**Interview 2**

**(person with MND)**

I: It should say it's recording? Ah yeah there it is.

P: Yeah, yeah.

I: ah okay. Uhm, so yeah, I guess I wanted to just start off by asking you how you got on with using the website?

P: Yeah, yeah fine. I mean, I'm used to sort of, the Internet and so I found it quite easy to use. You know we're clicking on the links and going to various pages, so yeah, it wasn't an issue for me at all, so I found it very easy to use.

I: Okay. And when would you typically decide to say log on? And look at this content?

P: It's usually been in the evenings because I'm working at the moment. So I'm working Monday to Friday, so it's either in the evenings or at the weekends.

I: Okay, okay and was it, was it sort of when you were experiencing any difficulties emotionally or more generally?

P: Not initially. When you first sent the link, I went straight on and I went through it all. But then I have dipped in and out because I have had a few blips over the last two or three weeks, and I've found it beneficial going in and just listening and reading. Just to get my thoughts back to how they should be, I suppose. But, but yeah, I mean when, say when I first logged on and I went through it all, I sort of made notes. And since then I've just been dipping in and out, and going on to various sections and, and just trying them out really.

I: Okay, okay. So it's almost like initially just to get an idea of what they are, yeah.

P: Yes.

I: Okay, I'm really interested to hear about like when there were particular blips you were saying that happened, and what um, what you looked at during that time? If you don’t mind sharing that.

P: In this week I've been on there because I’ve had a couple of falls this week. And that’s made me really sad. So I've been on and I've just listened to the audio. And just to try and relax and, you know, get my thoughts together, 'cause you do think you know, what's the point in going on. But I know things are going to change, and but, sometimes it's just little things that trigger it and you, you know, you think you know ‘I've actually got MND’. And I think it's just sinking in, because I was only diagnosed in August. And, I suppose that as time goes on, things are changing, you feel angry. So that's why I've been onto the website just to, I think just to try and get my head together, really. And that has helped, it has helped. Because that is the problem at the moment because everything is virtual. You haven't got anybody there to sort of talk to, that you can't join any groups you know and talk about each other's problems, and so it has been harder. But say going on to the website and just going through little bits and reading what people other people have said and it has helped. It has helped without a doubt.

I: Okay.

P: Because I feel I have got that connection there.

I: I'm glad. Is that the experiences of other people that were helpful?

P: Yes.

I: And some of the mindfulness exercises?

P: Yeah, yeah.

I: Do you remember which specific ones you looked at by any chance?

P: What did I go on?

I: If you describe them, I can, probably…

P: Yeah. I mean the one where the man's talking on the audio. I find that very soothing. And then I've been also on to the body scan.

I: Ah yes, okay.

P: I listened to the body scan, so yeah, they’re the things I keep going to I think at the moment. And say listening to them talk, I find quite soothing and relaxing.

I: Okay. Um I’m Interested in the body scan bit as well. Do you feel like it's kind of appropriate or relevant to MND as well?

P: Yeah, well yeah. I mean it probably be relevant to lots of illnesses I guess, but yeah. I think with the body scan you’re sort of closing your eyes and you're, you're thinking about everything. And I mean, when I initially went on I was thinking ‘well this arm’s not working that leg’s not working’. But now I've got to the stage where I listen to it and feel more positive I think, so.

I: Yeah, yeah that that was a bit I was worried about it as well. 'Cause sometimes, if you're thinking about your body may think about what's not…

P: What’s not working.

I: Yeah okay, but um okay. So the instruction, how did you kind of move from that to, just accepting?

P: I think the more I listen to it. And I think with when you're sitting in the quiet with your eyes closed. You're not thinking about anything else at the time while you're listening to that voice.

I: Okay.

P: So you your minds not as active. I don't think, or it probably is, but it's you're listening to somebody talking. And you forget about everything else.

