**Interview 4**

**(person with MND and family member)**

**I:** Yep, so the recording should have started. OK, so this is the first page on the website and I guess before I let you have read of it, I was just wondering what your thoughts were about the title. And if you got any sense of what the website was about from the title?

**P:** Just from the word CALM

**I:** yeah.

**P:** Not particularly, I thought it was you were trying to set the mood more than anything. I was expecting that with the C-A-L-M, you might have an acronym there where each letter stood for something, but I don't see that.

**F:** Yeah, it was on the first page

**P:** Was it? OK.

**F:** 'cause that was the first thing I saw. I can’t remember what it said, but it was I thought was quite clever.

**I**: It was coping and living well with MND.

**F:** Coping and Living well with MND.

**P:** OK, now I get it.

**I:** OK, from that if you read this page, um, I was just wondering if it told you what the website was about. I'll give you some time to read it.

**P:** OK. I'm not sure on the last sentence there. Why do you feel it needs to say ‘it doesn't mention things that are too upsetting’ if you're trying to get them to feel better.

**I:** OK

**F:** Yeah, I don't like that sentence either. I don’t like the negative of that.

**I:** OK, no that's fair. I think we were trying to communicate that it's positive, but that doesn’t really…

**P:** absolutely, makes it a filter.

**I:** Yeah, yeah. OK, um anything else about any of the other sentences?

**F:** As I read it, it makes me feel that it's going to help particularly with stress. And I suppose it… because there's a, another software product called Calm which is a meditation app.

**I:** Yes

**F:** So I was sort of making a link with that in my own mind, it's around helping to manage one’s state.

**I:** OK, OK yeah, you're definitely on the right track. It doesn't have too much meditation though, but um, yeah, I see the connection. Um, any other thoughts? Or are you happy for me to go on to the next page?

**P:** Yeah, I'm fine.

**F:** Yep.

**I:** This is who… [pauses, waiting for them to read]

**P:** Yeah, OK. It sounds to me that certainly, you don't have to be a person with MND to access the website. Somebody can access it on their own without being person with MND right? The third sentence family members.

**I:** OK, that's good to know that comes across. Um, does it come across um, in terms of how you can use it, whether on your own or together as well.

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

**I:** And just out of interest, how would you typically use something like this?

**P:** Uh, I'll speak for us to begin with. Normally do it individually because we’re just in the habit of doing that. We have computers in the same room, we manage our time differently, so probably it would be individually to start with.

**I:** OK.

**F:** The thing that is really good for me is the visual imagery. I think it's really important to have images on the pages. I was going to mention that the one before, I just feel it makes it more inspirational somehow.

**I:** Yeah yeah, I see that. OK, plenty more images. Can I go on to the next? OK This is about who built CALM.

**F:** Yep.

**P:** Yeah, that's fine.

**I:** Um, there are two buttons here. I'll click through them to show you where they lead… So this is the research team. I guess this bit’s quite straightforward.

**P:** Yeah, that's fine. It’s alright. If you could just, sorry. Just on your graphics that… the third picture there doesn't look as the same kind of quality as the other ones. The one of [name of team member] looks like it's a quick iPhone picture or something.

**I:** Yeah OK.

**P:** It look distorted. So if the three of you are face on then she should be face on also just to make it all quite similar.

**I:** Right OK, I'm just making a note… OK. So this is a patient and public involvement team. They are usually people who help advise the project. Can you see the screen?

**P/F:** Yeah, yes

**I:** Any thoughts about this page?

**P:** Oh what about [name of PPI member]?

**I:** Oh yeah, she didn't want her picture on the website, but I thought it would be nice at least just to mention her name.

**P:** OK.

**I:** Um, some people have told me also that, um sometimes the picture of [name of PPI member] can be a bit difficult to see and I was just wondering if you felt a similar way?

**P:** Well, the lighting is not great, but we can certainly see him on this computer. We’re working on a 27 inch screen so both [name of PPI member] and [name of PPI other member]. Sorry it's [name of PPI member] that you're talking about?

**I:** Yes

**P:** Alright, I mean everybody that has MND is familiar with the T-shirt and everybody is familiar with the neck problem too.

**I:** OK, um I was just wondering in terms of… does it come across as sort of too distressing or puts you off looking at the website further?

**F:** No, because I think you got [name of PPI member] on the left and [name of other PPI member] on the right. And it's about that, this website is going to be accessible to anyone wherever they fit on the spectrum.

