**Interview 3**

**(family member)**

**I:** Should get a notification saying it's recording, yeah? OK, so this is the first page. I guess I there's no back button here, but I don't know if you saw the previous page. The full title of CALM, which was basically coping and living with MND and..

**F:** I was going to ask.

**I:** OK yeah, I made a note to add it on this page as well. But I just wanted to know what, what the title, or if you heard something like that, what might you think it was about?

**F:** CALM?

**I:** yeah.

**F:** I don't know, but I would not first associate it with MND. I have, because I don't know, because CALM, none of the letters would like stick out to me as being about that. Um? Yeah, I think it's like obviously relevant to them. Like in like emotions. I could have told that it will be about that. So yeah.

**I:** OK, and what about this page? Does it make, is it clear what the website is actually about? I'll let you read through.

**F:** Yeah, yeah, it gives like a good overview. More detail like, like this, not details missing, but I'm like, I'm like oh how is it going to do this? But I don't know if this page is just to be a kind of brief overview, like a very brief kind of summary of the website, that makes sense. Doesn't say about like when it says CALM gives you tools, and it didn't say what kind of… you know what I mean, doesn't go into more specifics, but I don't know if that's the intention or not.

**I:** Um, there are more pages, so maybe will go through them and then even if at that point you feel you still… would have liked some information that isn't there you can let me know. Um, yes, if you click on to the next button. This essentially says who it's for.

**F:** Yeah, yeah. I think that makes it pretty clear

**I:** OK. If you go onto the next. Any thoughts about these pages?

**F:** I think with the teams bit is good to know like, I'm like, I'm glad that's there. To know more about who made it and kind of like the faces behind the website rather than it being a bit impersonal. This kind of makes it a bit more person, personal, I like that.

**I:** I guess, yeah, you sort of answered it, does it add to you wanting to look further when you know, kind of who?

**F:** Yeah, yeah no, no I think that definitely

**I:** yeah. OK, um if you go to the next page. I guess this kind of sets expectations in a way.

**F:** Yeah, I think it's good. I think. I would like, like from the start from the start, like the first kind of half for that to be expanded if it makes sense, like saying what can you expect from CALM just like a few more, another sentence or two more sentences I think would be nice to kind of give it a bit of a beefier bit. Because half of it is then just kind of saying about like further support further available here. So, I think just like first half would make it a lot better, yeah.

**I:** More like saying what it is up front almost

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

**I:** Yep. And this is just sort of an explanation why you will see lots nature images.

**F:** OK, yeah. Think it’s nice to have that explanation then to not wonder like any relevance to the images or not. Yeah, I think saying about like the research is interesting yeah. OK.

**I:** Yeah, I think this bit’s fairly straightforward, so we go on to the next. And this probably gives a bit more.

**F:** Yeah, yeah,

**I:** What actually is it? What are you thinking when you look at the page?

**F:** Its good its split up into different sections. So you can, if there's like something specific you want to do, you can do it where it's like… I personally would probably go for all techniques 'cause like I just don't really know this. I think it's good to have both options there and explaining what, what, each of them are. I think maybe separating the ‘adjusting to changes’ and ‘dealing with worries and stress’ like having, having three separate paragraphs, three different for three different sections to make it clearer

**I:** OK

**F:** If I wanted to do one of the latter, the last two I might feel a bit like I don't know which one to go with.

**I:** OK, yeah, that's fair. I'm just making notes as we go along too. Yeah, was there anything else about this page?

**F:** Mmm, I don't think so.

**I:** That's fine, I'm just double checking. Yeah, we can go on to the next. I think that's the last page in the introduction, really.

**F:** Yeah, like I think that’s a good summary almost of the introduction. This kind of, what it seems to me like it's tying it all up.

**I:** OK, yeah, so if you go on to the next. So this was essentially the introduction that I guess the first time you look at the website are taken through this section, but the next couple of times you log in, you come directly to this screen that you see right now. Um. And I guess from here on I'll probably be led by what you might typically use so. Yeah, you were telling me you'd usually want to see all the techniques in one go. Why don’t we look at the ‘all techniques’ section? Any thoughts about this?

