**Interview 19**

**(person with MND)**

**I:** I think it should show up now. There it is.

**P:** Yeah, I can see it.

**I:** So I guess just a very open question to start off with. Can you tell me a little bit about how you used the website and how you got on with it?

**P:** Uhm how I used it, I found it very easy to access umm... And I liked the fact that you could keep going back to the home page very easily, so you could find your way very simply back and go off into another tangent if you wanted to. Or you know, you weren't… it's not, wasn't like going round IKEA where you had to just keep following. (laughs) So, I liked that. I've had motor neurone for sort 2 1/2 years now so I think I probably used it differently now, than I would have done when I was first diagnosed. I think when I was first diagnosed the psychological problems, the issues of dealing with that information and you know the emotional part of it was… it was big. It was a big part of what was going on and I don't think it was very well, in my experience, dealt with at the time. It has been, but at the time it wasn't. So that sort of website would have been brilliant I think for me personally, earlier on. I’m still getting things out of it, but I've done a lot of my own research and I've done a lot of CBT courses and all sorts to try and deal with. You know, with the psychological effects of that information, so I think I've used it a bit differently of you know, now 2 ½ years into to the diagnosis than I would have done at the beginning. Does that make sense?

**I:** Yeah, that's really interesting 'cause I was also wondering whether you know, at what point will it be most useful? Because like some people say, things like early on, there's just so much information that you know, sometimes adding another bit of information may get a bit too much, but I think you found probably that this sort of information would be relevant even early on?

**P:** I think you could cherry pick what you wanted from it, so if it was, the feeling overwhelmed by too, so much information, then there was little sections on how to you know, practical tips on how to deal with that or whatever. I mean it's a personal subjective thing, isn't it? You know, I've got a slight medical background anyway, so some of that wasn't so important to me at the beginning, if you know what I mean, whereas the emotional dealing was so.

**I:** OK, just out of curiosity, did certain sections seem like it would have been useful earlier on or certain techniques maybe?

**P:** Uhm, I don't know. I don't know specifically like that really. I think probably dealing with difficult information. Is there one on difficult information and worries and stress.

**I:** Yes, yeah.

**P:** Probably that would have been a go-to at the beginning.

**I:** OK, and some of those...

**P:** There’s lots of other bits like getting more linked in with professional information or linked in with MNDA associational peer support and things which for me would have been a little bit later maybe. But for some people that might be their first go-to I don't know. But I kind of hunkered down with myself and my immediate family and just wanted to withdraw a little bit and deal with my head at the beginning before. I didn't want to talk to anyone you know, any associations or anything like that at the beginning. I didn't feel ready to talk openly with people who I didn't know if you like. So yeah.

**I:** Yeah, yeah, I guess it does change and it sort of, the information is sort of meant to be, you know, you can pick it up and use it whenever. How did you at this point in time, how did you choose say which sections to look at?

**P:** It is very much going on the introduction and depending on what I thought… what issues with... I was more curious to be fair enough. So I looked at everything, but I would deal, I would look more at the things that I struggle with more if you like So I veered away from I think there was a section on being nice to yourself and I can’t remember what it was called I’m sorry.

**I:** The self-kindness stuff.

**P:** Yeah, I kinda think cool and go on past that. Or it just doesn't suit my character or something, you know what I mean? So I wouldn't, I certainly didn't dabble around in that. But other bits were, sort of very much into at the moment, were practical tips and you know, getting rid of the negative thoughts and things like that. That's important to me at the moment, so that's where I went to, just depends on how I felt at the moment when I went, when I was looking at the website.

**I:** OK, OK and typically did you log on say when you would say struggling with some kind of emotion or was it more like in your spare time to look stuff up?

**P:** Uhm, I certainly did it in my spare time 'cause I felt an obligation doing this. If you know what I mean? I don't... not in a bad way.

**I:** Because it is part of a research.

**P:** I was interested in it, so I wanted to, I wanted to look at everything, so you know. The things I've used that I wanted, from my personal, would have been the activities and that you know, the little three-minute body scan, you know, the scans and things like that, the deep breathing. If I was feeling a bit down or then, I knew that I could just go to that site and go straight into the activities and pick up something that worked for me at that time, if you know what I mean? Is that right?

**I:** Yeah, so you almost looked at the whole thing when you had the time, and then if you needed something you’d dip into the specific.

