

MND Matters: Episode 7: Managing Emotions

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.

Becky: And I'm Becky and I'm an Area Support Co-ordinator down in Sussex.

We're delighted to have Cath and Ian Muir with us today. Cath's been living with MND since April 2014 and Ian is her husband and primary carer. They hail from Richmond in North Yorkshire and they've kindly joined us to talk about how MND has affected them emotionally.

Nick: Thanks Becky. We're also joined by two of the psychologists whose work with people living with MND is funded by the MND Association – Dr Emily Mayberry, a Senior Clinical Psychologist who works at the Motor Neurone Disease Care Centre for the Sheffield Teaching Hospitals NHS Trust and Dr Sian Hocking, Principal Psychologist for the South Wales MND Care Network.

Becky: Mental health is a massive area, and we're not even going to try to attempt to cover the whole issue or do it justice in just one episode. But we're going to focus today on managing emotions and we're exploring how MND can impact on mental wellbeing and also try and consider ways that people can cope with it. We'll look a bit further into the work that Sian and Emily do as part of their psychology work to support people with MND cope emotionally. But also looking at some of the other things that people can do to look after themselves and also hear from Cath and Ian about their experiences and, hopefully, that will help other people who might be listening to this sort of recognize some of the things that we talk about in themselves and how to get help and support. So, yeah, very exciting episode isn't it?

Nick: Yeah. It's a really exciting episode and an important topic.

For more detail about any of the topics raised please look at our website, talk to your local branch or one of our trained Association Visitors and there is also discussion threads around mental health on our forum where you can chat with others. And, of course, you can always call MND Connect for a chat or to be signposted in the right direction, including if you're interested in applying for one of our wellbeing grants. These can be used to fund some therapy sessions for instance or help you develop a new hobby.

Becky: And before we invite Emily and Sian into the conversation, I just want to say we're really delighted to have you with us today Cath. And I know you use assistive technology to talk so we're really thankful that you've spent some time preparing some answers for us for the questions that we want to put to you so thank you again.

So, yeah, I guess we'll just jump straight in. It would be really good if we could start with yourselves, Cath and Ian, and asking you what was life like for you before MND, before that came into your life and how you spent your time and tell us more about you.

Cath: Life before MND was good, extremely hectic. I was running a tearoom we owned in Richmond. I was doing all the cooking and baking, staff management etc and working about 60 hours a week. We also had a very busy social life and enjoyed the gym, exercise classes, eating out with friends.

Ian: So, as Cath's just said, we were I suppose like a lot of people with a very full-on life. Cath running the business, I had a full-time job of my own and, basically, when I wasn't at work I was assisting that and I think it was full on. You just fill your life up with everything. You know, the two sons, they'd both grown up, gone through university or college and left home so it was very much the two of us. The hardest thing was to find a break from work and actually have some time off because anybody that runs their own business realises that is very difficult to organise. And so, we were just pretty much working together, living together and going through everything together as a team.

Nick: And then Cath, you were diagnosed with MND in 2014. What were your main emotions at that point and then in the weeks after that?

Cath: At the time of diagnosis, I had had very worrying symptoms for about a year. I had already convinced myself it was MND by Googling my main three symptoms which were bad cramps, twitching and tripping over. I wasn't shocked. In some way it was a relief, however awful, to know what I was facing. I thought it was either sit in a corner and cry or get on with life the best we could.

I felt it was better out in the open. We immediately told our employees, sons, best friends and family. I found it difficult over the first few weeks as people were continually asking how I was and what was wrong with me.

Ian: We've often said the hardest thing is not knowing beforehand, because you have no idea really as to what you're going to deal with and then all of a sudden you're hit with this diagnosis which, there's no way around it, it's horrific. And I think different people respond in different ways and because we had a full life and a very busy life, it was possibly slightly easier to just say 'well, we'll keep going on as normal as long as we can' which is what we decided to do. But it was always there in the background. We always knew that it was only ever going to take an increasing part of your life. As Cath said, difficulty often is the continual people asking you 'what is wrong' and 'how are you' and often people saying 'well, I hope you get better soon' and that is often the most upsetting thing that we had to cope with.

Nick: Yeah. That awareness really and people understanding about the disease is something that we feel strongly is something that we try our best to improve all the time. You said it – you know, it's a year for you to be diagnosed – I guess through that period of time, that is a real struggle. Trying to be directed in the right place and really understanding what is going on and, whilst all of that is happening, that rollercoaster, you're actually trying to maintain your work and look after the family etc so extremely difficult I'm sure.

