same time, which is the detail the legislation. Actually having these changes enacted as well as just announced still goes on. And that again is where this behind the scenes letter writing slightly more sort of grinding work has to go on, as well as the important media splash and publicity work that we do as well.

Chris: Yeah, I, I think that's really important and I think I think where the APPG really comes in and the advice of MP's is in helping in those tactics to negotiate your way through the whys and wherefores of government. And as you say, sometimes it is about placards and it is about going to 10 Downing St and other times it's about those quiet conversations that you have with people that you can do so effectively. So I think that makes a huge difference absolutely and really important.

Andrew: Yeah, Sue's point was very interesting there about writing to to parliamentary candidates. I mean and candidates for elections. I mean, I've been a candidate for election 9 Times Now. In every guise going - District County, MEP, MP and do you do get a bit flooded with stuff from people when you're a candidate, particularly for the city candidate or the person most likely to win.

But all I'd say to campaigners is if you don't necessarily hear what you want to hear, don't be discouraged and do what Sue did and say to someone - Well done, you know you're in, so I appreciate that you've spent the last month knocking on doors and being on the road. And it's a bit difficult to keep on top of all the correspondence. But then when you're in, get in touch with the person who's been elected, because even if you haven't heard back from them in the way you would have wanted to, they will be very receptive at that point. And that's a good time to get in.

I mean, you know Motor Neurone Disease Association was brilliant at getting into me really early when I was selected as a candidate for Northampton South because you find yourself as a politician fairly full, fairly quickly, so the ones you've committed to early you commit to.

And then if someone comes along five months or nine months later, then, however worthy the cause is you're probably full. You're probably at capacity and, and that's the other point about our campaigns is to get in to get people to do commitments, make things easy for them because they've got a dozen competing priorities every single day, so they will be sympathetic. But if you make it easy for them to express how sympathetic they are, that will only help our cause.

Chris: Thank you Andrew. Yeah, it's really useful. That's really helpful, Nicola. I'd really love to talk to you about the United to End MND campaign, because it very much was a campaign led by people with MND from the very beginning. So it I'll be really interested to hear about your experience of that and also because it's a campaign about research, why research is so important to you as an issue.

Nicola: I think research is important to many of us with MND and probably for obvious reasons. It's the only way, really, that we'll see an end to this disease. It gives many of us a lot of hope, particularly the point where research is at now where we're seeing, you know a lot of different avenues where scientists are looking to develop treatments. So it is an area that does give us real hope.

And you're right that the United to End MND was started by two patients Lee Millard and Dave Setters and you know, to be honest, not many people could replicate what they did. I don't think I certainly would have the gumption to go off and, you know, propose this sort of very ambitious campaign to really set up a Research Institute in the UK. But I think to echo what Sue and Andrew have said, a campaign is a really, you know, quite a broad thing.

There are lots of elements to it where people can get involved in different parts of it. So my background I used to work as a senior civil servant for a government department. So that's really where I was able to bring that expertise in in thinking about how we contact civil servants. So to echo what Sue and Andrew have said in terms of United to End MND, we were in touch with multiple civil service teams. We were in touch with lots of MPs.

So for some patients they would be, you know, we had somebody whose MP was Rishi Sunak, so that's fantastic and she went to talk to him a couple of times. So there's lots of different ways people, and sort of more manageable ways that people can get involved. So particularly for patients you know many people with MND are not very well, you know they can't commit to getting involved in a long term campaign, but they can perhaps meet their MP or write to their MP. Or, you know, we had a patient letter that I think did make a real impact where we had over 500 people with MND who signed the letter supporting our ask for £50 million of new government funding into research. And alongside that people wrote a little bit about why that was important to them, and as a whole, that letter was incredibly moving and I think it did have a lot of impact in terms of the overall campaign.

And finally, getting the decision last November that the government would commit to that additional funding. which obviously has meant a lot to the community.

Chris: Yeah, it was very extraordinary moment. I have to say it was coming at the weekend as it did and I think what it was, everybody was quite in shock I think initially. Because it came out of nowhere, but it was one of those wonderful moments like Scrap 6 Months like and with that campaign just an extraordinary moment. A great credit to everybody who was involved with it, I think.

Helen: Andrew, I know that that you've done a lot of work as well on the United to End MND campaign alongside Nicola and a lot of the other people living with MND. Can you explain a little bit how about how you raised the profile of the campaign in Parliament from your experience?