**F:** I think, the first thing that stood out to me, I like that its got all the things I think having more kind of separation between the rows because it's like focus on the green boxes and then you kind of go to the grey writing to see which one its which. So perhaps having more like, making it clearer that these 3 are for that, these three are for that. But that's just formatting things there's nothing like that makes me …

**I:** I guess, to make it clearer, um where to go, what to choose? I guess coming to this page without too much background, does it, do you feel confused or…?

**F:** I don't think so. Um, no, I could, like to me it's not confusing, but I see it could be confusing. What exactly self-kindness exercises mean? Because the other three are all, like obviously pretty clear. But then self-kindness exercise I could see, could be a bit like it's kind of quite a new, unusual phrase is like, yeah I see.

**I:** OK, almost a bit of a description. Or um…

**F:** yeah, yeah. Yep.

**I:** And what would you, what would you pick? Any particular option? Are you being drawn to any particular one at this point?

**F:** Um? I think probably staying positive.

**I:** OK, yeah. Yeah, so there are three options there. Um.. let's start with benefit finding, um, yeah. This is just a bit of an intro.

**F:** Yeah. I think that’s a good explanation. I like the second line as well, and then you know like making clear it's not all like trying to be like completely positive and having to be everything. So yeah, I like that one.

**I:** Also, um I guess now I'm also looking at it slightly differently, but as family members, well, does it sound like it's relevant to you as well?

**F:** Um? Yeah, well I guess obviously having the, it's difficult having to, you don't wanna keep saying ‘you/being a family member’ like throughout the website, but obviously that makes it quite clunky. But then sometimes it can also feel like… if that makes sense

**I:** Yeah, as long as like when you're reading it, you’re not… You're not thinking this doesn't seem relevant to me.

**F:** Yeah, yeah, no, I don't feel, really feel that way, no.

**I:** Good. If we go onto the next.

**F:** Yeah, I think it's good. I like having I like the quotes and then obviously like what we were saying with the last one. How it then makes it more relevant by having like one of each people with MND and then also for their family as well. I'm think that’s good to have both.

**I:** Yeah, that's like a subtle way of saying it's for both as well. Um, yeah, if we go into the next page. I guess this is more the exercise.

**F:** OK, yeah.

**I:** From this level of instruction, I guess does it sound like it's something that you could do or? Or that you need? (laughs – sound from outside interrupts) sorry it’s coming again. Do you think I need to add anymore um information, an example or something?

**F:** Yeah, perhaps an example because you kind of like you have it there, but then it's all struggling to like… ok like you know, here’s a sentence that I can work to complete. But then yeah, I think having an example or something there were just perhaps make it a bit clearer.

**I:** OK. Just another thing 'cause I picked up from the last um last page. I think you mentioned it's good, it doesn't sound too... Like you're only looking at the positive. So, I guess even in this page. Does it come across? ‘Cause the task I guess is to look at the positive, but does it sound too positive in that sense?

**F:** Um.. the only one that I feel like sounds too positive is ‘I feel lucky that…’ I feel like maybe that needs I don't know like an, ‘although this has happened, I feel lucky that’ because then I feel like without, by itself, to me seems like too positive.

**I:** OK.

**F:** The rest I think, are a good like, a good balance. Yeah.

**I:** That's, that's really useful. OK, if you go to the next. Was a picture - there it is.

**F:** Yeah, I think that’s good as like a summary and then it's quite good as well to then think about like doing, like saying to do this activity regularly like to come back to it. I think that’s like a good like summing up and saying if you found a bit difficult not just kind of being, like finishing it and then being like OK onto the next. It's kind of saying like if it was hard like have a break. And guiding you what to do next I think is useful.

**I:** Yeah, yeah, just trying to. Some people might find things like this easy, but others might struggle as well. So yeah,

**F:** yeah, of course.

**I:** Yeah, um, yeah. If we go on to the next page that takes you back to this menu. Um can I just ask though, what, I guess what your thoughts were when you heard self-kindness exercises or seeing the ones listed? Just to kind of see what people think it might be before trying them out.

**F:** Um? I guess I had like the idea in my head of like what it was about. Well, I mean, it's kind of like self-explanatory in a way like just being kind to yourself and like making sure that you are looking after yourself, I suppose. And like keeping, making sure like… 'cause I do, I don't think there's any like confusion between that and staying positive, at least for me. I'm not like… but there's like I do kind of understand, see that they are separate, so I think that's like not an issue that there is potentially overlap

**I:** OK. Yeah, and what about the similar thing for like mindfulness and dealing with, I guess, dealing thoughts with difficult is also that's what it is.