**P:** Yeah, I think it's a matter of then you know what's there and what they are. So yeah, I’m a bit like that anyway. So I looked at everything and then I know what I can pick and choose when I want to, that sort of thing.

**I:** That sounds fair.

**P:** And it wasn’t too overwhelming, that was quite a nice thing about the site. It wasn't too much, and you know, sometimes it can be too much that you can't find what you want to or you know, it wasn't overwhelming with information. And I don't mean that in a negative way, that's a positive that you know, you could pick up what you wanted to quite easily, I found.

**I:** OK. Uhm, I wondered if we could go through the specific sections and if you didn't use it, don't worry I'll kind of remind you about what was in there, but if you didn't use it or didn't feel it was relevant, we can just skip over those. So, I guess that was one section about positivity and there were three activities about that, pleasant activities, finding positive things and values and goals. I wondered if you tried any of these?

**P:** Uhm I did. But as I said, I've done this, like a CBT course before, and it was a similar, a similar exercise. And to be fair, if I had been looking at this a year ago or something I would have, I would have been more involved in the activities, if you like… you know, writing down goals and trying to look at you know, writing down objectives. But I sort of, because when I did it with doing the CBT course online, I did, I was quite studious if you like, or you know. And I would have done, if it was the first time I'd come to that sort of way of dealing with things I would have sat down and done a bit more. But I tended just to read it on this occasion and just do it as a thought exercise rather than anything more you know, structured.

**I:** OK, just because I'm curious, what kind of CBT activities did you try or did you find helpful?

**P:** Uhm, I think at the time, for me personally, I was quite down probably almost depressed I, would say. And I did find it very useful too uhm… be forced to physically express by writing or whatever, alternative ways of thinking, for example. Or setting myself, I don’t know setting myself and small… giving some structure to my life I suppose really, and writing down small goals or things to do for that day or something, you know, that you could hook things on. Do you know what I mean?

**I:** OK, OK.

**P:** And not let yourself just sort of disappear into nothing.

**I:** Yeah as in almost doing things also to help your mood and emotions and that kind of thing.

**P:** Yeah, I'm quite practical person I think. So you know, I tend towards needing something to do and something to look forward to so.

**I:** Yeah, no, that's fine. Lots of people say they already do similar kinds of activities, so that's fine. There was another bit about anger, sadness and frustration and that had specific activities within them. Think you may have looked at the sadness one, is that correct?

**P:** Yeah, my overwhelming feelings were of sadness. I didn't, I've never really experienced a lot of anger, strangely, if you knew me. I didn't, I sort of bypassed those. I struggle with dealing with sadness, so I looked at the tips for that and the activities for that and they were helpful so.

**I:** And within that section I think was thought distancing, but it was also in another section you mentioned it as well. Did you find it relevant?

**P:** The thought distancing, definitely! Because I know it seems so obvious and it's common sense, isn't it? That we… and the way we over exaggerate things and sort of, you know, go to the worst scenarios and things. But you sometimes need to read that and accept it for yourself and then how to social distance, not social distance, to distance yourself from those thoughts and how to do that with some ideas of how to do that. Yeah, I found that useful.

**I:** OK, uhm, if you have an example, if you don't, don't worry about it, but like what context you kind of applied this, this kind of technique I'm just trying to see how it makes sense with MND as well…

**P:** You have to help me with what you looking for…

**I:** Just an example of see how you use it in relation to an issue that you were having, that was sort of MND related. I guess if any spring to mind, if you can't think of anything that's OK.

**P:** My… I can remember it says about… just reminding yourself that there are other ways of thinking things, and that sticks in my mind a lot there. Just stopping, taking up a breath, just taking a bit of time to say, ‘OK, that's what I'm thinking, that life isn't worth or whatever’ you know. And…but there are other ways of thinking about things and you need to just… ‘what are they’, there must be some other way of looking at it. And then just sitting and trying to think that through and I remember that was in there with the distancing ones and that helped quite a bit.

**I:** OK, OK. And what about the section on anxiety and stress was that relevant now or I think you mentioned it might have been earlier?

**P:** It was. Yeah, not so much at the moment, really. I did do, I did look at the things, but I can't remember many of the specifics about it.

**I:** That's OK. How did you find the practical tips and suggestions? I mean, I guess this was sort of across all sections really, but was it was it framed OK?

