

MND Matters: Episode 3: Volunteering

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

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

Steph: And I'm Steph. I work in the fundraising team.

Nick: We also have three very special guests with us today – Liz Groundland, fundraising volunteer with the Manchester branch, Mark Gately, chair of the North West Kent branch and campaigns volunteer, and Julia Peckham, Association Visitor with the East Sussex branch.

Steph: And we're going to be celebrating Volunteers Week which is an annual nationwide awareness campaign which marks the amazing contribution that volunteers make to society. More than 20 million people volunteer in their communities across the UK and, across the Association itself we have more than 12,500 volunteers which is absolutely incredible. They include volunteers who are active in campaigning and fundraising as well as those who have got direct contact with those living with and affected by MND. We are really excited to be sharing some of the stories of those volunteers now.

So, if we go to you Julia, I think you've been volunteering for quite a while now, not just for the Association but maybe for other organisations before, so what was it that inspired you to get involved.

Julia: Well, with MND it was very personal for me because my husband, Richard, was diagnosed with MND in 2012 at just 60 and he was diagnosed in the February and the disease progressed very quickly with Richard and in fact he died in the December of that year. The dark humour that a lot of us experience an awful lot got us through, and he was a great list maker apart from also becoming an incredibly good driving instructor when he had to give up his driving. And on his list really was, you know, 'right, can't do anything else for me now. You know you go and help other people with this awful disease'.

But my caring role does go way back. I was fostering severely disabled kids when mine were very little and I've always worked, I'm in the maritime industry. I've always worked in some capacity as a carer, usually with people who are in their dark hours so, yeah, I do go way back. I'm very old.

Steph: You're definitely not. You're definitely not but it sounds like you've got a wealth of experience as well and I'm sure you do an amazing job at the Association helping people affected by MND so thank you for that. I can tell just from your speaking how passionate you are about what you do and what is it that you get out of volunteering?

Julia: Actually, do you know, a lot of people say that to me, particularly family and close friends were saying 'You're doing all this. Does it not remind you and take you back, all the time that you're going through it?' and I said no, because I get far more back than I give and I've made some amazing friends. Really, really special friends. That is the one exceptionally good thing that comes out of MND. They seem to be incredibly special people. So that's really why I do it.

Nick: And Mark, you're heavily involved with your North West Kent branch and I believe you also have a role in an additional branch. How did you get into volunteering?

Mark: Once again it's a family connection. My father was diagnosed around 2007/2008 and, having done a bit of fundraising in my time and having done a bit of cycling, the opportunity to cycle from London to Paris, or no, sorry, from London to Reims arose. Reims being, of course, the champagne capital of France so there was an additional benefit there, of course. So, I cycled with a number of other members of the fundraising team from the Association, volunteers and staff and that got me into the branch and before long I was editing the newsletter. The next year I was secretary and remained secretary until March of last year when I took over as the branch chair. And I got involved with campaigning early 2016 and, as of about 6 months ago, because I have a connection with Suffolk, and I said well, look guys why don't I just duplicate the work I'm already doing in North West Kent area and do that in Suffolk as well.

Nick: You can see that since your dad's diagnosis in 2008, you know, that's a lot of time you've been involved in MND and it's great that, you know, you're making that contribution.

And Liz, you've been involved in fundraising for some time now. Do you want to just tell us some of your great fundraising ideas?

Liz: Just a bit of background with me. My brother was diagnosed with motor neurone disease in 2014. He was only 37 when he was diagnosed with it and he had two young children. He fought it very hard and brave and, unfortunately, passed away last February after fighting it for just over 5 years. That's what got me into it. One of the things you feel when someone gets diagnosed with a disease like that, I'm not a doctor, I'm not a scientist, I'm not going to find a cure, you feel very helpless so the first thing I did, I said to a friend of mine that I wanted to raise some money, to raise some awareness – there's a lack of awareness to the disease.

