**Interview 7**

**(family member)**

**I:** I get a message saying it's recording, Yep. OK, so this is the first page of the website and…Yeah, I just wondered what you thought about the name of it. So… coping and living well with MND. Um…?

**F:** Well, I mean I've got… I mean it doesn't jump out to me. I mean,I guess I understand where CALM comes from now, but I wasn't sure I knew what it was before.

I think… Well, I think I think there's different… I mean, for me the situation is different. I think it's the whole thing with MND isn't is that everybody's in a different situation and it develops and progresses at different levels with people. So in my case my father was only diagnosed in July. And he's already in an electric wheelchair and his upper body strength is weakening, so he's progressing very quickly, so living well doesn't seem to resonate very well with me. It's more like survival because everything is changing so quickly you don't get a chance to actually live it. You're kind of rushing around trying to deal with each thing as it as it happens. So I would say that's… that's for my situation, but I think for other people who are probably, you know, have got it and have got it for you, it is more about living well. So I think it's… I think it depends how you're coming after disease,I would say.

**I:** Yeah, yeah, no, that that's really good point. Yeah, I'm just making notes as we go along. Yeah, I wondered if...

**F:** I guess it also depends if living well refers to the carer and the family versus the person who's got it as well.

**I:** Yeah, so the intention is for this to apply to both. So also at any point if you feel like where it sounds like it's targeted more for the person who has MND and you don't feel like you related to the information, just let me know.

**F:** I don't really like the picture either to be honest. I know it's meant to be. I guess it's meant to be a calming picture, but I'm not sure it's relatable to MND do you know what I mean, maybe? I don't know you get more of. I don't know what... It's the… It's the blue cornflower isn't it? Is what the flower for MND? I don't know whether it would be… Is a flower quite relatable? If it's a nice field of those flowers or something would be more related to it, I don't know. I just feel the pictures are a bit disconnected. Although I appreciate it's what it's trying to convey, I'm not quite sure it fits.

**I:** OK.

**F:** And I’m not so keen on the colour, but that's a very personal thing (\*laughs\*). I don't think I like the green and the wishy washy blue; it looks it looks a bit like the NHS colour, really isn’t it? Maybe is it kind of… I don't know… bit clinical, I don't know.

**I:** OK, OK. Yeah, someone else said that as well. (\*laughs\*)

**F:** Do you want me to read the text?

**I:** Yes, please.

**F:** CALM was made… Well, I don't know what… CALM was made... is CALM an organization or is it just a website sort of? I don't know. “CALM was made” doesn't make sense. It depends what CALM is. It doesn't really ever tell you what… it’s coping and living with MND. But is that an organization or is it a… I don't know. You know it doesn't really say what, “CALM was made”. It doesn't make sense really.

OK, yeah. (\*reading out loud from the screen\*) “Going through difficult thoughts and feelings is completely normal when you've got MND”. So again, that refers... That's obviously referring to the patient, not the family.

And then you already referred to the patient, and then when you read the next bit, it says CALM gives you suggested activities to help you keep positive. Again that's referring to the patient. Then you bring back MND and then you bring back family members. But I think the two bits there are more connected to the patient.

**I:** OK, OK, yeah I see that.

**F:** Yeah 'cause you said when *you've* got MMD, not when it's affecting your family… you know what I mean? So you're automatically making it to the person...

**I:** OK. Um, if you go on to the next page.

(\*inaudible\*) should make it.

**F:** Who is CALM for?

Well, it doesn't even tell you who it’s for. It doesn’t answer the question straight; who is CALM for, it is for blah blah. It doesn't say that, it says (\*reading aloud from the screen\*) “you can go through the account website either by yourself or together with a family member or friend. Whatever you feel comfortable with, you may find it useful to include a family member, as they are able to help you”.

So again, it comes back to you may find it useful to include a family member, so it's again directed at the person at the patient, not at the family members. If I was looking at this. I would think it's for my dad to look at, not necessarily me. And their families and friends can also use CALM to help deal with their own emotions. But unless CALM… but you've already directed at the patient, so I don't know whether that's right. You would just be better off saying “Who is CALM for? CALM is for everybody! It's for all the family members. It's for the patients”. You know what I mean. So then you (\*inaudible\*) it’s general.

**I:** Yeah, say it up front, yeah.

**F:** And again the picture is a bit sort of… I don't know it doesn't… I mean, I guess this is a CALM scene maybe, but I'm not sure I guess.

**I:** The story… there’s going to be more nature, sort of pictures throughout. OK yeah, if you go

on to the next page. This gives a bit more background about where it came from.

**F:** Yeah, I mean I get it's… “CALM was made”... I mean it was designed or it was thought up by psychologists or it was instigated by them. Or it's a development and being… “CALM was made” sounds as if it's... I think… I don't know. It doesn't seem to… I don't know… If it's just a website, I don't know whether that's appropriate.

(\*reading aloud quickly\*) “Have been based on research… built through talking with… the stories and quotes you see… based on these interviews”.

I mean, I think maybe when it says, who is you know who is it for? You might have said some of this could have maybe been… Before… I don't know. And when you… “built”… “who built CALM”… that's kind of a quite an IT (\*for clarity, information technology\*) thing… that you build a website or something like that. Quite a sort of IT-ish kind of language isn't it? If you build a website… 'cause. You know who is… who is behind CALM. (\*inaudible\*) “Who built it” sounds… It sounds again a bit like you're not quite sure… I'm not quite sure what CALM is. Is it… You know, by reading this? Is it an organization? Is it a building? Is a charity? It's not clear that it's just a source of information on the website if that's what it is, then it has not said that yet.