**P:** I thought it was as I say, the things I've done before haven't been specific for motor neurone and they've annoyed me or frustrated me a little bit when they've given practical tips like I remember doing the CBT course, whatever it was and it was practical steps and things like go for a good long walk or you know get some exercise. Well, I can't walk really at the moment and it was, you know, I'd love to be able to, you know, you felt like ‘Aargh’. So this website didn't do that, it didn't frustrate, there were some things that frustrated me, but it wasn't the practical tips, in that it obviously was more appropriate for people who may have physical issues and things like that. It didn't tell you just to sort of pick yourself up and go for walk up and down the stairs or something when you might not well be able to do that, you'd love to do that but you can't do that, and so it was a bit more appropriate I think, to people or specific to people with motor neuron.

**I:** I'm glad that that's what I was aiming for.

**P:** It was the nature pictures,strangely, I'm sure I'm going to be in a minority here. But they made me feel, uhm, not down, but they reminded me I'd love to go for a good long walk, I’d love to go walking up a mountain, I'd love to go swimming in the sea. And there's a little bit of when you feel a little bit sorry for yourself. I know nature and pictures, of course, I'm outside all the time when you sit in the sun and things, (are good) but it was a little bit of a ‘aaargh’, I'd love to be there doing that. And it reminded you of the things I can't do or things I can't see necessarily, that was a bit weird.

**I:** Yeah, I don't, obviously can't fully understand, but also just with covid and being stuck indoors I can sort of see where…

**P:** It's like I think nearly every page had a nature picture on it, which I get, I understand that nature makes you feel better, and it's important to be outside and be there with nature. But just sometimes it kind of reminded me of what I couldn't do anymore.

**I:** OK, OK, so maybe some kind of a mix of different things rather than like a constant reminder of.

**P:** Yeah. It made me hanker after what I couldn't do anymore. I think 'cause I was very active outside and running and walking and things you know, kayaking and things now it just reminded me of beautiful times that I can't ever do now.

**I:** Yeah, but did any of the suggestions have a similar, like did you read something and go I don't want to do that because of my symptoms and things like that?

**P:** No, not because of the symptoms. No, the only other ones I wouldn't, I didn't want to do is start patting myself on the back and writing love letters to myself sort of thing 'cause it's just, you know. I know it's important to like yourself and all the rest of it, but I don't think I'm in that place anymore so I just didn't go there with those.

**I:** OK, OK. I wonder if you’ve tried any of the mindfulness exercises?

**P:** Yeah, I do some yoga anyway as well. So I mean there was a lot of, and you're gonna hate me, but I've done a mindfulness course as well, since I've had motor neurone. And it's a really important, I think it was really beneficial at the time doing the mindfulness course, so anything that taps into that I think personally is brilliant. I've never done anything until I got motor neuron disease. I haven't done any mindfulness or anything so, it was certainly a go to thing. So to have it on the side and be able to tap into little exercises on that I think is really important. It does put your thoughts into a bit of perspective I think. I get quite a lot out of that way of thinking of and doing those sort of things.

**I:** That's good. Were there any particular ones? It's OK if it's tricky to remember.

**P:** I can’t remember what come under what that was all really…

**I:**  I can describe maybe what the exercise was about and you tell me if there were any ones that you liked or didn't like. I'll mention them, don’t worry, I’ll make this easier. There was a compassion break one. There was a 3-minute breathing space.

**P:** Yes I did that a lot. (3 min breathing space)

**I:** There was a safe place meditation to think about, a place that gives you safety, comfort, that kind of thing and the body scan.

**P:** Body scan I did as well a lot.

**I:** OK, OK.

**P:** Because that something that you don't have to go on the site to use or anything like that. It's just yeah easy thing you can do sat in the garden or in bed it or whatever it is. So it just gives you those skills, doesn't it? Those little tools.

**I:** I wondered with motor neurone disease as well, is a body scan, does it sort of feel appropriate or are there times when you're like I can't really do this instruction?

**P:** I expect further down the line it might be different. At the moment for me, although I can't move my legs very much, I'm still aware of them and I can still tighten and untighten muscles and things like that so… And it just structures me to relax, it's just a way of calming down if you like and just getting back to where you are for a minute or you know, 2 to 3 minutes. So yeah, like I get what you're saying, it might be a bit uncomfortable for some people with motor neurone at some stage, but for me at the moment it was OK.

**I:** OK, yeah. OK, so even at this point if there was an instruction saying you know, think about your legs and how they're feeling today, that would not be too upsetting or anything like that.