**I:** OK, OK. yeah that is useful feedback. I'll go on to the next page if that's OK? Sorry this doesn't have a picture, but it's basically a bit more clear about what the websites for. [pauses] Any thoughts about anything on this page?

**P:** The only comment because we're all from different cultural backgrounds and language backgrounds, it’s just me reading the very last sentence ‘if you need any more support,’ makes me feel guilty. If I wrote ‘if you need additional support’, that would be better language.

**I:** OK yeah. Yeah, that's fair.

**F:** I agree with that. I had a little, sort of resistance to that last sentence. But that makes it absolutely clear it.

**I:** Yes, yeah, we're not trying to discourage people from accessing support, yeah. I'm sorry I cut you off.

**P:** It's OK. I think I said it. Just the word ‘additional’ instead of ‘any more’ makes it more affirmative somehow.

**I:** OK. I will move on to the next page, which kind of explains the use of images a bit more.

**F:** Yeah, I agree with all of that.

**P:** Yeah.

**I:** This is a bit more specific now about how the website looks and how to use it.

**F:** OK.

**I:** Does it come across how to use it? Or would you like any more information?

**P:** Just to double check again, the last paragraph on the last tab, ‘All techniques’ tab. Does that mean all three of those or does it mean more information than those three?

**I:** Um, it's everything that's there on the website, um…

**P:** OK, why do you need that one then? People can just come back and keep clicking one of those…

**I:** So the previous three tabs have more of information as well as techniques, whereas the ‘all techniques’ goes straight into the actual techniques.

**P:** Oh OK.

**I:** Yeah, so it's a question of some people may want to read information and learn more about whatever it is they're going through. But other people know that a particular technique suits them and would like to just do that straight away. So it's just to accommodate for that.

**P:** OK.

**F:** Can we open one of the tabs at the top?

**I:** Yes, I will. I will take you to that page, there’s just one last page on the Introduction. And then we go straight to the homepage.

**F:** Yes.

**P:** On your third sentence, ‘you can also dip in and out whenever you feel needed as little or as often as you like.’ Does it remember where you were on any of those three tabs, or does it always start back?

**I:** Ah no, it does start back at the beginning. OK, but they are quite, short little tabs, but that's a good point as well, to add that functionality.

**P:** If it’s remembering you by logging in. I mean, I don't know if it's practical, technically wise to remember where you were, but when you had the other previous slide up, I was thinking, ‘well, if it went through the first 10 slides and I didn't want to do anymore of that, and I wanted to go to slide number 2 and see what it was like. Or do I have to go back to number one, would have to go back to the start again of #1? So it does make me think the way it says that now, that it might be, it's a lot of lot of effort to do as opposed to it remembering where I was.

**I:** OK, um how about we try some of the tabs and then I will, I'll kind of ask you this point again. Because it does have some functionality, but it doesn't remember exactly where you are in that sense. So I'll ask you about this a little later. So at the end of the introduction, did you feel like you would like any more information, or do you feel this is enough in terms of introducing it?

**P:** Well, I think it's enough if I'm curious enough to sign into their website at the beginning, we haven't gone that far along to get frustrated or impatient, so…

**F:** Yeah. No I think we’re also very aware of these sorts of techniques. I'm trying to put myself in the shoes of people who perhaps have never done anything about like this before, and I think will they be asking themselves what are these techniques? I think there… an example of, like techniques before they go into it might be useful just to help you think, ‘well, what is this all about?’. Are we just gonna look at pictures of nature, it may just, may just be helpful.

**I:** Yeah, rather than just be vague about techniques or tips. Yeah, I see what you mean. OK. Um, so this is the actual home page where now we can click the button. I guess both of you might have different views about which buttons draw you particularly or what you'd like to explore?

**P:** I think every individual will, because depending where you are on the progress and whatever your personal backgrounds are, I think you are right, everybody will look at those three things. The most practical one at the beginning it seems, is the adjusting to changes. And I think you'll probably get most or more people clicking on that one at the very beginning because it implies practical steps or advice. And not everybody is easy to deal with the emotional side. So the first one [building positivity] deals with that or state and the third one [dealing with worry or stress] deals with that. So I think your pick up might be people being on number 2 mostly at the beginning.

**I:** OK, that's really interesting, because actually that section deals with the emotions in relation to the changes so… Why don’t we click?

