**Interview 23**

**(person with MND)**

**I:** I'll just wait till the notification… started. Yes, I guess to start off with just generally, how did you get on with using the website?

**P:** I mean, it was pretty easy to get in, there was, there was no drama about getting it and sort of navigating around. So that was all quite easy.

**I:** OK and uhm… I know you are taking part in a research study, but typically when did you decide to log on or have a look at different sections?

**P:** Well I did it. I mean I had sort of two goes on it, so you know, I had a sort of initial look around it and sort of read it and then went back later in so I haven't been into it very often, but perhaps we can come back on to that in due course but I just really when I had time to do it.

**I:** OK. OK, I'm happy to come to discuss that now as well if you want. So did you sort of go into have a an overview of what was in the site is? Is that more how used it?

**P:** Yeah yeah. Well, I mean you know, so obviously had a good look around the first time. And then subsequently went back in later. You know, I had a sort of, I suppose, I went through all the sections. I thought it's quite useful to read some of the text from various individuals, so that was, that was useful and you know, sort of different experiences. For me, going in and looking at the support piece, the MND link and going in to where it says ‘other support.’ You know. I sort of, so one of the links in there was to the sort of, MNDA forum, which I didn't know about, and I found that. So there are bits and pieces on that. I mean, you know the various exercises as we went through, I don't where we're going to come on to those in due course, but we can talk about that. But I think the most useful thing for me in terms of the three specific areas was actually just looking at some of the comments that people were making.

**I:** Yep, that's OK. Yeah, that's absolutely fine. Should we go through each of the sections one by one, is that is that OK?

**P:** We can do that if you want, yeah.

**I:** That's OK, even if you sort of briefly looked at something, you could also tell me why you didn't look further or something like that?

**P:** I mean I guess I could sort of, give you an overview. Would that be helpful? That might put it in some context. I suppose, I mean I had a look at it. Have I ever used any of these sort of mindfulness things before? No, I haven't. So I suppose I wasn't personally tempted to sort of, explore that. I had a look at some of the exercises and I thought, ‘OK, fine, I'll just have a look at them.’ And I suppose for from my perspective it was I suppose it could have been quite generic and I didn't necessarily… apart from the quotes, I didn't need to have MND to look at or do some of the exercises. So I could have had something else and looked to those exercises, and it wouldn't have, I presume it wouldn't have made any difference, you know, I think. So that's why I said the quotes from people were interesting to read. But I think the example to use, I suppose in terms of the mindfulness etc were not MND specific, would that be fair?

**I:** Yeah, I think that's fair. And do you think something like that would have helped if it kind of brought it closer to your context and?

**P:** Well, I think the context of the quotes helped to put it in context. I mean, I suppose, you know, I suppose for me, I had a look at these things and thought, ‘do I really want to do these exercises?’ And I thought, ‘no, I don't.’ But that's just me. So I think you've got to put it in the context of, yeah, I suppose for me I would have found it probably more use to talk to somebody rather than looking at some of exercises, I think. I think I'm sort of more of a one to one session, so if I was to sort of choose to have a chat to say, let's say, a counsellor. Not that I’ve, I've never consulted a counsellor on this yet, so speak to a counsellor or go to use a website. I would’ve chosen a counsellor. So I’ve had a look at the website now, OK. And thinking about it, yeah, I suppose it's offering a different thing, so I suppose that if you wanted to look at, it would give me some guidance. So I suppose that's what I was looking for. Especially on the adapting to change one, so it was all quite, I suppose, for me it was all quite linear adapting to change. But actually I think, certainly as I am now discovering with MND, there's different phases in adapting to change 'cause it is terminal, you know. There's getting a diagnosis, 'cause well I suppose what I call normal jogging or like what I’ve have at the moment, you know.