I: Okay. That's good. And I guess. Sort of linked to that, but how did you, how did you choose which sections to look at, or which ones not to look at?

P: I think initially because I went on everything, I then went back, and I mean I've been going on everything now even now, just to sort of get used to it. But it was the audio that has drawn me in now. More so, I'd say because you're listening to somebody talking. I say I do still go in and out and you know, click on everything and, but yeah, I'll say I tend to focus more on the audio now.

I: Okay, okay. So those audio exercises were useful?

P: Yeah, yeah.

I: Um. I guess, I’ve asked you that question, sorry, I'm just looking at my list. Um, why don't we go through some of the bits actually, so I know more specifically. Um, yeah, I’ll go through different sections of the… the website, and you tell me if you used them, or if you didn't use them accordingly.

P: Yeah.

I: There was the ‘positivity’ section. I think it had an activity about positive thinking and trying to do more pleasant activities and that sort of thing.

P: Yeah, yeah.

I: How did you find that section?

P: Yeah, I mean. It all, it all makes sense really, you know. To try and find the positives in what's happening. So that was, you know, I did read that several times because obviously there are times when you think everything is negative and so I have been going on that and thinking about ways that I could improve my positivity.

I: Okay.

P: But it's, it's obviously some days you can go and you don't have any blips. Other days, it's just little things and you know, but the positivity, yeah, I can see what I'm supposed to be doing. But it's whether I can actually put it into practice.

I: Yes.

P: But I think the more I read it and the more I accept that what I've got and, and sort of try and make the most of you know, what I've got left obviously. But, but yeah, it it's sometimes it's hard to be positive, but it does help to say, you know, go through the website and…

I: Yeah was it was harder on days when there was something going wrong?

P: Yeah.

I: yeah, okay.

P: ‘Cause you couldn't really find the positives, I think some days. But I think the more you accept the problem. I think you know it's nice to go in and out and think well, yeah, maybe that's how I should be thinking.

I: Okay. I was just going to ask you about that as well. Like the level of instruction. I guess does it sort of allow you to think of ones for yourself as well. Or do you think it needs a bit more examples or something?

P: I don't really think it does, no, I mean. Say I found it helpful reading the pieces that other people had commented on. You know the what, the how they felt and… so you know, I don't think you want to overload people, do you? So you know, I think if you, if you read it as it is, now, to me, that's enough.

I: Okay, okay. So it's more maybe about either repeating it or…

P: yeah, yeah.

I: Yeah, going back and looking at it.

P: Yeah, yeah.

I: I see. Um, okay, if we move to the other section ‘adjusting to changes’ so that had: anger, sadness, frustration. Um, and then each of them had either an activity or quotes or practical tips.

P: Yeah, yeah.

I: Did you tend to use the activities or the…?

P: I did yeah.

I: Okay.

P: So yeah I've tried everything as much as I can. But yeah, I mean, I've obviously looked at anger, sadness, and the frustration because you know, when there are things that you can't do anymore and so it makes you focus more. I think if you read, yeah, this is how I should be behaving maybe. So, yeah, I mean it has helped. And it's just given me another focus really.

I: Okay. Focus in terms of like how to manage?

P: Yeah. How to deal with angry thoughts and frustration and, and the sadness.

I: Did you try the thought distancing exercise?

P: Yes I did. I think I did that right at the beginning.

I: Okay, and how did you feel about that one?

P: I think I did it two or three times just to get my head round. But, but I haven't been back on that. I don't think now say I have tended to focus more on the audio.

I: Okay, and did you also look at the practical tips?

P: Yeah, I mean I say I have looked at everything and sort of tried to think positively and you know, practicing your breathing and…

I: You found the mindfulness more helpful?

P: Yeah, yeah. Yes, definitely.

I: Yeah um, I also saw you looked at some of the, ‘self kindness’ stuff.

P: Yeah.

I: Yeah, I love to hear your feedback, not a lot of people have tried some of those techniques.