**P**: Ok, that’s me at the beginning, totally misinterpreting what the language is.

**I:** Yeah yeah, no that's the useful point because other people would read it in the same way, perhaps.

**F:** Um, may I ask, what do you mean by building positivity, which is obvious, and by ‘and meaning,’ what does the ‘and meaning’ mean to you?

**I:** Um, so the meaning bit is about, um looking at what activities or what things are important to you and kind of building from there. It's a sort of a shift in perspective based on um, not focusing on things you can or can't do, but focusing on what's important and then working from there. But I can see how that would be a little bit vague just from the title, yeah.

**F:** OK, that has no resonance at all, that little bit. I like your discussion around it, I don't think that word summarizes what you just said.

**I:** OK, OK. Maybe let's have a look at the meaning exercise as well and, or, or both. Adjusting to changes too, because I think maybe that's where either there's interest or slight confusion as well, so I'd love to hear your thoughts. Should we, maybe let’s start with the meaning one first…

**F:** Yeah.

**I:** And these are a couple of examples…

**F:** OK

**I:** Would you like me to click on any or..

**P:** Just before you do that, can you just go back one slide, please?

**I:** Yeah, sure. I’ll get it up...

**P:** OK, I'm just a little, not put off it, just not sure on your… how would I call it, first person or you say ‘you’ a lot it seems. If you’re speaking as, let's say a son of a person or whatever you want to call him, then you could use the first person you know. Say, ‘when I experienced this’, ‘when we experience that’. On the other hand, on your statement there and ‘With MND you may often feel like…’ and then on the other slide it did the same thing. I got kind of, not annoyed, but a little with personal changes in ownership.

**I:** Yeah no, I see that. Me looking at it too often, I skip things like that. Is there anyone that sounds more appealing if I use ‘you’ or the ‘we’?

**P:** I guess, I think ‘we’, but I think that maybe the not dilemma, but the problem with that is that again, you're trying to build credibility in the information you're giving. So if on your panel or on your team there are people with MND, then I think you're justified using the word ‘we’ or ‘I’ right at the beginning, I think that's good. But if there are not people, if it's just doctors and researchers and scientists and so on saying ‘you, you, you, you do this, you do that and the other thing’, to use ‘we’ sounds false. But if you are using someone like [name of PPI member] or the two [PPI members], and that strength of that statement is important, then it's fine to use ‘we’ or ‘I.’ Because it's listening, and coming from someone in my position. As opposed to this message is coming from another bloody doctor, telling me a different thing than the first doctor told me.

**I:** Yeah yeah, I see what you mean.

**F:** I think this is an interesting point here, because the audience for this is both sufferers of MND and also carers of MND or family members of MND. So I think you know, you have included all the system in this development. So for me, I always feel using we is quite a… it's quite a positive experience that I have when it’s ‘we’ rather than a ‘you.’

**I:** And you would, you would feel included as a family member with using ‘we’?

**F:** yeah.

**I:** OK. Yep, are you happy for me to move back here?

**P:** Yeah, that's good. I just think, in the second line, just ‘this can be helpful improving “our” mood and well being.’

**I:** Yeah, yeah, I'll make that consistent throughout, I probably will have used different ones, I think.

**P:** You need a period after the word positive.

**I:** Oh yes, the last one, yeah

**P:** Are we annoying? (laughs)

**I:** No, no. It's exactly these kind of comments I need to hear, because, um, when you're developing it, you literally look at the same page again and again so you don't pick up on these things, yeah.

**F:** Can we click the buttons? [buttons taking you to two quotes]

**I:** Either one of them?

**F:** Both of them

**I:** Yeah, sure OK. [shows one of the quotes]

**P:** OK. That's good.

**F:** Good one.

**I:** And, then yes. [shows the other quote] Do these sort of quotes help in any way to reinforce the message?

**P:** Yeah, I believe so. It's not uncommon. I belong to the MND forum and I don't know if you've ever been on there but they’re full of conversations like this, you know, new members that join up and then they're depressed or sad. And then you get the really positive comments from people like me and ones in lot worse condition who are trying to make them positive, and make them feel positive. So I don't know if they give you access, but if you wanted to see more information you can certainly go on that Association and see kind of the discussions that happen. So they're consistent with what you put on there about Chris and Ann [names of the people with the quotes].

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

**F:** It would for me, be good just to have photographs of them or another, each, each one. It just brings out a more personal, is more personal to just the written word.