Ian: I think, because it's a process of elimination to get a diagnosis, it is a very long-winded up and down process. You're told 'well no, it isn't this'. Well, that's fine. Then you're referred to the next step and you have to cope with the next appointment and waiting for the outcome of that and it's quite a draining process to go through.

Nick: Thank you for sharing that.

Becky: Yeah. It must be a real challenge even now, but just constantly having to repeat yourself or tell that story again and again. So, thanks so much for saying that out loud on here as well because I

know that people listening to this, they will resonate with that. Anyone in the MND community will understand that emotion for sure.

But just to bring Sian and Emily in now at this point as well because, as we know, MND affects everybody very differently but also it can affect peoples' emotions differently as well. And I think, unless you work or are trained in the mental health field, it must be really difficult to understand emotional changes or the way that you're interacting with people now, having to talk about an MND diagnosis or come to terms with it. So, I guess my question to you would be what are some of the common emotions that you see in people that are diagnosed with MND or their family when they're going through understanding the diagnosis?

Sian: It's really interesting there Cath that you touched on a sense of relief and actually, as Ian was saying there, it's a diagnosis of elimination where lots of things are ruled out and, for many people, the diagnosis can at last provide a sense of relief. The unknown can be a really difficult place for us all to sit in psychologically so that sense of all of a sudden knowing what's causing the symptoms that you're experiencing can provide that relief. But it also, after the relief, what we notice is that people move into a state of denial which psychologically is a protective mechanism. Perhaps people might question whether it could be something else. Is there anything else out there that might explain the symptoms? I can see you nodding there Cath. And then shock as well. People often find themselves in a state of shock, just sitting there with 'I've got motor neurone disease and what does this actually mean for me?' Often people describe it as not really feeling real and not being able to really take in what it means for them and their future.

It's interesting Cath that you mention talking quite quickly after your diagnosis with your friends and family and some people definitely find this easier than others. Some people prefer to process it themselves before sharing and then other people will talk much, much sooner and those conversations will be part of the processing journey. There's an awful lot of variation between individuals in terms of how they manage and the coping strategies that they draw on. What we know from the literature is that there is a high prevalence of depression and anxiety symptoms around that point of diagnosis and then within the first year as well.

Emily, I don't know whether you want to add to that.

Emily: Yeah. I think you've all described, you know, the kinds of things that I would mention that I've seen and come across people experiencing as well. I guess it's really just to reiterate, you know, that it's different for each and every person. Sometimes it's different for the person receiving a diagnosis of MND and for their family members. People might be at different points at different times and the emotions that people feel don't just stay the same so they change over time and they might be one way one minute or one day and a different way another day or another minute. So just the variation kind of in different people and also within each individual as well.

Sian: So, no two people are the same in the way that they might respond to a diagnosis of MND. Like Cath was saying there, some people may initially respond with a sense of relief and then, afterwards, perhaps there's a sense of shock or denial. It sounds like Cath, you experienced something similar to that. Much of our work as psychologists is around supporting people to process the diagnosis initially. We often would draw on grief models to think about how somebody adjusted to the diagnosis and often the way that they've been understood previously is that there are distinct stages that people move through. For example, denial, shock through to bargaining, anxiety, anger and then eventually finding some level of acceptance. Previously the understanding was that people move through these stages in a linear way, but now we understand that it's very different to that. That people might ebb and flow, that there's movement within all of those stages.

Particularly thinking about motor neurone disease, there's not just the acceptance of the diagnosis itself but all of the changes and the loss experiences that come as part of the diagnosis. So, at different points, people might find that there's a new thing to adjust to, a new thing to accept, so perhaps the loss of speech or the loss of function or mobility. We know that there are several factors that influence that and, perhaps thinking about somebody's support network that they've got around them. Perhaps also thinking about peoples' individual situation, so somebody with a younger family, somebody who's working might face challenges that somebody who's older or not working won't face. But perhaps if you're older there may be other challenges in terms of access and support networks. We know that everybody is very individual and the support that they have is very individual. And how MND affects them also will interact with all of those different factors.

We know that depression and anxiety are particularly high for people with MND, particularly around the diagnosis period and within that first year as I mentioned earlier. What's really interesting I think is often people imagine that somebody's mental health goes hand in hand with their physical health and so, as somebody becomes more physically impaired, that they too become more compromised in terms of their mental health. That isn't always the case. We know that people are at their worst with MND around the point of diagnosis when they're physically at their best but actually the trajectory isn't the same. We know that people can adjust and live well and have good quality of life when even physically that might well not be the case. I think that's important for us to remember and I think that helps us to connect with hope and meaning and thinking about some of the therapies that are on offer there, the difference that they can make to people living with MND.

