**Interview 8**

**(person with MND)**

**Interviewer:** Notification thing yes it started. Yeah? OK sorry about that. Yeah, how did you get on with the website?

**Respondent:** I found it very easy to use, very user friendly, so I think even if you're not really up to date with various computer programs and websites, you will still be able to access it. I found it very easy to use.

**Interviewer:** OK, I'm glad. Uh, would you, would you count yourself as someone who's not as familiar with technology? Or do you use websites like this quite often?

**Respondent:** I do use the internet and websites quite often. But, for me, because it was so simple, I would imagine people that don't use websites too much will easily be able to use this.

**Interviewer:** OK, OK, that's good. Um, I guess, I know you were taking part in a research study and that's why you had a look at different sections as well. But when you were using it, when did you typically log on to the website and use it?

**Respondent:** I didn't have a specific time or… if I was… For me, I found the part for frustration fitted me because that's my problem. I get quite frustrated because I've always been a very independent woman. So now for me, its frustration, that’s the parts of the website that I accessed the most. I did go through the whole website to make sure I wasn't missing anything and I know there was the depression, the sadness and the frustration. But for me it was the frustration that I accessed even though I did go through the whole website. I found the others for me, weren’t relevant so I just stuck with the frustration section of the website.

**Interviewer:** OK, OK. And did you typically look at it, say when you were struggling with frustration or maybe more in your spare time?

**Respondent:** In my spare time. So, I think it's something you need to use. So that… when you don't want to throw something out the room because you can't open it and instead of being… stopping and saying to my husband please open this for me. Instead of wanting to throw it, you think then “No. Alright, calm down. Just ask for help.” So as I say that was the one I found the most helpful.

**Interviewer:** OK, let's talk about that section then, since it's the one you used quite a lot. Did you find the information or the practical tips helpful?

**Respondent:** I found the practical tips helpful. They, you know, when you listen to someone and there was nice pictures and they were talking you through being calm, try and do various tasks, I found that helpful.

**Interviewer:** OK. So you listened to the audio as well...

**Respondent:** I tended to sit with the audio one, sit back and just listen with my eyes closed and go through it that way.

**Interviewer:** OK. And how did that help with dealing with frustration?

**Respondent**: It helped quite a bit because as I say, watching it and doing it quite a few times. I don't have to be frustrated to sit down and think and go to the website to help. It is quite relaxing to do whether you’re just sat for five minutes, you have nothing to do, or you were feeling frustrated. So I didn't access it all the time when I was feeling frustrated because I've done it quite a bit. I can actually sit here and think right just have five minutes, calm down, do it that way.

**Interviewer:** OK, OK, so it was almost like you did it in in your spare time when you were calmer and then you had that in your mind, when you were frustrated…

**Respondent:** Yeah, yeah

**Interviewer:** OK that's good to know.

**Respondent:** I think it is quite good for that, because there's sometimes, I think if you were frustrated or upset to then start and get your iPad out or your phone or whatever you access it through. You don't always feel like it at that moment in time. So I found it all therapeutic to do it in my spare time and then if upset at some points in the day, I have just sat and remembered what was on the audio.

**Interviewer:** Ah ok. Is that the compassion break one? I think it was about taking a break and…

**Respondent:** Yeah, yeah, yeah, it’s…

**Interviewer:** Sorry, no continue…

**Respondent:** It is good.

**Interviewer:** Did you use any of the similar techniques like that? 'cause there were a couple of other mindfulness?

**Respondent:** Yes, I went through those in that frustration section and did those. And as I said, I found it for me, more helpful to do it when you have nothing to say, I'm not, I don't go out so to say I'm very busy, I'm not. But when you've just got 10 minutes spare, I would sit down and go through that section and do the mindfulness.

**Interviewer:** Yeah. Uhm, I guess, I want to know as well did you find those sorts of audio is easy or difficult to do? I ask mainly because sometimes with MND, you know you may have either certain physical difficulties that might get in your way, or certain worries…I just wondered whether you found it easy or difficult to do those kinds of mindfulness exercises.

**Respondent:** I found them easy and valuable. I took them in with me (gestured to her head) each time I did it so I don't have to access the program on my iPad. I could just sit and think so yeah, be mindful.

**Interviewer:** Ok, so you kind of adapted it. I wondered if you used one of the exercises called the body scan which said pay attention to different parts of the body and was that also OK to do?