**I:** yeah, I see what you mean. Um, that might be a little tricky to get because, I did interviews with these people previously, but it was just an audio recording of it. And yeah, I don't know what I can, but that's really useful for…

**F:** Actually doesn't matter whether it's pictures of Chris and Ann or not, it doesn't actually matter 'cause as you're… it's just to have a graphic, graphic of bringing a person together with what they're saying.

**I:** OK, yeah we can do that. OK, shall we go on to the next page? So this is the menu. And I guess the meaning bit was the values and goals exercise, but I'm happy to look at any other one if you were curious?

**F:** Well, I'd like to know. I mean, we know what pleasant activities are. What is benefit finding?

**I:** Um, we could go through both, if you like, um. Shall we click on it?

**P:** Try that yeah. [pauses to read benefit finding]

**F:** OK next.

**I:** Any thoughts on this page, just in terms of the way things are worded?

**P:** What are you, what are you trying to convey with the graphic?

**I:** That's… in a very cheesy way, almost. Seeing the light in terms of there being darkness, that kind of thing.

**P:** OK, I think it's very, it's very gloomy. No, I think…take a lot of pictures of sunrises and sunsets and you could make your point by, if benefit finding is looking at the positives then maybe looking at a proper sunrise, is good. Because the sunset would, may convey the wrong message and the picture you've chosen doesn't really convey either one. It's just darkness with like clouds. Make it obvious, a sunrise particularly if its over water is a good one.

**I:** Yeah, yeah, no, that's a good point. Probably the ratio of the silhouetted.

**P:** Yeah, it's 60-70% dark and less light And you can't tell time of day...

**F:** Um, can we see the next page? Yes I want to see what it is…

**I:** OK. Sorry if I'm going at a slower pace, just let me know.

**F:** Yes

**I:** so go on to the next page.

**P:** Things are fine. Quote seem OK.

**I:** So this is the actual exercise.

**F:** They’re excellent.

**P:** that's good

**F:** I like that.

**I:** OK. [moves to last page of benefit finding]

**P:** OK, now I'm gonna… if I was just going through this thing and I'm on this page. Well, after this activity, am I supposed to just look at the picture and have a feeling? Is that what you're asking?

**I:** Um… It's more sort of after you've completed those sentences, if there's a change in..

**P:** So its not related to the graphic just to be clear?

**I:** No, no, not the picture. Yeah but I can make that clearer.

**P:** Yeah, I don't, I said I didn't get the connection, I thought it was a new thing. Because you have such a, you know, good size picture there and it implies it's important based on the size on the page. And because there's a pathway and everything, it seems to imply some meaning or that could be the activity that I took from.

**I:** OK. Does this sound like something based on the information, that you'd be able to do or you think might be a bit difficult?

**F:** No, I think questions like that are really good. I'm a great believer in questions and you know, people might struggle a little bit to come up with answers especially if they’re feeling a bit depressed, it's hard to think what you believe. But it's really good to start, so I would find that very accessible for people.

**I:** OK. Um, yeah you happy for me to move on? [both say ‘fine’] So then it takes you back to this menu. So also, just because… just to see how it works in terms of the point you made earlier about like remembering where. So the activities in themselves are kind of short, but it keeps taking you back to...

**P:** The menus, yes yeah. I think that's good.

**I:** OK. Shall we try the values and goals section?

**P:** Sure.

[first page of values and goals]

**P:** Yeah, that's fine again, just again on the tense on the last one, identifying mixing the we and you.

**I:** Yeah, yeah. Is this clear about the meaning bit I guess?

**P:** Um, I would suggest that there's lots of people in your audience who don't know what you're talking about. We work… we are in, you know a lot of quite familiarity with values and goals because it's part of what we do and have been doing professionally for many, many years. So to us this is pretty general. And take... but if some, if you're talking to somebody, and I can think of another person I know who has this, who probably is never used the word values in his whole life. I don't he’d understand what the heck you're talking about. I think it's important I said, you know, even if you gave an example or something, just [**F:** that's what I was gonna say] 'cause he might say it was important to have a beer everyday. [**I:** Yeah, OK] Talking about values as you mean it. If you said just there ‘such as’ or they’re principles, or the ways we lead our life or the things we judge or measure ourselves against whatever language you have to explain values a little bit more

**F:** Yeah.

**P:** Goals people understand because you work with that entirely from the time you’re a teenager more or less, but values are awfully different to a lot of people.