**I:** OK not affecting you as much…

**P:** Yeah and I suppose there’s living with it, you know, obviously, you're gonna, there's, I suppose ultimately, you know you gotta be quite brutal about it, is preparing to die. So I think if I was gonna make one big suggestion on terms of improvement on that section, that would be one. Because you know when I get diagnosed about any of these things, not that I had it before, but you know you get a diagnosis and it's a bit of a shock. You know, I knew something was wrong and I had a guess I didn't know what it was. I thought it might be because I've seen something and read something. You know, so actually, in terms of. The shock factor is that you just go ‘Oh God right,’ so I suppose in many ways you could either at that stage you could either ignore it or try and find out a bit more about it. I try to find a bit more about. I read the MND handbook, I don't know if you have read that. I mean quite frankly it was horrific, It was horrific read really and I'm pretty resilient. Because you haven't a clue what's going on here and reading all this stuff and you go, ‘Oh my God’. So that's why, that really is probably, I think in many ways the most important thing, and I think that's probably when people would, might start looking at this. I think for me now, I mean I've got PMA, so it's not, it's not as fast as some people you know. So I've got time to plan and think I can, you know. Now this probably started, I got diagnosed last year just before lockdown, my sort of symptoms really started in 2018. So I've had it for a good 2 ½ years, so I know I'm lucky in the sense that I've got to plan. So I think it's a different, there's a different mentality there in terms of sort of living with it, let's call it that. And there are some people who you know, have got the bulbar version which you get diagnosed and the next thing you know you're in essence during the last phase of preparing to die. I mean, you can miss out that middle bit. And then you've got the, you know, ‘I don't know what's gonna happen but I've gotta start thinking about’ you know. I see it, you know, there's that sort of getting your mental, head around it. So I think that's quite a long explanation but I think it's, the one thing I would say is that if you have to look at it is that ‘adapting to change’ piece needs to be much more finessed round those three topics. And guiding people off to the different routes in particular, the first route, the first bit ‘finding out’ and the last bit ‘preparing to die’ are the two critical ones. The middle bit is, well, OK, fine, let's you just actually adapt to change but for me, you're adapting to physical change, mainly. You know 'cause my hands are going so you know, one stupid example is I've got my electric toothbrush, until two weeks ago it was fine, now I can't switch the damn thing on and off. So I've got to, I have to put it against its side. So it's almost, and it's a physical adaption, so you’ve just gotta get your head around that you've gotta change what you do. So there's a mental thing about changing what you do, and I think in that middle phase, but I think the first two, the first and last one, really crucial. So that's where I focus on OK?

**I:** Yeah, so that that's so almost like in the first few stages, it's getting your head round what the impact of MND potentially would be or also adjusting to it just psychologically, probably more than…

**P:** Yeah absolutely, because you know, it's not particularly painful, but it's things, things, do ache you know, we're all getting, I'm getting older and as you soon find out things hurt anyway as you get older. But it's the fact is there ain't no cure, I was only gonna get worse. So and I think from an MND perspective, you know if I had cancer there's always a chance that someone will be able to give me some radiography or cut something out and give me give me a few pills and bits and pieces, and I'll get better. But with this at the moment, there isn't, so I think there's, that's where the shock is, because… Yeah, that's where for me, reading that MNDA book was just… I don't wanna say horrific, but it's a fantastic document, don't get me wrong. But I… and I thought I was pretty resilient on most things, but I sat and read it when the family were all out and I just go ‘Oh my God,’ you know and that’s… I think you needed help really I just...

**I:** Yeah, that was a bit I was also kind of struggling with because I was wondering if early on you know how much information or. Yeah, but because of the shock, it might be almost too much, some people may just not want to...

**P:** Well, I think a lot of people don't. Yeah, 'cause obviously with lockdown I've only met one other person, but I mean it is a shock and you know, 'cause I had been in the gym in the morning and then went to the consultant and in the afternoon, and he said you got one to three years to live. So it's a... you gotta be pretty, you gotta, I don't know, you gotta be pretty resilient for it not to affect you. And so I think that's really, and everything is going around your head, so that's the point… I suppose if you are going to do an exercise and just, I suppose sort of, sit yourself down and calm yourself down and think about it. Absolutely, that's probably you know, and also perhaps pointing to people where you can get some advice and support. Now I think as things go on that you know, there is load of support as I found out whether it's NHS, MNDA, whatever. But at the beginning you're just going ‘oh my God, what's what the hell's here.’ And so if it's more a focus on just calm yourself down exercises if that's what you want to do, that's… I think that would be really important earlier on. Whereas, I think the middle bit is not such, because of course I think that's a mental thing around the physical changes that are happening. I think the preparing to die, quite frankly, everyone's going to have to do it at some stage, it’s just gonna happen a bit quicker than we planned. So, I'm just, you know, I think there's probably plenty around stuff about, you know, how to mentally get around that. Because it's something which you know, it's a bit like going to school. We're all going to experience at some at some stage in one form or another, but I think that it's that diagnosis where you know… I finish work in a week's time, you know, so there's me looking forward to retirement and now you know, really I was doing lots of walking and now of course I can walk for a couple of miles and that's it. So that's a bit that's, you know, just awful. So I think for me it's absolutely it's that diagnosis piece just, you know, calm yourself down and in fact really speaking to you now it's probably made it even clearer as well as you know, for me thinking about it before.

