**Interview 17**

**(person with MND)**

**I:** It'll just be like a normal conversation.

**P:** Okay.

**I:** Yeah, I think it's just started recording. So I guess just to start off, could you tell me how you got on with using the website and how did you find it?

**P:** I found the website, it easy to use, yes. No, no problem using it no. And you know, it's difficult the, obviously, like everybody I have negative thoughts and feel quite, you know, a bit frightened at times. I mean, I think that was one of the things that you said and you know, frightened of things and uh… I mean the website was sort of leading you to ways of distracting yourself from these negative thoughts and everything. I mean, that's basically what we tend to do anyway. I suppose yes, and it just reemphasizes some of the things you do. I mean you keep busy, don’t you? You try and keep busy, you try and, I mean, I play a lot of chess on the computer, you know, opponents all over the world on a chess site, an international chess site. And that keeps me occupied for probably a couple of hours a day doing that. And I’d say I've got still got my… I'm still working effectively, but very little. You know, I sort of think about 10 hours a month really, it is that I'm contracted to do. And you know, I do that and keep my hand into my old job. And I read a lot and you know, things like that to distract, yes. It would be nice if we had some better weather.

**I:** Yeah yeah.

**P:** I was looking forward to the summer. I mean maybe eventually we will get a summer.

**I:** Yeah, I think, especially today it's not looking very good, yeah.

**P:** Not looking good here at all.

**I:** Um. I guess you kind of hinted at this with feeling frightened or worried about certain things, but how did you choose which sections of the website to look at?

**P:** I mean, I looked at most of them. I think I probably looked at everything in there one time or another. But the, I mean, I think I looked at the one about being frightened more than the others you know. Just talking about distraction and things, I suppose I've been going through the last month a bad patch, in my problems. I had a urine infection which I couldn't get rid of, three lots of antibiotics, although it seemed, does seem to have cleared up now hopefully. Just looking a bit into the, what the future holds. I've got come to a stage now, 'cause I've been diagnosed now for just over six years so it is a very slow form I've got. Getting very close now to when I'm going to have to have carers in, to get me up in the morning and put me to bed at night, you know. And the prospect of that is not something that I’m looking forward to. It takes away another aspect of the freedom really. Because you then, you know, you’re committed to more, you know certain times of going to go after they put to bed at night at sort of 8:00 o'clock or something like that. And you know it's come to that next sort of stage and it's a waiting time now.

**I:** So some of the worries were about what might happen at that next stage?

**P:** Yeah yeah, I mean. I know there's some, others say don't worry about what's coming, you know and that's right, you know, you have to try and try and not worry about the future. But the future is there and it's gonna happen. And there are times when you inevitably have to do that.

**I:** Okay.

**P:** Can’t get away from it can you. The future is the future.

**I:** Yeah, so where you, were you maybe talking about the thought distancing activity which was about kind of putting negative thoughts aside and…

**P:** Yeah.

**I:** Was that the one you mainly used?

**P:** Yes.

**I:** Okay. Can you give me an example of sort of how, how you used it? Or like how it applied to a certain worry or something like that?

**P:** Well, I mean. I just tried to distract myself onto something onto something different really. You know, thinking about other things, maybe looking forward to something better like chats with my old school friends. I have a, I've got, four old school friends from back sort of 60, 60 years ago, 65 years ago now that I think of it. But we keep in touch and we have a zoom meeting every now and then, every sort of four or six weeks, we’re actually going to have one tomorrow night. And you know, look forward to things like that and plan, and just think of something nice to distract yourself.

**I:** Okay, okay. So kind of planning a couple of distractions in the future and things..?

**P:** Absolutely right, yes.

**I:** Yeah, okay. Um, I wondered if, if you don't mind, can we go through the different sections? And then so I can just ask you whether you use that one and whether you liked this specific bits. So I guess there was the first bit about positivity and there were activities like, just like the one you gave me an example about, doing things you enjoy and focusing on the positive and things like that, how do you find those? Was it relevant to your situation?

**P:** Well I mean, yes it was. It was interesting to read it and think you know, that's what you do and sort of think yes, well, I'm doing the right thing. (laughs)

**I:** Okay. Was anything easy or difficult about the way it was presented?

**P:** No, I think it was, it’s been presented very well really. Yes, I think I enjoyed going through it, you know it was, it made it interesting. And the anecdotes and things from different people, I think you've done a good job with the website. Yeah.

**I:** Thank you. Okay, so things like doing activities that you enjoy or focusing on positive bits are stuff that you generally do, so it was nice to see that you were on the right track. That kind of, okay. And there was another section about dealing with slightly more tricky emotions like anger, sadness, frustration.

**P:** Yeah.

**I:** Did you have a look at those or the information?

P: Yeah. Not, not so much, because I don't sort of, I'm sort of, I don’t have those sort of feelings, really, anger, frustration and things. It's not something that's causing me any problems at the moment. So I think I glanced at them, but not really properly.

**I:** That's fine. So it was mainly the next one, which was about like worry and stress and that kind of thing.

**P:** Yeah.

**I:** Okay, okay. Um I guess we spoke a little bit about the thought distancing activity. Did you try any of the mindfulness activities?