**F:** Yeah, yeah, that's, that's the rest are all pretty, kind of clear I think to everyone and makes it easier like if you don't know what to do, then those kind of say like ‘oh if you want to do this, do this’ and I feel like they all have enough separation where people wouldn't get confused between going between them.

**I:** And I guess is there any reason you would, you would pick one over the other?

**F:** I mean, I guess it would be how I would be feeling like at that moment in time. Because I like, I said I feel those are all separate enough that they kind of target different emotions, if that makes sense? If you're in like a stressed mood, then you might go for the mindfulness and relaxation. Like if you're in a certain mood I think it's kind of clear which one to go for and which I think is good.

**I:** OK, I'm glad that comes across. In some of the other sections, I sort of guide people based on how they’re feeling but that's good that comes across even on this page. Um? Is there any other one you wanted to try out?

**F:** I was intrigued by thought distancing

**I:** OK.

**F:** Yeah, I like that there’s an explanation of what it is before you kind of start doing it.

**I:** OK, OK, that's do you think something like that might be helpful for the other one too?

**F:** Um? Yeah, I suppose so. Yeah, I think then also it is quite nice to then have like the consistency between each one, that when you click on each one it kind of says like why. What this exercise is for, what it does. So yeah, having like a consistent sort of introduction to each one, will be quite good.

**I:** OK Um? Was this what you were expecting or. Does anything sound like it may not be relevant to you?

**F:** No, no, I think it was kind of pretty, pretty, clear.

**I:** Yeah, we can go on to the next page.

**F:** Yeah, I mean already, I like that like kind of examples. Yep.

**I:** Are the examples clear?

**F:** Um. Yeah, yeah, I think they are clear.

**I:** OK. That's good. Um? Yeah, just if you could tell me a little bit more. You said the examples that was helpful about this page. Is there anything else that was good or that we could maybe change?

**F:** Um. I mean…

**I:** If there's nothing that's OK.

**F:** yeah, I know I’m trying to read through it and find something. But no, I think it’s all pretty good and it's like, well explained yeah.

**I:** Ok let's move on to the next. This is the next step.

**F:** Yeah, I like that there’s like already a kind of dip, like it's giving you approaches, I like multiple different approaches to try.

**I:** OK. Is there any approach that you feel would suit you better from the three?

**F:** Um. I think that the first one is good, kind of like visualizing, like visualizing the distancing is good, it is one I probably would like and go for… OK.

**I:** Yeah, so this is basically, I guess the instruction, but there’s a bit more examples and stuff on the next page to kind of 'cause it is also slightly abstract. So yeah, just a bit more guidance to help you along.

**F:** I mean, I really like this ‘cos I really like metaphors, so this is like a good one for me yeah.

**I:** Oh, that's good.

**F:** Yeah, yeah, I think it's... Yeah, I mean like again I like the examples and having, like the multiple examples I think it's good.

**I:** That's good, let's shall we go on to the next page. Um, yeah, this is essentially the same thing, but if you would prefer to do it via like a technique.

**F:** Yeah, I mean again, well explained this is, this isn't something I like personally would do, just 'cause I would prefer like the kind of visual metaphor kind of thing to like the techniques, in anything. So it's something that I would not go for myself, but I can imagine like it would work for other people, which I think is why that's good and there's different like techniques to thought distancing that are included. Because obviously it's not gonna all like, if it was just this one, it wouldn't kind of fit, fit me. But there’s like different ones

**I:** OK, OK, I haven't seen it like that, but that I think that's helpful, yeah? OK, if you just go onto the next, I guess. If it's a technique that you wouldn't look at you may not want to explore this, but this is for people… just I guess examples of real-life situations. Sorry about the text, I will change the font.

**F:** Yeah no, I mean yeah all I was going to say is it… obviously straight away it does just seem very kind of wordy and overwhelming. Everything, even just like splitting up a little bit.

**I:** Yeah, yeah.

**F:** Yeah, I think it's good and then as well, when it is good to be using the STOP technique, having for each like action where it relates, kind of to each like letter of the technique, so making that clear.