**I:** OK, OK. is it also more that? At the moment, 'cause you kind of developed a way of coping with things that. I guess emotionally it's not as much of a struggle right now?

**P:** But I'm pretty pragmatic, you know, I'm quite fatalistic. I've never said, personally, I've never said why me, because actually there's never any point. So I think it's probably, you're just talking to… if you're talking to me as an individual, and I can't speak for anybody else, but I can, just I can see you know, other people will have a very different reaction. And I've spoke to people who say that, ‘we won't just talk about it,’ don't think anything's gonna happen, won't do anything to get themselves prepared. And I think everyone and this is a problem, is everyone's different mentally. Every MND patient is different in terms of progress, there is no thing as such… So it is difficult for you to try and sort of pigeonhole it and that's why I sort of, thought about those three, because everyone will go through that, you just maybe that you might miss the middle bit.

**I:** Yeah, I see what you mean, but I did anticipate that would be the case as well. And if people had a look at it and felt I don't need this right now, but I might need it a bit later or something like that. Unfortunately, I can't go back in time and give it to people.

**P:** I think the exercises for me I looked through it and thought ‘right, it's not for me,’ but that's not an insult to you. It's just that's not for me, but it might. It might be, and for some people think it might be quite good. It just maybe you might be able to finesse the exercises around those stages where… I don't if there are any studies or anything into what's you know, what's best for a traumatic change, which is right where first stage? What's there to sort of get you to think about and appreciate that you need to change, which in the middle stage and then, you know, and then the third stage, well, you know, actually come on, you gotta… you know, what exercises you need to calm you down, just get yourself prepared off. I don't know, I mean again and obviously well, you know, we’re, the culture we’re in, you know nobody likes to talk about it. You know, I mean, I don't know whether you’ve got sort of, Portuguese type background?

**I:** Yes, I am.

**P:** Which Catholic you know, slightly different, you know if you go to the Indian thing you're gonna get reincarnated anyway, you know. So again, everybody with their beliefs are slightly different as well. That's just an added complication into the whole thing, isn't it?

**I:** Yeah, yeah. Which is why I tried this kind of approach, where people use it as they feel they want to and then maybe just asking people about how or what was most useful at what time?

**P:** I guess yeah, so for me it wasn't particularly useful, but I did enjoy, you know, I looked at the quotes and I thought that was really good. But I like that link into the forum I thought great, it was really useful but the exercises for me probably at my stage. I just looked at him and said yeah, ‘OK, fine, it's interesting but I really don't want to do those.’ But that's just…

**I:** That’s fine. Lots of people feel that as well. And as you say, everyone has a different way of coping, so that’s completely fine. Was this also the mindfulness exercises specifically that you were talking about?

**P:** Yeah, well I think it was just generically the overall they're not particularly, but I think it was just all the exercises I think I used it as a term just to cover the whole lot.

**I:** OK. Uhm… Do you think these similar exercises would make more sense earlier? Even for you, say, would it have appealed to you earlier, no? Or was it just not the kind of exercises for you?

**P:** Uh, I don't think they're kind of exercises for me. I may be wrong, and it may be something I sort of think about, but did have a look at, you know, I looked them, you know on both occasions I went in and I thought you, ‘do I really wanna do this?’ there was nothing there that I felt I really needed to do. I didn't feel oh, you know, it's worth half an hour of my time doing. Now's probably 'cause I'm still working full time, and I've got enough, got quite a lot to do. So if I had not been working, would that have made a difference? I don't think it would, but I'm not, I can't be 100% [sure]. Because I might have said OK, I'll… let's spend the afternoon doing one of them, but I haven't had time to do that.

