**Interview 10**

**(family member)**

**I:** Notification I think.

**F:** Yeah.

**I:** Yeah, there it is. Okay, so I guess I wanted to just start broadly by asking you how you got on with using the website?

**F:** Yeah, I found it really good actually. And my dad used it as well. My dad's got MND and.. so he gave me feedback and said it looks really good and there's um lots of useful advice. And he thinks the sections are really good and he said it was easier, easy to navigate around as well. But for me, yeah, I think it is a really good idea, 'cause I definitely think that's something that's missing in terms of support with MND. So I do think it's really good to have that there actually. And yeah, I found it really easy to use and the same as my dad, I found the sections really great as well. It was useful to go through um, 'cause I think there was one on positivity. And yeah, I think it was just really good that was different sections that you could go into. And I also liked that you could look at all the activities.

**I:** Yeah.

**F:** Yeah 'cause I liked the way it sort of it you could like go through each step and go through like that. But then also I liked that you could just do an activity if you just wanted for five minutes. I like that you could just go through and do that. So yeah I did think that was really good.

**I:** Oh, that's good. Can I just ask how you used the website, did you sort of go through each section or jump through to the activities later on?

**F:** Yeah, um I think the first time I used it I looked through each section just to see everything that was there. And then when I went back to use it, I just jumped to the activities. So I found that once I'd gone through it once, I didn't need to go through each step of the section, but I could just go to the bit I wanted to so.

**I:** Okay, okay. And I know this might be different because you're taking part in a research study, but how did you choose which section to look at?

**F:** I think it was just sort of based on how I felt at the time, I suppose. I found the mindfulness activities really interesting, and that's probably why I'd gravitate more towards anyway, so that's sort of what I went towards more I'd say.

**I:** Okay, okay. So it was less about like ‘I'm struggling with the anxiety’ or something, but more ‘I could use the mindfulness’ and that's how.

**F:** Yeah yeah I think so, yeah.

**I:** And did you did you kind of use it differently with your dad, or was did your dad mainly like look to give feedback? Was it that sort of thing?

**F:** Yeah, so I let him look at it himself so I didn't look at it with him. So yeah, I think he looked around to see how to use it. But then also he's been doing mindfulness recently anyway, so I think those are the sections that are probably going to be helpful for him as well. But yeah, I definitely do think that side of things is, definitely there's more needed of that. Because he was diagnosed in May last year and I think only recently started having these like mindfulness appointments. So I definitely think that something like that would be really, as in the website, is really useful to have there so you can do it in your own time and have that there. 'Cause that definitely wasn't as available to us, I don't think earlier on. So yeah, I definitely see it as something that would be really useful for people to have there.

**I:** Yeah. I'd like to just find out a bit more about that. Was it, do you think your dad probably would have needed some kind of support like that early on and?

**F:** Yeah, I think so. I think when he was first diagnosed it was a bit sort of scary and you don't really know how to navigate it. And I think that it would have been great to have a little bit more support there. And I think they said something like they had more like face to face meetings and like mindfulness courses. But because of Covid they were put on hold, so I think it was more that they because it was fairly early on. But now they’ve started doing online stuff so I think the change just started happening in that respect so.

**I:** Okay.

**F:** Yeah, I think it's probably a mixture of things. It's a mixture of maybe there not being enough as there is, but also because of Covid there was sort of the change where we needed more things online, but things are a bit behind and catching up. So yeah.

**I:** Yeah, okay. Was this all given or suggested by the usual MND care team?

**F:** Yeah, I think we… I think my dad signed up with the MND Association and they had like a local branch he got in contact. They were really supportive in that respect, but yeah I do think it's definitely something that would be really useful to… I think it is missing slightly. Or maybe just not as obvious to get those sorts of resources.

**I:** Yeah no. I'm really glad you managed to access that as well because it, it's so different in different parts of the country too.

**F:** Yeah.

**I:** So yeah, that's great. Okay, so he's also recently started mindfulness and that's how this is quite similar in a sense.

**F:** Yeah.

**I:** How about you as well, did you feel you needed something like this earlier on?

**F:** Yeah, I think so. 'Cause um, I think I know on the MND Association website they have like a space for carers and there's a lot of useful information in there. But I do think it's just useful having something like this that you can just use when you might need to. And that's just easy to navigate around and get to. So yeah, definitely.