Nick: Thanks Sian. Cath, if we could bring it back to you at this point and ask you what your own personal response was given, as Sian's just explained, it's very individual for each person. How do you cope with your emotions as they must have been very intense at times?

Cath: We try to be honest and open with each other and at times we both get upset. Fundraising and raising awareness of the disease has helped us a lot. Also, getting involved in our local MND groups. I struggled a lot with how I looked such as having to wear splints, putting on weight, the first time I had to use a walker, go in the wheelchair, not able to talk and using NIV. I found lots of support from other people with MND, both personally and online. Talking to people in the same situation is extremely useful as they are dealing with similar problems.

Nick: Thank you. And how about yourself Ian? How have you felt emotionally?

Ian: Yeah. I think we kind of share the emotions between us. I think I'm a typical bloke. I don't show a great deal of emotion, for better or worse, but I think the hard thing I've found to deal with is, as the MND has developed, is kind of what I would call random emotions in Cath, in that she would become anxious or emotional or crying, almost as I would see without reason, and I would then feel guilty that I'd done something wrong that had caused the emotion. But because Cath was, as the emotion developed, she becomes more stressful, it affects possibly her breathing, obviously now that she can't talk with a normal voice, she couldn't explain to me what was causing the problem and that tended to create a sort of emotional block between the two of us. And sometimes I literally just have to walk away for a minute or two and then come back to her to try to create a break, otherwise we have this block where we aren't getting anywhere.

Nick: Yeah. I can imagine it must be incredibly difficult with so many different things going on between yourselves. In one of our previous episodes, Julia, one of our volunteers, said that a lot of the time there are some of these conversations on the doorstep because there are things that you might not want to say or appear to show and there are ways to discuss that. And it's interesting that

you say, you know, typical bloke. You know, this is, I guess, one of the reasons that we want to talk about this stuff because, you know, everyone needs help in different ways and there should be places for you to seek that help and for everyone to have, to open that conversation. You know, it's really, really important that we can try and provide that. I mean, I don't know if Sian and Emily or Becky, you want to touch on that side of things.

Becky: I was just going to come in and just recognise, so to share my personal story. My dad had MND so, for my mum and for my dad as well, although I think my dad tended to accept it a bit sooner, but the way we normally communicate how we think and feel is through our face and body language isn't it and then, with MND, you're not as able to do that as easily. You need to have like things that help you do that. And I think, just what you said there Ian about just taking some space and coming back, that was one thing that definitely helped us as a family and then just work out with my dad how he wanted us to respond next time or learn from that. And I think, thank you so much for sharing that and being so open with us because, hopefully that again, I keep repeating it in this episode, but it helps other people realise it's more normal than you think and it removes that stigma that we often have, even outside of the MND world, around emotions and how we express and how we deal with them so thank you.

Nick: Thanks Becky. That's getting to where we want to be really with this conversation.

Emily: I also just wanted to touch on another aspect of the emotional kind of changes that can come with MND that you mentioned Ian. And, in addition to the kind of the many emotions that come with this diagnosis and with the various losses you mentioned Cath, it isn't just a single, a single grief. There isn't one loss. It's multiple and it's repeated. And then, on top of that, some people with MND also experience changes in their kind of control of emotions or the emotions that come out might not quite match what people feel or they might be exaggerated. And that can then be distressing, both for the person experiencing that and for the people around them, the family members. And it sounds like, potentially for the two of you, that's been an added thing to have to adjust to and negotiate and find a way to manage. And my impression is that one of the key things for the two of you has been to talk about what works. So, if you just walked out of the room Ian, Cath might wonder what she's done wrong or what's going on, whereas if this is a kind of strategy that you both are aware of and you know that it works and that it's helpful then that's something that you can use. For some people, they might become very, very tearful or they might laugh uncontrollably and actually if people, for example, just sit there asking them 'are you okay? what's wrong?' over and over then it's harder and harder to stop and people can end up crying and crying longer. Whereas for some people their preference is actually to say 'shall I carry on the conversation?'. And having those conversations about what works for you as an individual and as a family I think is really important for managing that.

Nick: Thank you for that Emily. If people do decide to seek support, could you just talk us through the therapy process? I mean, we know for instance it starts with an assessment, but for some it might sound like quite a daunting word, assessment. How does that work?