I just said I feel so helpless and want to do something so we fundraised and I organised 100 miles for MND in September 2017. It was basically one day when anyone could run, cycle, swim, whatever you wanted to do in any part of the world. We have family in New Zealand who started off the event and we had family in America who finished the event for us and in between we had people in Dubai, Iceland, Ireland and everyone kind of filmed and put it all on and got their own money. We raised over £6,000 so it was kind of, you know, a big event for us to do and I kind of got into the branch that way and they kind of helped me plug the event and gave me a lot of support and the regional fundraiser at the time really helped me. And then they asked me to come and be on the Committee and I said, of course, I'd love to and that's kind of what started my journey with fundraising and with MND and I don't see it ever stopping. Like Julia said, you know, I can't see me ever not doing something for MND or not trying to raise money or awareness and funds, in legacy for my brother but also for everybody else that I've met since who's fought and lived with MND and the family and the carers because it doesn't just affect people with MND, it's everybody else around them that it affects so, yeah, that was my journey really.

Steph: Thank you Liz and thank you for what you do. And I know the three of you have talked about that sense of meeting people in similar situations and that community that there is and how did it feel to be part of that as a volunteer Liz?

Liz: I think it's amazing, you meet people that inspire you every day. There are people that do, you know, like I said just listening to Julia and Mark and how much you know they've done and then everyone in the Manchester branch. You know, people have come from all kinds of different backgrounds but come the same way in the sense that they may have lost

someone to MND or someone they're with is fighting MND. You know, just everyone is so inspiring and the strength that I saw in my brother for so long, the positivity that he had for so long, fighting the disease for him and his family, it just inspires you and you become part of this MND family that you know is just there for you no matter what and it's amazing and you just want to continue to raise money and raise funds and awareness and help more people until we eventually have you know a world without MND which is ultimately our goal isn't it?

Steph: Yes, absolutely. And Julia, you must experience some really difficult situations, you know, obviously before the pandemic, going into peoples' homes, people living with MND and their families and they need your help and support. How do you deal with those situations and what keeps you motivated to continue doing that?

Julia: The first time I was sort of you know out on the road to meet my first person with MND and I sat outside in the car and I thought ooh ooh because you don't know what you're walking into. I thought well come on, you've got to do it and actually he was an amazing gentleman, absolutely amazing. He lived on his own and he was at the stage where he was falling a great deal of the time and, you know, we chatted at first for about an hour without MND really being mentioned. We had quite a lot of laughter. He made me a cup of tea which was absolutely disgusting and we had a bit of a giggle about that. But yes, there have been some very difficult situations, how other people live and how they deal with it.

The things I find the most difficult is when there's some denial, either with the person with MND or with the family. I can absolutely understand it because, as you said Liz, you start to look online and it strikes terror into your heart or you think well that's not going to happen to me. And I think those are the ones that I find really quite challenging and quite difficult. What we've found has worked in the East Sussex branch is that we as AV's sometimes buddy another AV so, if there's a family situation, one of us will either buddy the person with MND or the partner or the family. And we found that works because we support each other and also we feel we can support the family. We also say, look, you know, pre-Covid, we can meet outside for coffee because I'm sure Mark you know you've all experienced the doorstep conversations where you know someone is desperate to say something and it happens as people are leaving.

I felt that with Richard, although we talked very openly, we'd worked together for years and years, but there were things I didn't really want to say to him. I didn't want to say how tired I was, how frightened I was and he was doing exactly the same and, as I say, the humour got us through because we got ourselves into all sorts of pickles. I do remember him once being stuck between the toilet and the wall, completely stark naked. I couldn't get him up off the floor, then he wet the floor because he was laughing so much and I had to go and get my son-in-law who lived a couple of doors away to come and help. Richard was on the floor, laughing so much but he wouldn't let my son-in-law come in until I put some pants on him. So, these stories do help other people, when you can say, you know, it's dreadful, it's terrible what's happening, however, the dynamics of your relationship is going to change.

Liz: I think, Julia, that Association Visitors are absolutely amazing and Phil's, my brother's Association Visitor, was fantastic, you know, amazing, and what they do is you know above and beyond sometimes. They support the person living with MND or their family as well and they are just angels, they are. I honestly am in awe.

Nick: That's great, being able to provide that support between people who've had similar experiences, you know, something that's really important. And you touched upon how MND does have such a profound effect on families and it's been a really tough time over the last

year for everybody, particularly with the pandemic, you know, would you like to just tell us Mark some of your experience of how the pandemic has affected your volunteering?