**I:** OK, maybe in a different sort of layout or something.

**F:** So even just splitting it up so it's like a line for each… like where it's like ‘stop what he did’ to like just to have a bit more and make it more like friendly. Yeah

**I:** yeah, yeah. OK. Yeah, I think if you could go next probably. Oh yeah, I guess the other example was pretty similar. Was there any other particular techniques that you were drawn to?

**F:** Um body scan again. I was like intrigued by what that meant.

**I:** OK. I think somethings wrong with this page. I don't know why it's not, um, come across. But there's some information missing, I’ll correct that, in the second paragraph…

**F:** Yeah, well yeah. I mean it has information missing. Yeah, but I think the first bit kind of explains it well and makes it like quite accessible.

**I:** OK. Um, if you click on to the next page… Gives you bit more information. Sorry I’ll let you read…

**F:** No, no it’s fine I’ve read it

**I:** Yeah. Have you tried anything like mindfulness before?

**F:** I think so I feel like I've done similar things I feel like I'm imagining a similar thing to this. I think helping to go to sleep or something.

**I:** Yeah, they do have similar kinds of exercises, so you sort of know what to expect roughly?

**F:** Yeah, yeah. So then because I know what it is already, I like, I feel like I don't really need as much explanation so I don't... I can't tell if it's explained enough or not just because it makes sense, but I'm not like, I can't tell, I didn't know what it was already.

**I:** That's fine. Yeah, it can seem also a bit repetitive if it's, if you sort of know what it is already. Yeah. Um, yes, hopefully this should work… Says it's loading, but I guess some of the instruction is a bit is more for um the person who has MND…

**F:** Yeah

**I:** but we can click the audio and see what you think.

**Audio:** This practice will take about 10 minutes or so. It's best to make sure you won't be interrupted for that time, and also that you are sitting fairly comfortably and well supported. This is a short mindfulness practice in becoming aware of some different areas of your body, how their feeling right now. How you're feeling. There are no right or wrong ways to be feeling. But of course, some sensations are more pleasant than others. Sometimes some sensations can be quite uncomfortable. And we can notice that some sensations just come and go. Also, we can notice that sometimes we start to have opinions about what we're feeling. If this happens as best you can, just notice the commenting and return to simply feeling. Remember non-judgment, curiosity, patience and kindness are all helpful qualities to bear in mind when practicing mindfulness.

**I:** Um.. We don't have to listen to the whole thing, yeah. Typically, do you think you would listen to an audio or reading instructions and trying to practice it on your own?

**F:** I think having the audio there is good to kind of like guide you through it, like I can imagine if you would like want to like sit down and like have your eyes closed then you could kind of listen to the audio. So I think having, having that option there is helpful because it could seem like obviously it’s a website there's a lot of reading to do, so I think to like break it up and having like little audio bits, I think it's good, yeah.

**I:** Yeah, OK. And then just initial thoughts about stuff... I mean we didn't listen to the whole thing, but just style tone or…

**F:** Yeah, I think, I feel like on this page could it do like a picture as well or even like a little like calming video, like a calming picture just to kind of tie in with it

**I:** OK

**F:** Like I think that like, um, [would be] nicer as well, yeah.

**I:** That's… I forget these things when I'm doing so many pages. Um yeah, I think if we click next it should take us back. Oh no there’s one more page..

**F:** Yeah, well, I mean again, like with the others, I liked there’s a kind of like a conclusion at the end of each one. Like before you go straight back into the menu again, so having those there's is good

**I:** OK. Um, let's click next. I just want to very briefly, if that's OK with you, show you maybe one of the other sections, maybe not in as much detail, but just to kind of see what you think of it. If we go to the home page. I'm trying to think either adjusting to changes or dealing with worry and stress. Maybe like let's pick adjusting…

**F:** Ok

**I:** So, yeah.

**F:** Yeah, well I think here… I mean like I know it's obviously hard. You want it to reach one because you’re obviously doing it to two kind of audiences or groups. But I think even just at the beginning of each section, so here, if you just had a bit kind of aimed at people with MND and then at the families like to have to be through everything, I think just at the beginning of like the sections.