P: Yeah. That I suppose I found harder. Because you, I don't think you ever treat yourself well, have a look at yourself with kindness do you and think about it? You think about doing it to other people, don't you? So that was probably harder to get my head around, although once I’d sort of gone through it and I thought ‘well yeah, maybe I shouldn't beat myself up. You know, it's maybe I should treat myself with a bit of kindness’ and but yeah, I did. In fact I listened to that this morning. I read that this morning so, just to get, you know, get my mind back up to where we were going. So yeah I've been on there this morning and yeah. I mean I can relate it, you know, thinking about your friends and your family and so, yeah. I say I've done that this morning so.

I: Yeah, I mean it's more of a reminder, really. Just…

P: Yeah.

I: Yeah, we, it's something we sort of know, but…

P: we don't do.

I: Yeah yeah, but do you feel like the way it was framed or pitched as well, was it relevant to your experience of being diagnosed with MND and things?

P: Yeah, I mean, I guess before I sort of looked at it, I hadn't thought about it. I hadn't thought about it you know, being kind to me. Until I thought, well, yeah, maybe I should you know? Not beat myself up because I can't do things and you know, so. So yeah, after I sort of thought about it. And I thought, yeah, I can see that yeah, I'm kind to my friends and my family. But you never think about it for yourself so but yeah. So the more you read it and go into it you think, well, yeah, ‘why shouldn't I be more kind to myself?’ You know it's not my fault that I've got it, you know so. But yeah, it is something you say you just don't think about.

I: Yeah.

P: Until somebody puts that thought in your head.

I: Yeah, yeah. And then you think about it's like...

P: Yeah, yeah.

I: Um, okay. I think there was also the anxiety and the stress section, but I think that also in a way linked to a couple of the mindfulness exercises.

P: Yeah, yeah, it did yeah, yeah.

I: Just so I know as well, so initially you went through the sections and then did you use the kind of all activities and just jump to whichever ones you felt was useful?

P: Yes, yeah. So I have been through them all over the time I've had access to the website and just tried them all out really and you know. Because I'm the sort of person that will look for information to help me really and I'll research that and I'll research it to the, you know, till the cows come home and so it's nice to go to a website. And find hints and tips and ways of dealing with the issues, which I haven't found on the MNDA website.

I: Yeah yeah. I think there's some information about coping.

P: Yeah.

I: But it's not like..

P: It's not focused on you as a person really, is it? It's you know, your website is focused around me and what I need and what I feel is going to help me.

I: Okay, you haven't found any other similar things?

P: No, no. I mean, I've got, joined groups on Facebook and... But again, if the people are giving you tips on what you could do, where to go to find information and things like that, but, but yours is the only one that contains everything as a whole, you know that will help me. And my partner. I mean, he's read through it too.

I: Okay, okay.

P: So because obviously it's hard for him. Probably helping with it, as you know, as I am coping with it. So he's looked at it as well, so great together.

I: Would it typically be both of you looking at it separately or looking at a section…?

P: First couple of times we both sat and did it together, but then he's been on it. And, and vice versa so…

I: Oh right.

P: When he's watching football on the TV, I've come and sat at the computer and you know, and likewise when I've been watching something that he doesn't wanna watch. He'll come up and, and go through it. And he's picked up things I think as well, that'll help me and help him I think.

I: Okay. Can you give me some examples?

P: I think coping, because he's feels angry I think, a lot of the time, because it's happened and so I think he's now of the mind that yeah, it's not our fault, it's just one of those things and this is how I've got get over it. Um and I think, for him, I suppose it's difficult for him because he's not in my position, but when we sat and looked at it together, he was saying ‘well, yeah, maybe you should do that. Maybe you should think about yourself. Maybe you should take some time and you know, take stock’ and you know so. But yeah, I mean I think he's found it useful as well.

I: Okay, okay. Yeah, 'cause I wasn't sure whether it had information that was useful even for a family member but at the same time I didn't want to leave people out because actually you’re going through this together in a way.