Mark: Yeah, well, it's had obviously a massive impact on all the operations that the branch carry out. Our first casualty was our AGM. Our AV's haven't been able to go out and visit their existing patients and, of course, anybody that's new to the branch hasn't been able to be visited by one of our AV's or Alex, who's our first point of contact. Our branch support meetings via video conferencing now which has had a mixed success, you know, a lot more people with mobility problems have been able to join meetings and we've sat and we've seen them.

Overall, we've kept fundraising going. We have a number of donation boxes in local bakers. Quite a lot of our boxes are in bakers so they've remained open, and fish and chip shops, so we've been fairly lucky on that front. And one of our fundraisers, Alex's sister, Jean Finlay, has held table top sales outside of her house, in her front garden, where, for most of the time, she has an honesty box there for plants and people have been putting money. And Jean at the age of, I can't remember if its 91 or 92 or it might be 93 even, but any way, she's raised over £2,000 in the last year just by putting a table with some bits and bobs and what we call our, yeah well, I say collectables, it's more bric-a-brac really than collectables. So, but, once again, people have been buying it and occasionally we get some nice little bits of bric-a-brac and so that's been great as well. Yeah, difficult but we've managed to find ways to get through.

Nick: Indeed. Difficult times. I mean volunteers are so important to do the work we do and your comments about how dedicated people are who are involved in MND and the MND community is certainly reflected in the people that I work with at the Association. We know we've been very fortunate. People have actually gone above and beyond with the fundraising side of things during the pandemic and difficult times. How have you found that with the people you're working with?

Liz: So, last year was very hard, you know I can't lie. But, you know, we had some raffles, we did kind of a Christmas raffle and a daily raffle. We did the 12 Days of Christmas which was different events and days. There was one day where my daughter got in an ice bath as one of the days – she was braver than me because we were both supposed to do it but I chickened out and she did it, bless her. Or, you know, sing a Christmas song one day and that raised some money for us and some people did kind of walks on their own and walked every day and so, we did all right. We probably raised about £3,000 last year which wasn't great but it's still money and we're proud of the fact that we did that.

Steph: That's absolutely amazing that you're doing that and all three of you have got different volunteering roles and it's really interesting to hear the reasons behind why you were inspired to get involved in those ways and Mark, I think your volunteering role covers quite a lot of different areas. You seem to be using a lot of different skills so it would be really interesting to hear what sort of drove you to do all of those different things. You know, your campaigning, your heavy involvement in the branch in different ways as well and whether it's a skillset that you've had you know and developed over years or whether they're new things and the reason behind you getting involved in those different areas.

Mark: Well, I can answer the reason why I'm involved in so many areas. Well, I say I can answer it, it's my wife's answer. She says 'Mark, you can never say no' and that's about right, hence I'm here today when I was asked would you do the podcast? So, that's the short answer. The long answer is, well, lets take the campaigning for a start. Some inspirational people I sat with and they just encouraged me. They said it's a great thing to do and I was a

little apprehensive at first because I've never done campaigning before. I didn't really know what campaigning was about. Yeah, so that's campaigning.

Why am I chair now? That's a good question. I suppose a natural progression really. Yeah, I worked very closely with the previous chair, Alex Finlay, in my secretary role and he helped me out as secretary and I did some bits and bobs for him. You know, he's not on the computer and, good on Alex, he realised he wasn't being quite as effective as maybe a chair should be without having, you know, when things ping through on my computer I can do them straightaway, whereas Alex would wait for the snail mail to come through. Yeah, so, that was, as I say, a natural progression and the fundraising side of things that I do, well, you know, I just find it amazing that people will give me money to do something that I want to do.