**Respondent:** All those. Yes yes, as I say I've found it helpful and easy to do.

**Interviewer:** And you could do that despite any physical symptoms or anything like that?

**Respondent:** Yes, I just sat where I am now or in bed and did them so, easy enough to do.

**Interviewer:** OK. OK, so that was the frustration section I guess and, anger and sadness you looked up, but you didn't really use them…

**Respondent:** Yes. Sorry I didn't use them because I tend to be quite an upbeat person, I don’t tend to… well, I don't get depressed. I have no idea what depression is like. I’m very lucky in that respect and I tend to be quite… somebody that is positive. When I was told that I got MND, and the time span is up to 10 years. I went. “Oh no, I'm gonna live way past 10 years. I'll prove you, well, wrong” and that was nine years ago. So I am quite a positive person. I've just…I'll tell you a little tale. I've started talking to a lady that has MND. And she is finding it hard to cope with, so we're being sort of trying to be positive with her and helping her. This study how long will it be before other the MND patients can access it? 'cause I think this would be good for her because she’s finding it very hard to cope. Because she's very emotional and I thought this would be quite good for that lady.

**Interviewer:** Well, the thing is, is for things like this to be actually implemented does take a bit of time. Once all the research finishes and all of that, but I can still give you see a link to a version of the website or something so she cannot look at in the meantime. Or even if she wants to take part in the study, that's also that's also a possibility. So it will take some time to come into like normal practice. But you know, while the study is going on, I'm more than happy for her to have a look at it.

**Respondent:** So if I give her, call her [name of person] that's all I'll say, and I will pass your details to her about this today and see if she wants to do it.

**Interviewer:** Yeah, I can, since I have your email address as well I can send you a little bit of information if you want then you can just send that across to her.

**Respondent:** Right. Thank you.

**Interviewer:** That's OK. I guess that links quite nicely onto the section on positivity. I guess being a quite a positive person as well, how did you find that section?

[door bell rings]

**Respondent:** [looks confused]

**Interviewer:** Should I tell you what's in the section?

**Respondent:** Yeah

**Interviewer:** It's uh, it had a little bit about doing pleasant activities, values and goals and also thinking positively, so think of the positive things as well that are happening…

**Respondent:** Yes, well, as I say I did look at that, but I felt for me it wasn't as relevant as the other section, because I do try to find the positive in things. It's like when I say to people that I've gotten MND, and then I say, but I'm lucky and they go. “What do you mean you're lucky?” And I'll say “because I've got PLS,” which is the rarest form, but it progresses slowly. And I know a girl I went to school with she got ALS and died within a month so to me, I'm lucky. I see that as a positive, even though I’ve got MND, the form I’ve got, I’m lucky to have that form. I do. I'm not somebody that ever goes, “Why me? Why have I got him MND? What have I done to deserve this?” That's not me. I just crack on with it. Even if I said to somebody “why me? What have I done?” I’ve still got MMD, so I might as well just crack on with it, try and cope with life as I can. The longer I go the better.

**Interviewer:** Yeah, yeah, that's a similar thing we were trying to do in some of those sections where it said, do still do things you like and enjoy. And it just means finding a new way or a different way to do the same thing. Do you find you already do things like that?

**Respondent:** Yes I do, I try. I like gardening and I still… my husband will sit me down outside and bring everything to me so that I can still plant up planters and hanging baskets but everything is brought to me. Likewise baking, I do a lot of baking with my 2 great nephews and my niece because they love baking. And when, before I had MND I always baked so now I sit down to the table, kitchen table. The children will sit with me and my husband brings everything to me, the mixing bowls the ingredients, so I still do that. Yes, it is hard and I feel exhausted sometimes when I've done it, but I'm still doing it and it’s memories for the children. I do, I used to do a lot of exercise. When I was diagnosed [name of professor/neurologist] in [name of place] asked me to carry on with my exercise and I used to go to the local gym three times a week, obviously do exercise adapted to me. I certainly couldn’t go on the treadmill or lift weights but I do things that's adapted to me. The trainer is there, we’ll do things adapted to me, to my ability. But since lock down, I haven’t been able to go, so I actually have a static bike and I go on there. It takes a lot, of getting on and getting off you know, but I still manage to do it.

**Interviewer:** OK, that was actually going to be my next question because with Covid and restrictions and things like that have you still managed to do these sorts of activities to keep you happy and positive?

**Respondent:** I have yes, as I said about the gardening. Because last summer and I was doing pots and one of my neighbours saw me and she said, “oh, you were an inspiration.” I said “why, I'm just sat down.” She said “no, but because of what you've got,” I said, “well, I don't just want to sit in the house and wither away, that’s not me”. I have… obviously me and my husband haven’t been able to go anywhere. We’ve had our second Covid injection two weeks ago, so I am hoping next week we’ll be covered and we're going to go for a little ride down, just sitting in the car. You can’t just sit in, I will not, I'm not that kind of person, I'm not just sitting down and waiting to die. Some people may do, but that's not me. I've never been that kind of person.

**Interviewer:** Yeah, I mean this is not related to the website, but just so that I can learn from you as well. Are there any other things you do to keep this positive attitude?

**Respondent:** I have done in the past listened in bed to wellness tapes with my little headset. I have listened to some Wellness tapes. And as I've already said I’ve found on your section of your CALM study I've have used those quite a bit. Other than that I don't use anything.