**I:** Yeah, that's really good. Yes, this is the kind of um, way, I guess it directs you through similar techniques, but structured, more based on how you're feeling… Would you… do you think you’d still prefer the other sort of approach?

**F:** Well, I think that the other approach is one I would go for, like when I do it first, I don't really know what to do then. Like once I kind of know what I want to… like what I'm looking for, having these different like adjusting to changes and having these different sections is good. I think it's just the first time I’d probably go for like ‘all techniques’ just to get like a feel for it.

**I:** OK, that's really useful. Just very briefly we won't go through the whole thing, but maybe let’s pick anger I think, 'cause that's a newish exercise. Yeah, so it almost selects a technique for you for that specific thing as opposed to in the other technique section, yeah.

**F:** Yeah, so I think again that's good then if you kind of, not like know which technique you want to do , but know what you're feeling 'cause like having these sections of like the ‘adjusting to changes’ and stuff and then having the emotions. For people who might not understand what you know, the actual exercises that were there, like what each of them are, having this option where you can kind of be signposted to a specific exercise, I think it's good having like both options there.

**I:** OK, OK. I'm. Yeah, we can go quickly. I think maybe across… it's a similar sort of mindfulness type activity. I’ll yeah go into the next, and a similar audio, don't worry, we can skip it. If we go onto the next... I just wanted to show you one more thing. Yeah, that's the practical tips…

**F:** Yeah, I think this is good then having something that people can like take away with them. And instead of it being like, you know something that you have to be on the website on your computer and have the audio then also having the thing like, kind of teaching you what to do and like how to just do this in like everyday life.

**I:** OK, OK. Yeah, so you almost learning about it. But then when you feel the particular emotion you can do anything you like

**F:** It just feels like giving you examples or like scenarios when to do it or like how to do it and stuff like that, I think it is helpful. It kind of makes it a bit more specific and like how and gives people like an idea of how they can actually use this and like apply this.

**I:** OK yeah, I think if you click next it goes back. Oh, it gives an example.

**F:** Yeah, well, I mean, like when there are like the quotes and stuff like that, to kind of tie in that like personal aspect of it and not just to feel like it's like some website where you're just going through, like different calming techniques like it ties it into MND I think yeah. No, I like when there's the quotes.

**I:** OK. Yeah, I think that's it from this section so we can go either back or to the homepage. I think. Yeah, return to homepage. So just sort of giving you an overview of the different bits of the website. We won't go through all of them, it would take ages. But I think, do you have any overall thoughts or feedback about the website on the whole?

**F:** Um well, I mean on, on the whole, I don't really have like any overall like negatives. I think there's just like some specific things where it's not too clear. But overall, I think it's good and I like that there’s the different options. So, if you know what you want to do and where if you don't know what you want to do and kind of signposting you, I think it's good. And that has a lot of different like techniques you can do here on the computer and then stuff you can take away and do in your own time. So I like that it has the kind of variety of things to do in it.

**I:** OK, that's good. Does it seem I know this is sort of hypothetical but does it seem like something you would genuinely use?

**F:** Yeah, I think if I was in like, in the like headspace where I know I needed something like this and yeah it would be something I would use or go to if I kind of felt like I don't know what I need to do right now.

**I:** More like say, if you were going through any of those emotions or if… it's hard to sort of predict, but if you felt stuck or I don't know, felt that there were negative emotions and didn't know how to cope? Is that what you're talking about?

**F:** I think yeah, any of the three. If I just had like any kind of feelings about like the whole situation, then it would be something I would go to if I was like, I don't really know how to deal with this right now. I think it would be something I would kind of like to, especially like just for me personally, I probably would pick like the adjusting to changes and dealing with worry and stress just to kind of look for like specific things.

**I:** OK, just going to quickly see if I asked you everything. No, I think I've covered all my questions. Um, is there anything else you wanted to tell me, either about the website or potentially using it or something like that?

**F:** Um, I don't think so. I feel like I've covered everything

**I:** That's OK, sorry, I rushed you through the last section

**F:** No, no, that fine

**I:** Do you want to take a look at anything in more detail or not?

**F:** No, I feel like I've got like a pretty good idea, yeah.

**I:** OK, no that's fine. What I'll do is I'll stop the recording, um, I'll still be on the call…

**[End of recording]**