**I:** Okay. Um, I wanted to just go through the different sections just to kind of get more specific feedback. I’ll check with you if you looked at that section or not, if that was something that you used. So the first chunk was the’ positivity’, so that was the ‘pleasant activities’, the ‘finding positives’ and ‘values and goals’.

**F:** Yeah.

**I:** So did you think that this section was relevant to you?

**F:** Yeah, definitely. I think that's definitely an important, I think all the sections were really spot on with what sort of needed around for carers with MND and people with MND. So I think they were really spot on. But yeah the ‘building positivity’ one is really important I think. And yeah, I think it was really useful and I'm just looking at my phone 'cause I made some notes. But I think, there are sort of practical tips for worry, I think I saw, oh no maybe that was a different section, I think. But I found it useful in general that there were sort of practical tips and also like the audio, and I like those different sort of resources so you could use it how you want. And yeah, I liked how they were practical things to do as well. 'Cause sometimes I find with things like this it's a bit like vague and you can't really relate to it. So it's useful when there are practical things that are just easier to relate to.

**I:** Yeah, yeah, everyone copes so differently that yeah, it's good to kind of have options if people’s style is different.

**F**: Yeah, definitely.

**I:** I wonder if, did you try out any of these activities? Or were the kinds of things that you already do in a sense?

**F:** Yeah, I think I did. There were different things you could do, I remember there was a section on like different things you could do and it said about like taking a walk and things like that. So I thought it was useful to just have all those suggestions there, 'cause sometimes you do just forget these things, even if they're really simple things, so it's nice to have those reminders. So I did like that section. But there were a few, one of the I've just written in my notes. One of the activities that suggested was having a snack and that made me think 'cause some people with MND can't swallow food anymore. So I thought maybe that was even though that would be fine for me as a carer.

**I:** Yeah.

**F:** That might not be ideal for someone with MND.

**I:** That’s true.

**F:** Then there was, I think there was one about taking a walk which again is fine if you're a carer, if you still can walk, but then some people can't. So my dad uses a wheelchair now, so we can't go out as much as we could, but it could just be for that, like just getting fresh air if you can, even if that's just opening a window or something like that.

**I:** Yeah, yeah.

**F:** Just so it’s, you know, accessible for everyone I guess. But yeah, that was my only point on that part.

**I:** Linked to that as well, um. Were there any kinds of activities say that you tried out that maybe were not on the list? Say that you tried to do even with your dad that, you know it's linked to the similar concept, I'm just trying to learn from other people's examples or so.

**F:** Yeah. I guess what I've learned before is about there’s a technique called ‘worry time’, where you like throughout the day you try and put your worries aside and then you have a set time during the day where you just say ‘oh I'm going to think about everything that's worrying me’ and then. So I think that's something useful that I've used in the past. But yeah, I guess something like that because I think it's just useful, you know, if you do have loads of different worries going on, having techniques like that that can help, so yeah.

**I:** Yeah, that's really useful. I hadn't heard of that one, I'm making a note of it.

**F:** Yeah. Was that anything else about the that specific section or any of those activities?

**F:** No, I don't think so. Yeah, no, that was all good.

**I:** Okay and the like the level of instruction or the guidance was all okay?

**F:** Yeah, yeah, yeah.

**I:** Um, okay, so the next one was about adjusting to changes, and specifically I guess dealing with emotions like anger, sadness and frustration. Did you have a look at any of those and how did you find them?

**F:** Yeah, I looked through and I think it would be really useful, but I don't I don't think it was for me at the time. I guess I wasn't needing that section as much.

**I:** Okay.

**F:** If I was, I think it would be really useful. And I do like how it splits the emotions up so that if you are feeling really sad at the time, you know you can just go to that section and it's really helpful. So yeah, I did think it would be good.

**I:** Yeah. And the other one I guess was anxiety and stress, was the one you had more of a look at?

(Connection problems)

**F:** I'm sorry I think that’s. Yeah, it’s stopped now, sorry.

**I:** I can hear you clearly now.

**F:** Oh good. Yeah, definitely that section, I used a bit more, the anxiety and worry one. I think that was really useful and I think that's definitely something my dad would find useful as well I think. 'Cause yeah, I think with MND there is a lot of anxiety and worry and uncertainty. So yeah, that was really useful this section I think.