Emily: So, an assessment really is not the best word for it in some ways because we're not assessing someone's ability or we're not assessing someone as a person. Really what we're trying to do is understand you as a person, you as a family and trying to think about what would be helpful. And sometimes in the work that I do, actually an assessment is therapy in a way because what we're doing is we're having a conversation about you, so a little bit like we've done today, I think Sian and I would probably both very often start by asking a bit about your experience of receiving a diagnosis of MND and, in fact, even the time leading up to that, find out a bit about life before MND and what's important to you now so that we can help think about what might help you do the things that

matter alongside the MND. And so the assessment is really an assessment of support needs, not an assessment of an individual if that makes sense. And then based on the discussion that we have, which is really just a conversation, then we would think together about what would be helpful. And sometimes that might be therapy, which might involve us working together to keep identifying what's important to you, to help you learn and develop new skills or new ways of looking at things or interacting with thoughts and feelings. And sometimes the next step might be to say 'actually, you know, maybe therapy isn't what's most helpful now'. Maybe, actually, you want to spend your time doing those things that matter or there might be other things. It might be connecting with the MND Association or getting support in other ways so it would be having that conversation and deciding together what would be most helpful.

Becky: I was just going to jump in there, and you've mentioned it at the end, about like the other things that the Association can help with. Locally, and I know Cath and Ian you're involved with your local Support Group, there's lots of local support up and down the country and if people reach out to us, we can link you in and help you with those things that you enjoy doing, those parts of your identity. Like Cath and Ian, you said about you guys doing everything as a team and socialising with your friends and hopefully you still get to do that and it just looks a bit different and we can help people do that elsewhere as well. It might look a bit different now, but we've got that support mechanism in place to remove any barriers because we always talk about the social model of disability and it's not what your body can't do anymore, it's the environment around you might make it harder but, if we can remove those barriers and help you keep hold of your identity, then that's going to help boost your wellbeing and help with those feelings of anxiety.

Thanks for explaining the complicated systems to us because I think a lot of people don't understand the psychological assessment and that sort of thing so hopefully it helps people feel less scared of what that actually means. It's not an assessment of you, it's more just an understanding and I think that's a lovely way of describing it.

One of the therapies that we're funding at the MND Association is a research trial which I know, Sian and Emily, you're both involved in, is Acceptance and Commitment Therapy. So, I was wondering if you could you tell us a little bit more about what that therapy is, how it works and use that lovely simpler way of explaining things that you just did there so we can all understand? It sounds really interesting.

Emily: So, Acceptance and Commitment Therapy, or ACT as we call it - it's a bit of a mouthful otherwise, is in my view, the way that I think about it and the way that I tend to explain it to people, is that the focus is on trying to find out what's most important to you and really clarifying that. So, for example, someone might say that going out for meals with friends. I think you mentioned that that's something you two used to and perhaps still do enjoy doing. But sometimes it's doing activities that are much more difficult to do now so, someone might say it's cycling. That's my passion. That's what I've always spent my free time doing. And we might not be able to help the person cycle again but what we might be able to do is think with them about what they enjoyed about that activity, what was important to them. Was it about getting together with their friends and doing that together? Was it about being outdoors? Was it about looking after themselves? And if we can understand what's really important to the person, then we can find perhaps slightly different ways of engaging with those values. It doesn't take away the loss of that particular activity but it can help people improve quality of life.

And another thing that can happen is people can become very anxious about doing activities that they enjoy or that are important to them because of MND. So, it might be, using the example of going for a meal, sometimes people feel very self-conscious about eating and the way they look

when they're eating or needing help to eat. And that can sometimes, quite understandably, mean people don't do the things they enjoy any more. And so ACT is also about helping people learn skills to interact differently with thoughts and feelings so that they still feel more able to do those things that matter and that they enjoy in spite of the difficult emotions that can come with it.

Becky: Okay. We are drawing to a close ever so slightly now, but I know Ian, you've got a question haven't you that you wanted to pose to Emily and Sian so handing the mike to you.

Ian: Yes. I was wondering what your thoughts were on this from a carers point of view. Would it be useful for carers to have some sort of similar therapy or assessment, although I'm not a big fan of the word 'therapy', again being a typical Yorkshire bloke. And I often think that the only people who really understand what we are going through is the people who are stood in the same pair of shoes as I am, caring for someone with a terminal disease. You know, what would therapy bring to the table to a carer like me.

Sian: We know that it's a real challenge to be a partner of somebody living with MND. You, yourself, are going through your own experiences of loss, of change – loss of the expected future, processing what's happening – plus also perhaps stepping into a different role. All of a sudden now you get referred to as maybe a carer and actually you're a partner or you're a husband and that might be quite jarring. We know that it's a very individual and psychologically challenging experience. When it comes to what therapy would offer, I think again it's very individual. I know for some of the family members that I've met with, it's the space. It's the space to be able to be really honest, to process those difficult emotions. Often in a family, people can be very concerned about how everybody else is doing so there are times where particularly family members might not always be open about what they're going through because they're worried about the impact of that perhaps on the children, perhaps on their partner, not wanting to burden them. And so, sometimes, that therapeutic space becomes a really important place really for people to open up, to be honest and to process that emotion, process what they're going through.