P: Yeah, that’s right. Yeah, yeah. So yeah. I mean with say we both looked at it and picked up on bits and…

I: Okay.

P: Well, you know maybe we should be doing that and not sort of say looking, focusing on the negatives. So yeah, we've both been sort of going on there and just having a look around.

I: Glad. I guess linked to that as well, the other support section, which sort of points you to other resources. How, what did you think about that? Was that information you sort of already knew what…?

P: Yeah, most of it I'd already got so, but I mean it is useful you know, to have everything in one place really, so you know it was, it was good.

I: Okay. I think. Was there anything that you would have liked to see that maybe we didn't cover? Any topics or…?

P: I don't really think so, no, no. Not from my point of view anyway.

I: Okay. And I guess, now, how do you feel about dealing with emotions and those sorts of difficulties?

P: I think I probably, I'm more positive I guess, and know I have ways of, you know, when I do have bad days. Say I’ll go and listen to the body scan or any of the audio, because I can just close my eyes and listen and just refocus I think.

I: Okay. And in terms of things that you might, was there anything that you feel you might use even in the future? Beyond this research study?

P: Um, definitely the mindfulness. And I mean, it would be nice just to I mean, because I presume, is it going to change at all or? Depends on what your research finds I guess.

I: Yeah, I guess it's, I don't know yet how it will change. Depends on feedback that people give. But it's likely to in its approach be the same.

P: Yeah.

I: Yeah, so I guess a mindfulness exercise wouldn't change, but maybe how it's presented or trying to make it easier for people to use that sort of thing.

P: Yeah, yeah. I mean, I did find it easy to use and to navigate around. So and you know, it was clearly everything was clearly signposted, and so you know from my point of view anyway, I found it excellent to be fair.

I: And I guess from, well using this now with Covid and restrictions and all of that, and I realise that some of the suggestions would, especially practical tips and things like that, would be difficult to do. Did you find anything, just difficult within this situation?

P: No, I don't think so. I mean, I'm really I'm a keen gardener. (coughs), excuse me. So, um I’ve sort of just sat, just on the patio, really, and just, just looked at the garden. And I mean we obviously haven't been out for walks, so I, I mean I had my wheelchair delivered yesterday, so I mean we have got it. I've got a little buggy so we go out for a walk if it's nice, you know. But it’s, it’s finding the time to do that I think and the right, because there's a lot of places you can't go.

I: Yeah.

P: So we ended up just, you know, taking the buggy and walking into town, and because we weren’t really supposed to be leaving home. So it's, it's been hard, but no.

I: Okay, you’ve been shielding?

P: Yeah, yeah.

I: I see. Okay, yeah, so in that instance some of the suggestions may not have been easy to do.

P: Yeah, I mean I say, you know we have gone out and just sort of just for some fresh air really and 'cause you saw, I mean I'm cooped up in an office all day for five days a week and then you come home and you can't go out so. It's been quite hard. But say I, I've got my garden so, which I've got a little wheelie thing now that I can now go out in the garden, perhaps potter, and do little bits. ‘Cause that’s what, I mean I know I’m the sort of person that I used to be out there from the first thing in the morning, until last thing at night. And so you know the time just, you know, just, it just goes. So I mean, it's harder now, obviously I can't go out there and do what I used to do, but I do find it therapeutic so.

I: Yeah. And that option is there even with the restrictions.

P: Yeah, yeah.

I: Yeah, I see. Yeah, I guess that was most of my questions really. I think is there any other bit of the website that we haven’t spoken about that you either looked at and…?

P: No, I say don't think so. 'Cause as a whole, I found it really beneficial, so and say you know the, the STOP was another thing I made a note of, of ‘stop take a take a breath, observe and put some perspective and proceed’, that I've got that written on my notepad.

I: Okay. Can I just ask again for an example maybe? Or how you tried this out in like a real life situation?