**P:** Not at the moment 'cause I'm thinking about them anyway. You know what I mean? You can't leave them.

**I:** Fair enough. I’m just trying to see that was… those were most of the sections. Uhm… did you feel that there was anything that you would have liked, information that we didn't cover?

**P:** Uhm… It’s a hard one, what did you miss out. 'cause I didn't want it to become… I wouldn't have wanted it to have become too packed with information. You know what I mean? Or too complicated as a site 'cause I think that puts people off a little bit. And anyway that, the site sort of directs you to where you can find more information. Uhm certainly didn't want any medical or physical advice on it particularly, 'cause again you get that somewhere else. Uhm… in my, I mean probably just more of the same. If there were just some more activities, you know, to do. So, you could mix them up a little bit because it tends to be sort of two or three on each. Maybe for some of them, it's like you know, like that one, but don't like that. But yeah, you know if there, maybe, if they were just more of the same if you like, so that you could use different techniques. So, for the mindfulness ones, if there's other techniques you can do, if there was just a few more to pick up from.

**I:** Yeah, especially after you gone through the site once and looked at everything. Then yeah, more variety I guess. Do you feel anything has potentially changed post using the website or in terms of like managing emotions and things like that?

**P:** Uhm a little bit to be fair, 'cause I think it's just reinforced what I'd already done and it was quite nice to do that again, and have access to that. Because when I did the CBT course whatever it was an online one and it's taken off you once you've done it, if you know what I mean? So I didn't have access to you know, breathing exercises or whatever it was, so it was quite it was nice to… I know if it had been the first time I'd have done anything like that it would have had a you know, it would have helped a lot. The fact that I had done stuff like that before and it, but I wouldn't have gone back without having access to that site. It's helped me because it has made me do those things again or allowed me to do those things and reminded me of the positive effect I suppose, of some of those exercises and ways of thinking and it just sort of, just confirms it really.

**I:** Yeah. Uhm.

**P:** At the beginning you feel I've done the mindfulness course, I've done this CBT, I've seen the counsellors and then it all stops. Do you know what I mean? So having something like that… OK, I recognize a lot of the little practical tips and the ideas and that, but I haven't got access to them without this site so that it's helped in that respect. And anytime you do any of those things, even if it's just a quick body scan or a three-minute breathing exercise or something, it has a positive effect I think, at least for the next hour or two you know, I mean, so all is good.

**I:** Yeah, I hadn’t thought of it that way, actually like, In terms of access and it just it being something that even if you're not using at the moment, it's there for when you're struggling.

**P:** Yeah, 'cause I was thinking about that before speaking to you today, I was thinking does that… is that it now? I never get access to that site now, you take it away from me. (laughs)

**I:** You'll get it for like the study period, but I'll tell you more about that later.

**P:** You know what I mean? It's like, you could just tap in. Instead of you’ve gone to your courses, that's the end of it now, your sessions have ended.

**I:** Are there any techniques overall that you thought were really helpful and you might use in the future if they even once you stop using the website?

**P:** Uhm the ones I've already mentioned and just the general ways of thinking positively and things like that and stopping and just looking at things from a different angle and not letting you know… I think you pick up just general ways of a different sort of mindset if you like, from all the bits and pieces, don't you? Trying to turn it into a bit more positive way of dealing with thing or giving yourself time to feel things and think things through, and then you know leaving it there. So those sort of practical ideas.

**I:** Yeah, that's all my questions. I was wondering if you wanted to add anything or if there were any other aspects you liked or didn't like?

**P:** I just wrote some things, but mainly it’s… I like the way the site cross references you, I said that haven’t I? And can direct you to find more help in specific areas, like the mindfulness course, counselling. Uhm… Just that the activities section I liked, that is a good idea 'cause you could just dip it in out as you wanted to. The other thing is, there is an app you know called CALM.

**I:** Yeah, yeah, I did think.

**P:** That’s the only other thing, there is an app out there and that people would get that confused with that at all 'cause that's obviously a meditative sort of help thing as well.

**I:** So yeah, I know it started off as being the name of the study, but then I can see the name of the website as well so.

**P:** It makes perfect sense. It's just that you know.

**I:** Yeah yeah, I see that. I can stop the recording, if you're happy and we can still be on the call, but it just won’t be recording.

**P:** Okay, no problem.