You know, I've done a number of cycle rides across France. You know, it's okay cycling in England but where I am in South East London, probably not too brilliant. When I'm up in Suffolk, quite nice. I cycle over in France and Holland and all that on my long distance rides, absolutely wonderful and somebody will give me money to do it. You know, it's a great way of raising money as far as I'm concerned and, yeah, the repairing bicycles bit and selling them on, well, yeah, I was never mechanical in my business life. The most mechanical I was when they used to have Dictaphones and you used to have to flick the switch backwards and forwards and that was as mechanical as I ever got so when I did sort of retire to look after the family and things like that, yeah, I decided that I would get myself on a course to learn bicycle maintenance and then, you know, people started saying 'could you do my bike Mark and my mates bike' and I just thought, coming from an insurance background, well I don't like the idea of having any liability should I fail to do a nut up. I thought right, well hang on a minute, I can do up a few of these old bikes I've got and get rid of them and sell them and, having set the company up, I thought hang on a minute I can get some trade accounts and get the parts, instead of paying the full price, I'll pay the trade price. And that's what I do now, I get them in for trade price and I don't want to look out into the garden as Mrs Gately says its Steptoe's yard out there with the number of bikes. Yeah, some of them are a bit no hoppers but I strip them for parts and bits and bobs and, you know, that's been most successful and because of the pandemic, thank you very much indeed, it's been very, very successful to the extent that the local micro pub on the High Street asked me if they can help in any way. They've been very supportive of MND. It's called The Hoppers Hut on Sidcup High Street everybody – any way, that's payback. So, yeah, they said 'well, how about putting the bikes in the pub while people come in to get their take aways when they were able to do that'. I said yeah great, thank you very much indeed and that was over a thousand pound raised the first time I did that in the first lockdown. Yeah, I think I've just fallen into a number of these roles with my inability to say no. Others, as I say with the fundraising, I haven't really fallen into that. I'm just doing something I enjoy doing and people pay me.

Steph: Thank you so much for that. But you'll all work with different people and other volunteers who may not have as much time to give but still want to help. Liz, I'm guessing you've experienced this with some volunteers with the branch. And how important is it, you know, obviously not everyone can give all their time as they have other commitments as well but what sort of role do those volunteers play that can only give a certain amount of time rather than being available for 24 hours like Mark which is absolutely fantastic but everyone's at different areas but I'm sure they make a very valued contribution as well so what sort of things do they get involved in?

Liz: Yeah, it's a really good point. I work full-time, I have two children you know so, for me, sometimes the volunteering has to take a backseat as I have a day job. Funny enough,

someone said to me recently on our fundraising committee 'Oh, I've not really done much to help and I've only raised £200 or something' and I said no matter what you do, even if you give a small amount of time and you raise even £10, £20, whatever you do and you're raising awareness about the disease, you are contributing. It doesn't matter and we say to all our volunteers, and I say it to our committee, our fundraising committee grows as more and more people want to be a part of it and support us for different reasons. You know, any time that you are giving up, no matter what it is, you are supporting people. So, sometimes I've had to take a step back and someone else has stepped forward and that's absolutely fine. No-one should ever feel guilty about that. We're volunteers. We're here, we give up our time but, you know, we just try to encourage them to think that no minimum amount is not enough. Whatever you do is absolutely fine and sometimes people drop in and out of it because they may have a personal connection to MND and sometimes they can cope with it and sometimes they need to go, you know, I just need a little bit of a break from it for a little bit.

Mark: Yeah, I think you're absolutely right there Liz and I support everything you say and, in fact, I say to anybody joining my branch that, you know, the first rule is family, work, volunteering and it must be in that order.

Nick: And in terms of meeting people from different walks of life Julia, in your role you must be visiting people from all different walks of life.

Julia: Absolutely, very, very different, I mean they are. Each one of them has been very, very, very unique. One delightful young man I'm supporting at the moment was actually one of my grandsons' Chemistry teacher so, and he's absolutely an amazing, an amazing, amazing person. But his, where he taught, the College where he taught at have been incredibly supportive, not only on a personal level with him but they have raised lots and lots of money. You know, if I know that he or someone locally needs it, I can actually ring up and say right but we need it within 24 hours, we can't, this is really important. But I go to the school probably, well really quite often to meet with the Head and the Deputy Head who are close personal friends. They have been amazing and they will continue and, in fact, what was very lovely is there is a new science lab that was just opened in the school and they have named it after this very special teacher.

So, that was very different to also meeting a young mum, a young single mum with three children, no money, living in a three bedroom flat with no access so very, very different. And that is again where the fundraising, you know, to actually be able to say to her, her young 18 year old son was trying to hold down three jobs so that he could help his mum and pay for taxis because he wasn't able to drive so our local branch just came up with the money straightaway for him to go onto one of these, they call them crash courses which I think is mad, but one of these courses where you learn to drive in three or four days and he passed his driving test. And he phoned me and just went 'I'm just going to take my mum to her appointment'. It was wonderful. That was fundraisers. And I think those personal stories really, really help. I'm not sure that all the people that fundraise, it's when you can actually go look, we're lucky as Association Visitors. We actually see the difference it can make, you know, from even that £10 to someone that you can say 'you can have a manicure, you can have some aromatherapy, theatre vouchers, you know, take your kids out' and it's huge. It makes a huge difference.