**Interviewer:** OK, so similar kinds of I guess mindfulness, yes there are a lot of there as well. So that is with the positivity section. I wondered if you used the… there was one bit on anxiety and worry or feeling stressed. Did you have a look at that?

**Respondent:** I did, yes. But I don't tend to get stressed. The only…this sounds silly, but the only thing that's like stresses me about going out is accessing toilets. You know, like disabled facilities, yeah, but it's not to the point where I won't go out. But sometimes I do think oh yes, they've got a good disabled facility. We have a shopping complexes like an outlet, not too far about 10 miles away, and I like to go there because they have a lovely big…Excuse me, they have a lovely big one of those bathrooms that's got the hoist on the table. But as I say that it doesn't stop me going out, but sometimes you do think yeah, well have they got a bathroom I can access.

**Interviewer:** Yeah, it's just one more obstacle…

**Respondent:** I don’t have a problem with anxiety and depression, thankfully. If I was anxious about anything, it would be about accessing bathrooms and getting there in time.

**Interviewer:** OK, OK, that's fair enough.There was one exercise I think itwas called thought distancing.You may have not looked at it,that's OK, but I just thought I'd check.It's about putting some distance between a negative thought and yourself**.** So just taking a step back andgetting some perspective did you..

**Respondent:** I did look at them because, as I've already said, I did go through the whole study but I've found for me the frustration more relevant. So, things like that, I’ve been anxious and 'cause I know there was a section on anxiety. So I didn't I did look through them and went through everything. I listened to people's stories on different sections. So they go through the whole study. For me, the first time I listened to where everything's I sort of worked out what was for me and what wasn't.

**Interviewer:** OK, OK, yeah, so you sort of had a look at everything first then jumped into specific technique.

**Respondent** yes. Yeah.

**Interviewer:** OK, that's good to know, was that process fairly easy to find and all of that?

**Respondent:** It was yes, which is my, I think for the lady I’ve started talking to, I think this study might be gone for her because at the moment she's very emotional, very anxious. She'll go out first thing in the morning because she doesn't want people asking about her MND. So when I was made the appointment to speak to you I thought this would be quite relevant.

**Interviewer:** Yeah, yeah, no I’m happy to share that.

**Respondent:** I did Look through every section at first, but as I've said I knew what would be for me and what wouldn't and the distancing, I didn't think I listened to it and went away, but I thought no, this isn't for me so that's fine.

**Interviewer:** Yeah, that that's completely fine. I just thought I'd ask just that I'm not missing out anything. Umm but did you, did you think that there was some areas that either you've struggled with that we haven't covered, some information you would have liked maybe?

**Respondent:** For me I thought, only for me I thought more mindfulness exercises, different ones. The ones that were there where good and I have access them a few times. But for me, different mindfulness would have been good.

**Interviewer:** OK, OK. I'm just making a note of that. Uhm having a look through my questions uhm yeah, so even in terms of like any advice or techniques that you might use in the future from this website, you said the mindfulness was particularly.

**Respondent:** Yeah, yeah.

**Interviewer:** Uhm I guess you've kind of answered this throughout different questions, but has anything changed for you and how you deal with emotions since looking through the website?

**Respondent:** Uh. Well, as I've said the mindfulness I do it was quite a bit and laying in bed I’ll just sort of put my head back when I’m sat up in bed and just go through different parts of the mindfulness. For me that's the most relevant.

**Interviewer:** Yeah and that's helped you deal with frustrations...

**Respondent:** Because I've accessed it quite a few times, I can actually see without the program and sort of go through it.

**Interviewer:** OK, OK, just follow the steps basically. Well, that's good to know. I think I have actually one more question really, because you said you had PLS for some time now. Do you feel something like this is, I know you mentioned it's useful for you now, but if you could think back as well, do you think something like this may have also been useful closer to diagnosis or?

**Respondent:** Yes, definitely yes. Because like this lady I'm telling you about, she's not long since been diagnosed and for her, as for all of us, it's very stressful. You go from being up it down here to down here. Yeah, I do think it would have been good start of the process to access something like this.

**Interviewer:** OK, OK, so it's good at the start, but it's also useful later, so I guess yes.

**Respondent:** yeah, I will keep it all the way through. Sometimes you forget about things you don't access them. A person may think, oh, I've got that I can do that to help. So I will keep on using it.

**Interviewer:** OK, OK. I think that's most of my questions, I don't know if there was any other aspect that we haven't covered uhm.

**Respondent:** No, I don't think so. As I said, the only thing I was asking was when will this study become live for everyone to access?

**Interviewer:** Yeah, I can tell you a bit more about that. I'll is it OK if I stop the recording first? I'll still be on the call and talk to you about it.

**Respondent:** Yeah.