Emily's just referred to ACT, Acceptance and Commitment Therapy, and I would say I would use that as much with family members as I would do with the patients themselves. So, what's important, what matters, how do you want to live, how do you want to be? Just a day talking to family members about things like self-care, who do they want to be in this, what keeps them going, what keeps them themselves in the midst of living with MND, living alongside MND? So, I would say it has an awful lot to offer.

I think you're right Ian. Sometimes that idea of therapy can be quite jarring for people but many of the people that I work with have never stepped foot into a psychologist's room before, never have been involved in any mental health services. It's entirely new. Their only experience perhaps is watching some American drama and perhaps lying on a couch or something like that. You know, it's very different to what it's like in reality. Getting rid of some of those stereotypes really and just thinking about this being an opportunity to talk to someone, to be open with somebody and then to think about how you want to live your life. So, some people will say to me 'ooh, you know, mindfulness, that's not for me'. But actually it might be something else like Emily was saying. Connecting you with something that makes your life worthwhile, that makes you be connected to the things that you enjoy. That might be the focus of the session. But it may well be sometimes that just having that opportunity to talk to somebody, you do touch on things. Much of the work that I do with families is what needs to be talked about, what needs to be said, is there anything that you guys need to talk together about and perhaps we might use the session to all get together and go through some of that that can be difficult to talk about on your own. So that would be my answer. I don't know Emily whether you've got other things that you think would be worthwhile.

Emily: No. I think you've said it very well there Sian. I guess the one thing that I would come back to Ian was your mention of, you know, people who haven't experienced this not knowing what it's like and I completely agree and I wouldn't ever pretend to know what it's like to have a spouse, to have a family member with MND, to live with MND myself. But, saying that, I sort of think of it, there are different ways that people might be able to help and there might be different kinds of help you need at different times or different people might prefer different types of help. So, this isn't the best kind of metaphor in some ways, but I guess it's a helpful one for me for thinking about what therapy looks like, which is that if someone feels very low, very down, a bit like they've fallen in a hole and they can't get out, then there are different ways that someone might help. One would be someone might jump down in the hole and be there with them and see it from the same perspective and make the person feel less alone and you might be able to work together and problem solve and better find your way out together and that's okay and that's a valid way of helping someone or being helped and that might be the most helpful thing. But there are also other ways. One would be someone sort of standing above the hole and saying 'okay. Grab here. Grab there. Do this. Do that' and again, that might be helpful and it might help someone climb out but actually the person down in the hole might still feel quite alone and stuck. And therapy to me is trying to do something in the middle. So, it's quite helpful I think if we can use our knowledge and skills and maintain a different perspective but, if we also try to connect with where you are. So, it would be a bit like me kind of lying down on the ground and trying to stick my head and my arms as far down in this hole so that we could speak and we could see one another but you could still have your perspective and there would be things you could see and understand that I wouldn't and there would be things perhaps that I could see and understand that you wouldn't. And so together we could problem solve and find a way forward that combines both of our knowledge and understanding. So, it's not to minimise the benefits of speaking with other people who are maybe in a similar situation, but I think what psychology or therapy or other kinds of support, whatever we want to call it, can be that slightly different perspective and that kind of teamwork that can either help you find a way out or perhaps see where you are a bit differently. And sometimes its about finding ways to appreciate what it looks like from where you are now because we can't necessarily change the situation as well.

Nick: Thank you so much Sian and Emily for that insight. Really, really interesting, powerful stuff. Cath, to bring this episode to a close, is there any message you'd like to give to listeners who are either living with MND or caring for someone and struggling with their emotion at times?

Cath: Try to forget about the things you can't do any more and focus on the things you can still do. Don't suffer on your own. There is support out there from the MND, both locally and nationally. Just talk to someone. There are grants available from the MNDA for quality of life and wellbeing issues.

Becky: Yeah. Thank you so much for that. I think it's an absolutely perfect place to bring the podcast to a close. So, thanks again Cath and Ian for being so open and honest so that other people can, you know, reach out and know that it's okay to not be okay or to understand and feel like they're in a similar situation to yours but obviously very individual.

And thank you so much Emily and Sian for taking the time to come and join us today and educate us. It's been really, really interesting so thank you.

Nick: And again, if you'd like to find out more, contact your local branch or Association Visitor if you're in touch with one, take a look at the mental health section on our website or connect with others in the MND community through our online forum or call our MND Connect helpline.

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