**I:** Okay, okay, and there were two suggested techniques there that was a mindfulness exercise and thought distancing.

**F:** Yeah.

**I:** Did you try the thought distancing?

**F:** Yeah, well I've I didn't try it but I have tried it in the past. And I did find it really useful actually, I think exercises like that are really useful, where you can just sort of spend a couple of minutes doing it and it does help you sort of relax a bit as well.

**I:** Okay, okay. Yeah we can we can talk about the mindfulness one 'cause I think that's the one which you probably gravitated more towards.

**F:** Yeah.

**I:** How did you find exercises like that helpful for your situation specifically?

**F:** Yeah, I did. I do find it really useful 'cause I think um, it's useful to just focus on something like that, even if it's just a… Also, I like how they are quite short as well and it makes them easy to do, 'cause if they’re longer it would just put me off and doing it. So if it's like 5 to 10 minutes, I find that really good, 'cause then I know I can concentrate for that time and set that time aside. And yeah, I do find those really useful 'cause it means you can just focus on something else rather than just powering forward and doing everything else. I do find it really useful to have that time to just stop and think, so I think that's definitely useful.

**I:** Okay, okay. Would you typically do it, say when you're struggling with something? Or is it more of like a regular ‘I'll set some time aside and do this exercise’?

**F:** Yeah I think for me it's more if I realize I'm struggling and want to do it. But I know for my dad I think he does it, he tries to do it every day now, now he's had the mindfulness appointments. He tries to do these exercises once a day and he's found that really useful. So I know that is a benefit of doing it regularly that it does help. So that’s definitely something I'm going to look to do more towards now that I've, you know, done these exercises. But yeah, definitely.

**I:** I just wondered whether from the list of the ones presented, did you find some more to your liking or more relevant to your situation than others?

**F:** I think there was a body scan one.

**I:** Yeah.

**F:** And I found that really useful 'cause I think sometimes with mindfulness my mind can just wander off and I can't sort of concentrate on it, but with body scan, I find that really easy to follow and focus on. And so yeah, that was probably my favourite one out of them all.

**I:** Okay, 'cause it's more sort of directed?

**F:** Yeah.

**I:** Yeah. Okay. Um, yeah, I think there's three main sections. There was also… (audio echoes) There’s a bit of an echo, has it stopped?

**F:** Yeah.

**I:** There was another support section. I wondered if that was useful at all because I know you also access the mindfulness group so…

**F:** Yeah, I only looked at that once I think, so I didn't really click on anything more from that, I don't think. But in general, I do think it's really useful to have back there 'cause you know, after you've done an exercise or something, you might need something else that you know can't be done in the website. So it is useful to have that there, definitely.

**I:** Okay, okay, um and just in terms of the ‘all activities’ section, again when you did go there, did you mainly try the mindfulness exercises?

**F:** Yeah that's what I used it for really. 'Cause I just found it useful that they're all there in one place and that I could just click on the one I wanted. So yeah, that's what I mainly used it for.

**I:** I just wondered did you use any of the self-kindness stuff?

**F:** No, I don't know. I didn't.

**I:** Okay. Some of them were kind of through mindfulness exercises, so it is a bit confusing, but, okay you didn’t try them, that’s okay. Yes, I think I've covered pretty much all the sections. Did you feel like, especially from a family member's point of view, was there any information you were looking for that was not covered or you would have liked?

**F:** Um, I'm not sure. Well, I don’t know if there could be more. I don't know if it could be split into or some exercises or information split into family members or carers and then people with MND because I guess some things are different and it might help if it was a little bit more specific in that way. Because I know the guidance I looked at on the MND Association website for carers, it said different things about dealing with different emotions, you know when you're a carer and how to deal with different things when you're trying to support someone. So I guess and I did find that useful, so I guess more that side of things would be useful I guess.

**I:** Okay, okay. Do you have any examples of which bits you may have felt were more relevant for carers as opposed to people who have MND?

**F:** I guess maybe the ‘building positivity’ section. Yeah, I guess maybe that was more relevant, but then I guess I think all of it really was appropriate for both. So I think it did completely cover both and it works well for both carers and people with MND. But it could that yeah, there could just be some areas that are a bit more specific that could help with those sort of emotions, I guess that maybe carers would feel more than people with MND just in terms of, I guess supporting and that side of things really.

**I:** Okay, okay. Yeah, I think especially stuff in terms of worry and so.

**F:** Yeah.

**I:** It’s a different kind of worry, I guess.

**F:** Yeah, yeah, yeah that's true.

**I:** I guess linked to that as well, did you find that there were enough examples? You know, sometimes there were quotes and examples for carers as well.