**I:** That's OK. I wondered if you looked at any of the practical tips 'cause just being a really pragmatic person, I wondered if something like that appealed or..

**P:** And I did look at the tips and I sort of read all the bits and pieces that were on there. So I went through, but I think, as I said, I found the quotes most useful because that's quite interesting, really just finding out what people were saying. So whether there's… you know for me I would say that was the best bit. And you know, whether there's something you could do around that…

**I:** Sorry how were they helpful? Was it mostly to just hear other people's experiences or get ideas?

**P:** I think it’s more experiences I mean, you're looking at a fairly benign environment, so actually you're not having to quiz somebody. I say that, I can only… 'cause I've only met one other person with MND just in between the lockdowns. And that was for me, that was probably the most useful thing I've done apart from speaking to the MND nurse. But actually what you would put there was, you know, I thought, ‘OK, you know it's quite interesting’. And I also know those quotes you gave were more geared around to some of the exercises that you would do. But I did actually generally find those quite interesting. And you know, I could put it into the context for my wife as well. But actually then sitting down doing the exercise. I thought ‘no, I can't go there.’

**I:** That’s OK. This kind of support is also different. People prefer it better there, so that that's absolutely fine. I just wondered as well whether… did you have any previous experience of any other avenues of support like this or for any psychological support?

**P:** Well the only other thing I have seen before 'cause you got us to fill in a form, at the end which I think and I noticed…I did make a note of it now. Was that from the psychology department or something? I don't know who. So I have filled in something like that similar before because my father died of dementia, but I joined the probably about seven or eight years ago, the dementia study.

**I:** OK, OK..

**P:** And they got quite sophisticated, so they just asked for volunteers, and then, in essence they're going to track people through over the years. Now, when I got diagnosed, I said, ‘look, I cancelled it,’ but it was the same sort of thing. So in terms of collecting a pool of data and someone taking it away and analysing, you know when I filled that in I thought absolutely, that's what we should, you know, I can absolutely relate to that. You know, it's quite interesting, well, I think I was quite interested to see if my scores had changed. Well, I know they've changed because of obviously the physical deterioration. You know, so I would have quite liked to see, ‘oh you did this last time.’ I suppose 'cause I quite like data, so I quite like you know, it's almost gives you a measure and if you we're in denial that things were changing and actually had a little score to say this was your score last time, here's your score now. Actually, that could be useful, it might… for some people that might not be. But you can't, you know, you could almost give yourself a score on that and just to show you. So I thought I was really good, but also it doesn't mean that you're collecting data for one of your successors doing their PhD or whatever in due course, and I thought yeah, absolutely. But, so for me I actually really like doing that.

**I:** OK, OK, I could give you the score later, but I wasn't sure if everyone was interested in it.

**P:** Absolutely, I think something like that where you give people that.. I mean I would go and speak to, I don't know who's doing it now with dementia research people...

**I:** I don't know about dementia, but there's a big one about neurological different neurological conditions…

**P:** It might be part exactly well, I don't know, but I think it was [name of university]. I think it's down at [name of place] now, but I… because I thought I pulled out the study, I can't remember. But I just said ‘Oh right, this is very similar.’ So absolutely you know, if you sold me [own name] fill this in every two weeks or every month, I would fill that in for you. If you told me go and read my wellness exercises I probably wouldn’t. So I think, but if you could link something in like that because I think in many ways it does, I suppose it almost addresses that middle piece. You can say like ‘OK, I've had the shock of it. I'm now tracking the changes’ and actually that might sort of prompt you to think about more things. So you know, there is a link in too.

**I:** Yeah, almost relate the content you look at based on how you're feeling or how…

**P:** Yeah, there's a physical piece that in there, and there's a mental piece. Now I know in rare cases, MND would affect you mentally, I think it's quite small in my understanding. But in essence it's a physical deterioration and that would affect you mentally.