Andrew: Yes, I mean again, very much like Scrap 6 Months. It was just carefully working with MND about who to target, who to write to, when to do it, when to take advantage of the, the fact that we got you know, Doddie Weir and Rob Burrows. And Stephen Darby as well. So we've got rugby and football covered, gave us an opportunity to achieve a higher media profile which then in turn got Members of Parliaments interest. And I think one of the key things to get across to MP's was the fact that this, that there's this expression of moon shot about it all that kept coming up. And it was to try and sort of define that expression that this wasn't an attempt for research funding that may or may not find something in that sort of graphene sense that you just sort of plunge into unknown research and hope something

comes up. The point about the timing with the Research Institute and United to End MND was to build on and capitalise on very significant genetic research breakthroughs. So it was to get the sense into people's heads around Westminster that this wasn't just if we spend lots of money, we might find some sort of cure for MND. It was, We've now got some very clear indications of what the route to finding cures and serious treatments are.

So we know where we're going, so it's a moon shot in the sense of not just firing a rocket up into space, but saying there is the moon. We can actually see where it is but we need to, you know, we need the rocket fuel to actually get us there and come as a result of that we had a Couple of MND Research briefings which were extremely well attended.

I mean again all party groups often have a sprinkling of MP's and then a lot of activists and a lot of people in the relevant charity or industry or campaigning field. This one has achieved both of those, and I wrote an article for the Daily Express and we had the Westminster Day of Action, which again we coordinated very carefully to ensure that we maximised the publicity and we maximised the encounters that look like chance encounters, but aren't where we manage to get secretaries of state and Ministers of state in front of people with MND and their carers so that they can actually hear those personal testimonies and stories, which is something that The all party group specialises. That we actually do make sure that we have people with MND and people with their experience of MND telling their story and speaking about what their experiences are, not just hearing about it second or third hand and it was as a result of that we had a huge splash. I say my own constituent, Emma was with us as well, and then it was almost like one of those sort of TV dramas because the spending review came out that we were all hoping the announcement would be in and it wasn't, and I remember putting a sort of tweet together which I put up, you know, no, this is not acceptable. We must, you know, this must happen, but let's keep pressing, let's keep and then just a few days later, separate from all the rest of the spending announcement. It came out as a as a stand alone and you know, so it was almost like that sort of TV drama moment where you build up to something and it doesn't happen and then suddenly just at the last minute it pulled off.

But much like Scrap 6 Months, we've got the announcement of the funding, and again that technical grind. That detail of yes, fine, but when's the money actually arriving and how we're going to, you know, arrange its allocation and how much flexibility are the university research departments and MNDA going to have over how it's all set up. That's still going on. So again, as we Scrap 6 Months, we go there. In terms of the announcement, that's the key bit for us then to say fine, but where's the detail? When's it actually going to happen? So much like our other campaigns, this one still goes on in a different way as well.

Chris: Yeah no, I think that's right. I do think, I don't know if Nicola wants to comment, but I think that day on the 21st of September last year was a real coming together of all those constituent parts to make it happen, wasn't it?

Nicola: Yeah it was. It was really amazing and I think, you know to be involved and to see the commitment of Andrew and all these other MP's who have got you know enormous demands on their time and to see them make the time to come. And you know sit with us to learn about the campaign. Particularly, I think Andrew's commitments you know, as he's just said. Is we've got the announcement, but it's not over. He's still supporting us, advising us, helping us to make sure we get this money in the way that we want it.

So it is, you know, it's a tremendously rewarding thing to be involved in. I think for me, you know, I don't quite know where MND will leave me, but it's given huge meaning for me to be involved in this sort of campaign. You know, giving meaning for me in terms of sort of having the disease.

Chris: Thank you, yeah, I think that's so important, isn't it? For people, and for many people that I've met as campaigners for us over the years have said that to me actually. About this. It really gives you hope. It gives you a real commitment to the cause and it is, I think as Sue says its is an amazing community. It never ceases to amaze me as a community its extraordinary.

Helen: Thank you to all of you really for sharing your stories on how you've got involved in campaigning for the MND Association, but also for you know, your parts that you've played in it, because you're all coming from completely different angles and stories. But together I think what you've proved is that we can raise a bigger voice and make a bigger impact for all people affected and or living with MND. So thank you, yeah thank you again for kind of sharing your experience and and hopefully you know inspiring other people to come and join us, to come and join that voice and try and move things forward and join our other campaigns.

Chris: Ah yeah, thank you all and to everyone who is listening. Thank you for listening to the podcast today if you'd like to be kept up to date with our campaigning work, you can sign up to our campaign network, which already has over 9000 members. It's completely free and you can find the link to sign up in the description of this episode.

Helen: And if you have been inspired by Sue, Nicola and Andrew today, and you'd like to become a dedicated campaigns volunteer, please, please, please email campaigns@mndassociation.org or again, check out the link in our description of the podcast.