**P:** Sorry the?

**I:** The mindfulness activities, there were a bunch of different ones. Did you try any of that?

**P:** Yes, yes um…

**I:** Should I name them? Is that, would that be easier?

**P:** Go on, name them, yes.

**I:** So there was ‘compassion break’, ‘body scan’…

**P:** Oh yes the breathing one.

**I:** Yeah.

**P:** The breathing thing yes. Yeah, um, I did try. I'm not sure that I've really mastered it. (laughs)

**I:** That's fine, yeah.

**P:** I mean, I did look at that and I did have a try it at trying to clear my mind and…

**I:** Yeah.

**P:** …concentrate on the breaths and things.

**I:** Do you typically like those kinds of activities or not so much?

**P:** Not particularly, no. (laughs)

**I:** (laughs) That’s okay.

**P:** I’ll try to have to look again sometime or that, I mean it's something that you could… presumably the website is going to be remain available, is it? I don't know.

**I:** It is still about until September and then I need to work out what I'm doing next, because that's when I finish my PhD work.

**P:** Right

**I:** Yeah, but maybe it's completely fine as well not to. I put a variety of techniques because some people like mindfulness, some people like some of the other techniques as well, so yeah. It's your personal preference, really. Um, I was just wondering they were a couple of other exercises about like self-kindness and things like that. Did you have a look at any of those?

**P:** like what?

**I:** Self kindness.

**P:** Remind me what that was.

**I:** Um there were ones called ‘compassion break’ and ‘self-kindness letter’. Things like that, (participant shakes head), no?

**P:** I vaguely remember looking at them. I don't remember what.

**I:** That’s okay. So I think the main things you found useful were how to deal with these worries and thoughts and that kind of thing.

**P:** Yes, absolutely yeah.

**I:** Okay. Was there anything you didn't like about the website?

**P:** No I can't say there was anything I had a problem with or disliked, no.

**I:** Okay.

**P:** I mean, I think like all these things, it’s a, it has an immediate effect perhaps when you’re doing it and all that. But it doesn't last for very long. You know, you tend to drift back into the same old ways, you know the same old worries, suddenly they're back again. You know, they don't…

**I:** Oh okay.

**P:** But then there’s nothing you can do about that. I mean, that's what they are and will always be like that. All you can do is try and push them down, like your beach ball.

**I:** Yeah. So did you did you find it helpful, say when you will looking at the computer or looking at the website, but then not, they would keep coming up in real life?

**P:** Yeah, you know, it did, yes. It was you know, it was helpful and I just kept thinking about it and trying to push them away again. Yes, try and work at it.

**I:** Yeah. Did it get easier by any chance?

**P:** Sorry?

**I:** Did it get easier by repeating this technique?

**P:** I don’t know really.

**I:** You can be completely honest, don't worry.

**P:** It’s difficult to say, I don't think it, you know, whether it gets easier 'cause I mean, it's something that you’re doing naturally anyway. I think you know, with… it's just that the website reminds you to do it a little bit more. And gets you back into the habit, perhaps if you’re drifting away and spending too long worrying.

**I:** Yeah.

**P:** Not distracting yourself enough.

**I:** Yeah yeah, I see that. It may have not got better, but it could have got worse or something like that, yeah?

**P:** Yeah.

**I:** Okay. And I guess linked to that as well, was there any particular time of day of that, when you logged on to the website? Was it say when you were having a difficulty or just when… in your spare time or something like that?

**P:** Usually yeah... Well, I've logged on usually when I was thinking, ‘it might help me,’ yes. Perhaps I should have a look at it again and do some of these exercises and uh... So I did, I did use the website to sort of unorganized way, so when I felt I needed it.

**I:** Okay. And I guess, are there any bits of advice or techniques that you might continue to use in the future?

**P:** Well, yeah, I mean it's as I say, a lot of it is just remembering to do it and then making the effort to do it. Because there are… the techniques really, you already, you do do them unconsciously I think. Try to distract yourself and do something else and stop worrying and find something else to do. So the website acts as an aide memoir really to remind you to do it, you know? When you think about it, let's have a look at [name of researcher’s] website and it might help me a bit better.

**I:** Was this the kind of thing you expected when you signed up to the study or were you expecting maybe…?

**P:** I didn't know what to expect really.

**I:** Okay.

**P:** At all really. No, I had no expectations.

**I:** Were there any other say difficulties that you encountered in terms of dealing with emotions and stuff that say we haven't covered in the website or some other help that you might have liked?

**P:** Um, it all sort of interconnects really, I think, but I mean the, the great worry that I have and I don't think that it’s there in the website, is the effect I have on my carer which is my wife. You know, I mean it's all very well for me, I sit here like a cabbage and she waits on me hand and foot. And I'm very conscious and you know, so it’s a worry that's always there, what I'm doing to her.

**I:** Yeah. That is a tricky one, but other people have said similar things as well, so. Yeah, I understand that it's worry about being trouble for someone else and that kind of thing.

**P:** Yeah, yeah.

**I:** Yeah, and you tended to use this by yourself as well. Is that correct?

**P:** Yes, yeah.

**I:** Okay. Can I just ask, because you mentioned you had trouble with your hands as well. How do you normally use the website?

**P:** Trouble with my hands, trouble with my hands did you say?

**I:** Yeah did you use any device or something to help?

**P:** Yeah, yeah I can still use a mouse, but my fingers are getting are getting worse. But I mean I can't, I can't, I have great difficulty in typing anything other than sort of two or three words. But the mouse isn't too bad so I go along with that.

**I:** Okay, okay. So in that sense it was okay with just clicking the different bits and?

**P:** Absolutely yeah.

**I:** Okay, but typing would be tricky?

**P:** Typing is very tricky. Yeah.

**I:** Got it. I think that's most of my questions. Was there anything else you wanted to say about how you used it or anything you liked or didn't like?

**P:** No, no. I don't think there's anything I have any comments I’ve got other than what I’ve said already. So are you finishing your PhD this summer?

**I:** Yes, I'll just stop the recording and then I’ll still chat with you.

**P:** Okay.