**I:** Yeah, yeah.

**P:** So, it's almost, I suppose you could almost take the physical deterioration as a predictor of where mentally you're going to have to get to. Which might lead into you know, how do I cope with that? how do I deal with that? OK look, you know, my legs might go, so I might be in a wheelchair, how am I gonna deal with that? You know, I know I'm gonna lose the use of my hands you know, so how am I gonna deal with that? So that's the mental by-product of a physical deterioration, and it's about like, you know it's no different to getting old and… I live with my 88 year old mother who is quite sprightly, but you know she's been moaning for ages about all sorts of things which I can relate to that now. But my deterioration, my hands are going so quick I'm now having to ask her to open the crisp packet. So, uh, so that’s a physical thing as I sort of, you know, just gotta get over asking an 88 year old to open your crisps. So I think that at that score and… well, I think as I said, I think there's research aspects into that. I think it would help mentally, just to see how you're going. And because in essence, if you have a score, I know it's crude but you can't almost deny that things are getting worse. And I personally found it quite interesting.

**I:** Yeah, I see what you're saying, but there's also just 'cause people cope differently, it’s slightly different with… We tried something similar with like a tracking, not so much of ability, but of the kinds of activities you were able to do. And I thought it would have more of an encouraging impact, but I think people saw it as I'm looking at my deterioration almost so…

**P:** Well, you are absolutely.

**I:** But that was… I guess for some people more scary than…

**P:** Yeah, I can absolutely see 'cause you don't want to say that you're getting worse, but actually, you know you are. And I say, I can't remember, I know my scores were lower because my arms over, since Christmas have got so much worse. So they might, they must be.

**I:** Yeah, it's just some people like to know the problem and then face it and deal with it..

**P:** yeah, but it's like anything I mean, you give me an exercise and I may not want to do the exercise. But you could give people an option to say, you know, here's an option if you want to sort of just track how you are. So don't, I think I suppose I'm saying is don’t pander to the people that don’t want to, but give people an option, ‘here you are, you know this might, you might find this useful.’ You might find it, might be useful to sort of share with your partner or family and say ‘look, this is where it’s… this is how it's going, this is where I was, is where I am,’ you know. So… and what that might do is prompt people to actually, who are in denial to think, ‘right, I've got to do something about it.’ Again, I think, I don't know, I mean, you probably interview lots of people, but I'm relatively practical about it and pretty pragmatic. I'll try and plan ahead. I've been trying to plan ahead to try and make it as easier, as easy as possible for me and the rest of my family later on so… My views, I don't know 'cause I don't really know anybody else in the same position, but for me, bring on, you know, give me a form to fill in a survey.

**I:** Yeah, knowing that and planning that would almost bring a sense of relief. And yeah.

**P:** Yeah I can… I think it just puts it... I know it would be a crude score, but at least it would just give you a feel for where you are. You know 'cause you know it ain't gonna, you know, unless they find something which can sort of block it, you know, you're on a slope and you just gonna keep rolling downhill. So, you know, there's nothing… unless there’s a piece of medical stuff that comes in and stops you. You’re not going to go any faster, not like snow, you know, snowball where you sort of keeps getting faster, you're on your trajectory and that's it. So yeah, for me it might be worth I don't know..

**I:** I agree though having options for people makes sense and it's good to sort of understand why it works well for some people, and it doesn't for others.

**P:** It won’t work for some people I actually agree with you...

**I:** And I've heard other people say similar things as you’ve said, so it's just about making sure both groups I guess get the right support too..

**P:** That’s it. I mean we’re all individuals, everyone is different and different things will hit different people. And I'm sure you've spoken to people who say, ‘well, that's really useful’ point to that exercise, and now it's giving me a, you know, I've gone off and done that, it's been really useful. I absolutely can see that.

**I:** That’s fair. Although we haven't sort of gone through each section really, I feel like I've got an overview of which bits of the website you liked or didn't like and how it could potentially be modified. I don't know if was there anything else you wanted to add in terms any other feedback?

**P:** I'm just looking, I mean I think I’ve probably overtaken all your questions, I'm sorry. You’re gonna have to unpick all this later on. No, but I think that was it really. I spoke, you know, I suppose in conclusion, for me I've just written down here, I think there's a difference between the sort of mental and physical, but the physical will impact on the mental. And in those three phases each bit becomes more important, or less important. I think that would be my sort of overall thing and give me a survey anytime.

**I:** (laughs) No problem, I can do that easily.

**P:** (laughs) But would this be linked in through the MND Association website?

**I:** Yeah, potentially. I'll just stop the recording and I'll still be on the call