There's something very special that I find about people with MND. There's something I find in them, they become very, most people become very inspirational. I mean, Doddie Weir and Rob Burrows at the moment are raising so much awareness.

My experience of the first most difficult question is 'how long do you think I've got?' I get asked that 90% of the time so we use the standard which is true 'MND is unique to everyone. You know, I can't predict how long you've got but what we can do is try and ease your journey. You know, in the darkest hours we are going to be here'. MND Connect is brilliant. I've rung them not only for people with MND but myself, saying what do I do, how do I help and, yes, you bring your lifeskills. Everyone, we're all different on this day you can bring your lifeskills to it. Having a sense of humour I would say is absolutely essential for an Association Visitor. So, yeah.

Steph: It's an amazing role and it sounds as though you've got lots of support amongst other Association Visitors which I think is really important. Obviously, I can't even imagine how emotionally taxing something like that is but I know you've talked about how much you enjoy doing it as well. And, just in a couple of words, can you sum up the best bits about volunteering?

Julia: In a couple of words, I don't do just two words which you've probably noticed.

Steph: Neither do I.

Julia: Rewarding – that's one word. Rewarding, challenging.

Steph: I think that really balances out the things you've been talking about really as well because of the different complexities of a role like yours as a volunteer as well so its really interesting that you've chosen those two words and you've definitely put that across. And Liz, what about yourself?

Liz: Oh, I knew you were going to come to me. Julia did really well then as well. I suppose I don't know how to put it in words because, for me, volunteering, you know obviously because it's still raw for us losing Phil just only over a year ago but, for me, it makes me feel, you know, I feel inspired. I feel inspired every day with the people that I meet. I know that's more than one word but I do. It inspires me and it inspires me to continue on the journey of volunteering and supporting people living with MND and I feel that, you know, ultimately I do it as a legacy for Phil. So that's what make me feel, I feel that I'm doing something. I'm not helpless in the fight.

Steph: That's really lovely. I'm sure Phil would be so proud of everything you do and we're very grateful. Yeah, that's really lovely. And Mark, you've had a little bit more time to have a think about what you want to say so how would you sort of sum up volunteering and the best bits about it in just a couple of words.

Mark: Well, it's quite easy really. Its, the two words are 'the pay'. There's an old quote that volunteers don't get paid not because they're not worth it but because they're priceless, but the pay isn't monetary. The pay is developing yourself and, if I was still in business, I'd have had loads more skills now from my volunteering with the MND that I didn't have and that I could have used. Other things that people have already mentioned. The pay is great because you make some great friends. I've made another two today, sorry, four if they include the Association staff, of course. And, yeah, it's nice that ever so occasionally, and as often as required, the Association send me through a little note saying, you know, thank you.

Steph: Yeah, thank you. That's really lovely and it's nice that you all picked different words, different ways of expressing what it means to you and I imagine we could go on for so much longer and any volunteer would say something slightly different but something that you all understand and you've all really understood what each other said and it seems like it feels

the same for each of you. There's just so many words so, yes, cutting it down to two was difficult so thank you for giving that a go. But really you are all remarkable people and we're very grateful for what you do and I'm sure people will be inspired by what you do.

And if anybody listening, if you're listening and you think that you want to get involved yourself and volunteer for the Association then please do get in touch. The details are on our website. We would love to hear from you and explain there's lots of different ways, as we've heard from Mark, Liz and Julia, to get involved and I'm sure we'll find something that is something that you want to do to help so thank you. And thank you all for sharing your stories as well today.

Liz, Mark and Julia: Thank you.

Nick: Yeah. Thank you very much and thank you for listening to this podcast from the MND Association and on behalf of Steph, myself, our guests Liz, Mark and Julia and everyone at the MND Association, thank you for joining us and we look forward to having your company next time for another MND Matters podcast.

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