**F:** Yeah, definitely yeah.

**I:** Yeah? Okay.

**F:** Yeah, yeah, I found those useful as well 'cause I think sometimes, especially when you're doing these sort of things from home like online and it's not like a group when you're not talking to someone else. I think it is really useful that there's those examples there and that you can also play the audio and hear someone's voice as well. I think that's really useful to have as a feature there as well.

**I:** Okay, okay, so it may not be necessary, different sections but for carers, maybe a bit, maybe more strategies than you would have suggested.

**F:** Yeah.

**I:** And little more in depth, that kind of thing.

**F:** Yeah, yeah.

**I:** Um, yeah. I wondered if anything had changed for you, now having looked at the website in terms of dealing with difficult emotions and things like that?

**F:** Yeah, I think it's just useful knowing that that information is there and just knowing that I can use it. And I think in terms of the ‘building positivity’ section that really helped as well. So I definitely learned things from there that I maybe wouldn't have really considered before. And it is also useful just having those reminders as well, of things that you might have already learned but just, you’re just getting on with everything else and have forgotten about. So I think it is really useful to have those there.

**I:** Okay, okay. I know I'm kind of jumping with this question, but it just struck me when you said about the reminders and practical tips as well, because sometimes there would be like a suggestion of say a mindfulness activity, practical tips.

**F:** Yeah.

**I:** So you used both of them?

**F:** (Nods)

**I:** Okay. And um. I guess with the practical tips, was it enough to just kind of go through once and then you know what to do? So when that emotion did occur, then you sort of had a go to strategy or something like that. Or did you find yourself kind of going and reading through those sections again?

**F:** Yeah, yeah. I think for me I think I probably had to read a couple of times and take it in. Because then sometimes in situations where you are worrying and it's not going to be the first thing you think about. So I think once you’ve taken it in a few times and tried it a few times and then you know, you remember to do it and are more aware of how to use it. 'Cause yeah, I guess probably the first time I'm aware of it and understand it, but I may not necessarily remember to use it and know how to use it. So I guess it probably takes a few times and reading through and trying it. Yeah.

**I:** yeah. So almost like going through it a couple of times and then yeah, I get that.

**F:** Yeah.

**I:** Yeah. Because of Covid, were any of the strategies potentially difficult to use or yeah, not applicable or needed some adaptations or something like that?

**F:** No, I don't think so. I think it was all you know I could all do that from home. Everything all the activities and advice. Sorry that's a train going past. Yeah, I think it was all useful really and that you could do everything from home quite easily so.

**I:** Okay, yeah. Yeah, I think that's all my questions really. I don't know if you had any other comments, about anything we haven’t covered?

**F:** Yeah, the only general point I was thinking was that I used it on my phone, mostly really and so I think it would be yeah.

**I:** Oh ok, I hadn’t tested it on a phone

**F:** Yeah I used it on my phone mostly, but um, my dad used it on his laptop and it still worked absolutely fine, but it would just be useful with these sort of things I tend to use apps on my phone. So it would be useful if that was an option as well as the website just for it being easy to use. But yeah, it still worked absolutely fine on my phone.

**I:** Was the layout and all okay? I actually haven't tested it on a phone so.

**F:** Yeah, it was fine. It's just when my phone was portrait it was like, landscapes it was smaller, but then when I turned my phone it was like filling up the whole screen. So it was still, like this layout was still absolutely fine and it was still really easy to go through. But yeah, just in terms of how I use things like this like mindfulness, I’d use an app more than I would a website I think, but yeah.

**I:** Okay, okay. So it's mainly issues with portrait.

**F:** Yeah 'cause it was just sort of, the screen was like landscape on my phone so it was taking up like half the screen…

**I:** Okay.

**F:** …but then once I turn my phone landscape it filled it fine but yeah that was the only.

**I:** Did the pictures with the audio also work?

**F:** Yeah, yeah, everything else worked absolutely fine, yeah.

**I:** Uh, yeah, you're the first person who has told me that, I've heard about people using it on a tablet as well. But I’m glad it works.

**F:** Yeah, yeah.

**I:** Okay, um. Did you have any other comments?

**F:** No, I think that's everything, yeah.

**I:** Okay, um I can stop the recording, but I'll still be on the call.

**F:** Okay.