**I:** Yeah yeah, and mean different things, I guess to different people.

**F:** Just a couple of examples on that second sentence to focus on our values, such as you know, so people say that's what the value is.

**I:** OK, OK. I can't remember if I may have made that more explicit on the next pages, but maybe just to see… Yeah, but I see what you mean as well about prompting people early on as well.

**P:** Yeah. You shouldn't say roast dinners because it's now making me hungry.

**F:** Yeah, no, that's good. That's, that's a very good page.

**I:** OK. And then I guess these examples again.

**F:** Yeah, let's see Jo and Nick… [page with quote options]

**P:** It's nice

**F:** Wonderful, yeah, wonderful that one,

[moves on to select Nick’s quote]

**P:** yeah it was good.

**F:** Very good, I like those.

**I:** Do they seem sort of relevant to your situation as well? [both: Yes, yeah] OK. Yeah, so that's just to prompt people to think about that. And then I guess another, sort of, you don't have to do it in this way, but um, just how to get you to start thinking about that. [worked example]

**P:** OK,

**F:** Very good, yes.

**I:** Um, any thoughts about example or?

**P:** I think it's fine as I said, you're making people stimulate their thinking. Yeah, I think that's being done OK.

**I:** So yeah, it's sort of I guess doesn't give you an exercise, but examples of how to do it because there is no particular way yeah, I guess

**P:** yeah, I think they’re very good examples.

**I:** OK. Yeah, so any other thoughts about this section?

**F:** No, that's good.

**P:** No, I think not.

**I:** Let's go back to the homepage. Um, I just wanted to probably show you the adjusting to changes, mainly because, it might not be clear just from the title, OK… [first page of adjusting to changes] Um? So then from this page does it come across that it's more about the emotional side than the practical?

**F:** Yes

**P:** yes it does, yeah.

**I:** OK. And then it breaks it down like this. Any first impressions about this page?

**P:** I think there's three good examples. Yeah, three good options now.

**I:** As a family member as well, so do you feel like these are representative in some way?

**F:** Yes, I'm there is a, there is a sort of anxiety piece which I'm not sure where that would fit in.

**I:** Yes, I have another section on anxiety.

**F:** Ok

**I:** Uh, yeah, that's anxiety in the ‘worry and stress’ section um? But if you felt there was any other bits that needed to be added, maybe..

**P:** You mean other options or other language?

**I:** Yeah, other options.

**P:** I think those three are probably very predominant.

**I:** OK. Um, would you like to explore any one of them or?

**P:** Yes, sure we can go through them and go through them all as long as it’s quite quick. [**F:** yeah] Anger is OK, yes, we can do that. I could do anger before I got sad and before I get frustrated. [laughs] We suffer from ASF [anger, sadness, frustration]. [both laugh]

**I:** (laughs) OK, um, let's go through anger. It may be a lot to do all of them, actually. So I was wondering if there was any one that stood out more to you, we could do those. Um, are you still happy to stick with anger? Yeah?

**F:** Yep. Let's go for suggested technique. [pause to read] Can we have a different picture? 'cause that's a repeat of the one we've had before?

**I:** Yes, yes, I will do that.

**P:** So I'm curious on the next part. Is this the end of the technique or is there more information?

**I:** No, there is more. This is just an explanation of the technique. And then… oh, sorry, there's more explanation. I guess it's trying to, um convince people of the importance of doing it, but I wondered what your thoughts on whether all this information was needed?

**P:** I'm still a little confused about your language of a 3 minute breathing space. Are you telling ‘take time out’ or you're telling to take 3 minutes and breathe in a certain way?

**I:** Uh, yes, it's referring to the particular exercise which last three minutes so.

**P:** And that’s still to come, is it?

**I:** Yes, yes. I guess this bit is just still the persuading someone to try it, that sort of thing. And then you could either listen to an audio, or if you prefer to read written instructions, you can do that. Um, we can actually listen to a little bit of it, maybe we won't go through the whole thing, because, um, just to give you a flavour of it. Can you hear that?

**P:** No. No, only you.

**I:** Now? [plays the audio louder]

**F:** No no.

**P:** We can only hear you, can't hear anything else.

**I:** Sorry was that better?

**P:** No, all we can hear is your voice. When you say something, I can't see any other audio control. Speakers are quite loud again, it's not playing right now.