P: I think one was. I had a fall, and your immediate reaction is ‘God how am I gonna get out of this?’. Because once I go down, I can't get up. And I really used to, I mean, most of the time I'm pretty sensible, but there are times when you try and do things like you used to do, which I can't do anymore so. Oh my, I fell on Sunday actually and and I just, my husband, sort of come running in. And I said ‘right you just gotta stop now because I need to get my head together before we start trying to start to get me up’. So I stopped. Took a few minutes to sort of collect my thoughts and then progressed to ‘help him to help me up’. But it, it sort of made sense because you know, say I stopped, I thought about it, looked to the problem. ‘Cause the trouble is my husband's one of these where, he panics a bit.

I: Yeah.

P: So I think when I sort of said ‘right, we need to take stock now of what I've done. I've gotta think about how we're gonna get me up’. And, and, you know, make a decision. This is how we're gonna do it. That is the time I think when I am stopping, rather than sort of falling and or doing something stupid and know you sort of swear and things. But now I find myself stopping and taking a breath.

I: Okay.

P: And thinking about what I should be doing now. So because you do, I mean it is hard, you, you’re so used to doing things the same for years and years and you do one little thing and you think ‘well that was stupid’. But, so this has been good for me to stop, take a breath, think of the problem and how we're going to get over it. So you know, that to me as I say I've got that written on my pad.

I: That's pretty good.

P: Yeah.

I: Yeah, we typically have, the answer is already in us, it's just…

P: Yeah. You have to stop… (voices overlap).

I: …take a break and take a step back from it.

P: Yeah yeah, so my husband is one of these who will just rush in and not think about the consequences of trying to yank me up and he just panics and but you know, it's just. And I think that would benefit him to be fair.

I: Okay.

P: He needs to stop. Take a breath. Think about it. And then we go on to do what we need to do that. So I think I might put that on his notepad as well.

I: Can I just ask then, so having looked at the website and you came across this technique and you read it, did you sort of decide to maybe, I don't know process or practice it at that point or…

P: No, no.

I: … it just happened in this situation?

P: Yeah, yeah. So the more I went on to the website and sort of everything, sort of sunk in. And I thought, well, yeah, you know so I made these notes and. That I think to me has been really good, the stop, and it's easy to remember as well, isn't it, so.

I: That's good. Where there any other techniques that either you disliked or you skipped over because you thought it wasn't useful for your situation?

P: No. I say the body scan I find quite good. Which you know, the lady talking on there, it is just so relaxing and it makes you think and so that one is one of my favourite pieces I think on there.

I: okay and yeah, and those typically would be whenever you open the website.

P: Yeah, yeah.

I: Did you also, I wondered how easy it was to use, did you try different devices and things like that?

P: I've only done it on the PC. So I’ve not tried it on my phone to be fair.

I: No that it's just based on convenience, really sometimes.

P: Yeah.

I: Some people like it with them, but some people like to have it in a set place.

P: Yeah, yeah. But no I've just sat on the PC and say I mean I've got most things on my phone, but I must admit I didn't think about putting that on my phone, so.

I: I don’t actually know how it looks on a phone to be fair.

P: No, I might try that actually and see if it's any different. I mean, it's easy on here, isn't it? When you're on a PC, you, you've got the full page and it's nice and big and yeah.

I: That's true. It might be a bit squeezed together on a phone.

P: Yeah, yeah, probably won't be so easy. I mean obviously perhaps for people that are used to using their phone for everything, but I'm one of the old-fashioned people and I use my phone to sort of make calls and texts and use the PC for most other things so. But yeah.

I: Yeah that that's fine, as long as it's been good. Um, was there anything else you wanted to mention or no?

P: I don't think so. No, I don't think there was. I mean, I was happy with it. More than happy with it so.

I: Okay, I can stop the recording, but I’ll still be on the call.

P: Okay.