**I:** I'm sorry I don't think that might work then. That's strange that you can hear that, though. Sorry, I might have to just work that one out. Should we go to the next one?

**P:** That's fine. OK.

**I:** It's a lot to read, I’m thinking...

**P:** Yeah it is a lot.

**I:** Yeah, I think it probably makes more sense listening to it because reading probably takes a lot of attention and then you're not doing the exercise.

**P:** Yeah

**I:** But essentially, do you get a flavour of what kind of…

**F:** Yeah, yeah.

**I:** Yeah, you've probably done similar ones.

**F:** Yeah, very familiar with those, yeah.

**I:** Then I'll probably move a bit quicker through this then. Um, so it's the three steps and essentially takes 3 minutes. And then this is a bit of a motivational bit at the end.

**Both:** OK, yeah.

**I:** And takes you back to here. Um… Any thoughts about that kind of technique for anger? Would you use something like that?

**P:** I think in the beginning yeah, so to calm yourself down, if that’s the goal. I don't think it deals with the questions of the anger really. But actually, I mean that's what it's meant to be as a calming technique. But it doesn't deal with the four points you put on the screen. And I'm not suggesting that you know how to deal with that.

**I:** OK, OK. Yeah, I see what you mean. It's a kind of almost like a starter.

**P:** Yes, it is like if I'm angry and my hearts racing then to say take up, take a minute, take a breath, sit back let's just be calm about this and take some deep breaths. Then I can understand how that works, but it doesn't necessarily take away the anger without some maybe discussion or contemplation of some kind.

**F:** On the actual guided meditation that will be the helpful thing for people to listen to it and do it as they go along. I think the guided meditation is what's required and it you know, there's lots and lots of very good guided meditations to help people understand anger. So you know, I'm sure that's perfect.

**P:** Why don't you find out why don't you get in touch with Deepak? He's got the greatest voice and it has the soothing meditations you could do. (laughs) Anyway, we’re being frivolous.

**I:** Yeah shall I go ahead, show you some of the practical tips. This is basically some people may like to do things like meditation, but some might not, so it's just offering other options.

**P:** Yeah, that's good.

**I:** Yep. Any thoughts about this or shall I move on?

**F:** Yes, I mean we don't know, that for some physical exercise, maybe it’s very difficult to do it, their in quite a… If we could, but I do agree that it's something around..

**P:** Um, it's something around, comfort and calming. So I think yeah, give yourself a bit of space, give yourself some time to think.

**F:** Its letting people know what is it that they find can change their mood so you know, what is fun? Is it a film? Is it a… you know, looking at photographs. It's around… so I'm physical exercise is very helpful, especially if it's ‘going out in nature’ I would have in there. I know you said ‘going for a walk’ or whatever, but for me going out in nature like the picture it should actually be. Going out even in a wheelchair would be a wonderful thing for people.

**I:** Yeah, almost making it a bit more open so you can add whatever activity that you prefer that sort of thing.

**F:** Yes

**I:** Yeah, OK, no, that's a good suggestion.

**F:** I do think it’s of importance of you know, even in the middle of a city, to go into a park or to look at a tree or… It actually does take away an anger.

**I:** OK. Um shall we go into next? This is another quote, I might change the format of it, I think.

**F:** Oh, there you go. [read’s Chris’ quote] Yes, very good. Very good.

**I:** And then it takes you back here. Should I, should I go back? Just because I'm aware of the time, I was just wondering if we could do maybe worry or anxiety just to show you something different?

**P:** OK, sure.

**I:** Yeah? I’ll let you to read this. [intro to section]

**F:** Can we look at this stress and feeling burdened?

**I:** Um, yes we can. It offers quite a similar technique in that sense, like it’s a meditation thing, but we can go through that.

**F:** OK, so it's the same guided meditation, that’s good? OK, that's fine.

**I:** Yeah it takes you to a meditation, but a different kind of meditation. So this one is more about a relaxation and to give yourself a break, almost. And also particularly for stress a lot of self kindness exercises. So essentially they are all meditations in a similar format, but focusing on different things like being kind to yourself and giving yourself a break, that kind of thing. Um, does that sound like something you would use?

**P:** That's alright, yeah.

**I:** OK. As a family member as well, [name of person] did you feel like this is relevant?

**F:** Yes, I mean I think it's really important to have, um, something for carers where they can realize that they need to look after themselves, you know, put your own oxygen mask on before you do it for someone else is, so the self kindness pieces is quite important.

**I:** Yeah yeah, I think this tab was mainly I mean, I guess it can be for both, but um mainly with family members in mind. Can I just show you some of the practical tips maybe?

**F:** Yeah, that's good.

**I:** And I think there's a little more.

**F:** Yeah. They’re good tips

**P:** A quick comment on your pictures again, it seems like you're repeating. This is the second bluebells picture I've seen and about the third mountain top. So I don't know if you're getting them from a service or you're just getting them from people in your faculty. Find other examples.

**I:** Yeah, I'll pay attention to that. I guess the other thing as well, just do the tips speak to both of you?

**F:** Yes.

**P:** Yeah

**I:** OK. Should we go back?

**P:** sure.

**I:** How are you both feeling in terms of energy or tiredness?

**P:** You mean with this process today or in general with this?

**I:** Right now I can't see your faces, so I can't judge.

**F:** We can speed up a little bit 'cause we now know what we're doing.

**I:** OK. Yeah, let's go through worry and anxiety a little faster. [intro page]

**F:** Yes.

**I:** Yeah, OK, I'll go to the suggested technique as this is slightly different. All OK with this page?

**P:** Yes

**F:** yes perfect. A bit of CBT. (first page of thought distancing)

**I:** OK, you're aware of CBT. It's basically trying to use those techniques, but in a way that's simple for people. So I guess you'd be familiar with examples.

**P:** Yeah, but they’re good ones

**F:** Good ones.

**I:** Do they sound simple? Like if you don't know the technical term as well, you’d still understand?

**F:** Yes, I think that's quite, they're quite good statements and examples.

**I:** OK. Yep. [TD – step 2]

**P:** OK

**F:** yeah, very good.

**I:** Any comments on this page?

**P:** I think it's alright.

**I:** So I guess that was the technique, but now it's just explaining it with different kinds of examples and strategies. But at the heart of it's the same thing. [metaphors]

**P:** OK. I like the second one, the online shopping example is really good. [F: very good]

**I:** OK. [STOP technique] Again, the similar thing, but using a technique if people prefer that method.

**P:** OK

**I:** And then an example of that. Sorry I will… I realize the writing is a bit small. Can you see it okay?

**P:** Yes we can because we're on a big screen. But if you're just on a laptop, it's really difficult.

**I:** Yeah, I will change that.

**P:** Yeah, OK.

**I:** Any thoughts about this example?

**P:** Good example

**F:** Yeah. It's always good to have examples. It makes it real for people, case studies are good.

**I:** But does it seem, relatable I guess?

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

**I:** OK. Sorry, I don't think there's a family member on this page.

**P:** But yeah, I think the last one, the stop technique can apply to either.

**F:** Yes, it's very good.

**I:** Let me go back to the menu, I guess. So you've got a flavour of what it's like…

**F:** I would like to have a quick peek at all techniques...

**I:** Yeah, I was just going to show you that at least to see the format in which it's given.

**F:** Yeah, great.

**P:** Yeah, yeah, that's good.

**I:** So essentially it's if say, used three minute breathing space and you just wanted to jump straight into it

**P:** Yeah, yeah, that's great.

**I:** And I think, yeah, you've seen most of them.

**F:** Yes, it's really good.

**I:** Yeah, is there any particular way that you think you would use it? And this question is to both of you really, as in, would you go through the sections or an all techniques style thing?

**P:** Again, if I was just signing on to this thing first time finding it, I'd be quite inquisitive. So I'd go through everything. Um, I think from what you've got on the screen now, every individual will have a slant towards one of those three. [3 main sections on homepage] So again, I think I would go to adjusting to changes personally, which I think is also what I said at the beginning, but that's the one that I would take. But people who are very discouraged and very angry again, going with one of the other two. Probably you know people seem to react to negative things more than the positive things, so they might go to dealing with worry and stress before they go to building positivity. Just again, it's just my opinion against…

**F:** And I think for some people myself, I'm using myself here, I would just jump straight to all techniques first. (laughs) I'll go straight to that just to see this sort of thing. And then I'll say, ‘oh, that's quite interesting’ on a click on that and then I'll go backwards and look at the others. It's only 'cause I… it's the way that my brain would work and it may be that others work similarly. But given that, it doesn't matter where the entry point is, we can get to all of it.

**I:** OK, that's good to know. Um, yeah, and I guess having an overview of what's there you can then explore the sections at your own pace in your own time, that sort of thing. Also overall, was there anything you liked about this kind of website?

**P:** I think just the things we've said about making the language as personal as you can do it. First person, personal and the pictures, just the pictures are so powerful a tool. And they’re good size on the page so... So you know the people who can pay attention to them as opposed to just look at it and say that's a picture. They can pay attention to the content. Yeah, and just the variety that you don't repeat anything. You could have similar but don't repeat it. It just makes a thing look like it was cheap as opposed to... (I: yeah)

**F:** I think you know emotional well being is huge. It's really powerful, and I love the fact that you're introducing mindful practices to every everyone who may have never had even thought of trying out these little tools and techniques. My only additional thought would be that I've met in.. with, alongside [name of person with MND] many people with MND and carers of MND, and they're all, well that's not true, many of them are very well educated and very um, very able to um, read up on research and technical aspects. And I think it may be helpful, not perhaps in this iteration of the website, but to have a link for people who would like to be signposted to more rigorous, um activities. It’s very much an introduction.

**I:** OK. Some more activities or more research about these kinds of techniques?

**F:** I think about more activities, accessing different meditations, useful websites to go to, things that other people… I just feel it. Um.. if people are very, very quick to learn and read, they’ll skim this very quickly.

**I:** Right, right. So it may be limited.

**F:** It's like… better signposting to you know, if you're... If this is sort of like an introduction to mental well being for people with MND love it, love it. But also there's a lot more deeper stuff that we can signpost you too and… That's yeah, that's what I'm saying. It is a simple introduction.

**P:** So they don't understand that this is the end or the only thing available.

**I:** OK, I see what you mean after a couple of times of doing the same meditation practice you might just be a bit bored of it and want something deeper as well.

**P:** Yeah or yeah, just a variety. If someone tried it and it didn't work for me, too bad there's not another one I can try. If there was just the way to signposting, even just blank suggestions that this may not work but if you know YouTube well you know, there's hundreds of easy exercises, there's routines and programs. There's meditation of any kind or sort you want, so just you know, other resources available, signposts to YouTube or signpost into some other research that you have access to or you know, programs that you know about.

**F:** Yeah, you know we don't in any way want to undermine what you're doing. We think this is a really good introduction to mindfulness, but for many, many people who have never touched it. Wonderful! We're always sharing that… we feel very committed to this type of work and you know, we know that we can support people by signposting them to many different directions of things that would help with MND, help understand ?‘ikigai’ practices of ikigai that you could put into people who are experiencing MND, which would really help with them. So we’re… we see what you're doing is wonderful as far as it goes. Just saying, not to let people think that that's it.

**I:** Yeah, yeah, I think that's fair. And that's exactly as you said, that's the purpose of it also to almost give a kind of introduction. But then people may prefer doing different techniques some may even want to actually visit the psychologist to have that kind of therapy in that sense as well. And it's not to say ‘this is the only option’, yeah, it's one of the options, but yeah.

**F:** Yeah, one of the options, very good.

**P:** It's a very good package you've put together. Very complete and practical, is not airy fairy.

**F:** It is very practical, very simple and very good for understanding. In simple language it's very very important. Yeah so forgive us if we've been a little bit you know… that's what you wanted us to look at, what's going on for us as we do it.

**I:** Yeah, no, that's exactly what I wanted and I think you're right, I have information about these general techniques as well. But tweaking it in a way that's relevant to someone who has MND or a family member as well, and that's the important thing. When you read it do you think ‘yes, this is my experience and I understand this.’

**P:** Yeah, yeah.

**I:** Is there anything else about the website you wanted to say? Or I can stop the recording as well and still be chatting with you if I think it's fine?

**P:** Yeah, I didn't have any expectation. I think it's well laid out as far as readability, graphics wise. You picked up on the same thing of the text in a couple places, like reading a book, and on a small screen it might be difficult. So however, you change the format somehow, that's the only thing I would suggest, because people that are already using small screens or laptop things in their wheelchairs or on a local little table, iPads and things need to be able to read it too. So they'll be able to see the graphics easier than they'll be able to read. I mean, they'll see the pictures easier than they can read the language if it's not crystal clear and not in smaller chunks somehow for those detailed pages.

**I:** OK. I'll go ahead and stop the recording, if that's OK. I'll still be on the call.

**[End of recording]**