**I:** You need to say that clearly then yeah.

Um it if you see the two buttons at the side, could you click them and tell me what you think?

(\*pause while reading\*)

**F:** Well, you gotta read it to know what it is. I don't know why you… why I wouldn't... I don't know why this is maybe… I would prefer to have like a bold title of the name of the person. And then maybe a bit of information about them rather than having it all to be reading… I don’t know…

**I:** OK, OK.

**F:** You know it could be, you know… You know… your CALM expert team or your CALM helpers or something. Make it a bit more… You know it sounds quite clinical as well. Not very sort of consumer-ey.

I’m not being disrespectful, but maybe maybe you as a PhD might not be the best one to put first as well. You might be better off being in third position 'cause I think maybe people will want to know more about. A professor of health psychology or a psychologist. You know… it might have more credit than a PhD student, so the fact if you only ever read the first one, you might think, oh gosh, it's just designed by some students. You might not go further. Do you know to mean I just think…

**I:** yeah, yeah. OK... (\*pause\*) If you look back, I think. Yeah, I'm keen to see what you think about this page 2.

**F:** (\*pause while reading\*) Well… One, I have no idea what “PPI” team is. But I’d have to read up… public involvement… so that would be err… I'm not quite sure what that is, so that would be.

That maybe needs to be explained a bit more. Yeah, with an explanation to this and that before you link onto them. Because I wouldn't have known without reading that who they were.

**I:** OK OK yeah I can do that.

**F:** I would not be sure why I was clicking on it. The CALM website was made- typo- *by* working closely with members. But I still don't like “the website was made”. Or do you mean… I don't know…This information or this website or… I think *created*, *designed* to help or I don't know. You know, there's.

**I:** What do you think about the pictures and information about the PPI members as well?

**F:** Well, I think Philip. I think seeing Phil here was would probably be quite scary. Depending on where in your journey you were over MND. I'm not saying you shouldn't show people, that's how it… people will be, but that for me I find that quite… quite upsetting because I know that's how my dad will end up.

So I don't think it's bringing me a calming nature to see that picture. Otherwise, you know, I think again it depends what stage you are with all of this I guess.

**10:52**

**I:** Do you think the writing helps at all? Or is it just the picture that's stronger and that's why…?

**F:** Well, here you said “the CALM study”. There's been no mention of a CALM study until now, so I'd be going... I'd be like, oh, so is this a study? What… what is this CALM? I'm still not convinced. I'm still not 100% sure even though I've read a few pages. Now they know what CALM is 'cause now. You see here. It's a study where is actually someone else would have thought it was just a website, so I'm confused myself now.

(\*gesturing to a picture of Phil, a patient in an advanced state of MND\*) And how long has he had MND? You know, “I'm at living with MND for X amount of years”. I think that's what quite a lot of people want to know

**I:** OK, yeah. I’ll add that.

**F:** And I guess as well again Karen's quite short (\*referring to the length of text below a picture of Karen\*). You know, how long did your dad have? When did he die? You know we had it for so long. Maybe make her a bit more relatable 'cause it's not… OK, we know she's this and she's… her dad has died. We don't really know much more about her, so maybe that would be more relatable if she said, you know, having my dad had it for X amount of years or I don't know. Or I can really relate to the shock I had. You know, I wanted to help people because I remember the shock I had when my dad was diagnosed blah blah blah. So make it more engaging.

**I:** OK, OK yeah.

**F:** I feel like we live with MND services and (\*inaudible\*). Well, I mean, I guess he says a bit more doesn’t he, so I suppose he's not.

**I:** Yeah.

**F:** Shall I go back?

**I:** Yeah. Go back. Yeah, if you go on to the next page. Sorry, I know the introduction is a little long.

**F:** Yeah, I mean I prefer that picture of all of them to be honest, I don't know why. (\*laughs\*)

(\*Reads aloud from screen\*) “You’ll find pictures of nature on almost all pages of the CALM website. As well as being there to make the pages brighter, research has shown that…”

Yeah, I can understand that, but the whole… but I can see maybe why that you put the pictures in but the pick the… the design of the website and then images seemed slightly contradict each other, so I don't know whether… There's something more to do with the whole design of the pages to make them more nature focused. I don't know. Do you know what I mean, it just seems a bit like the pictures... OK, the beginning. I understand that pictures are meant to be calming, but they just look as if they've been put there. You know, with… So I can't....

**I:** The rest of the design is a bit on the clinical side and then the pictures are. Trying to take you to another place… is that…?

**F:** Yeah, but it doesn't seem to. They… they don't. They need to be more interconnected, even if there's I don't know. I mean, I don't know how you can do it, but I don't know where the picture was the background and the… the text was on the picture or something. You know? This pic if the image was this whole screen or something, I don't know. It would just be… They would then be more integrated, whereas you just see that you read the text and the pictures is (\*sic\*) just something on the side… It's not something…

**I:** Yeah.

**F:** It looks like it's filling up space as well because… The writing is quite big and things on the screen as well, so it feels as if you're… filling up space by having a picture.

**I:** OK, OK. Um, yeah I'll try and find a way to sort that out. If we go on to the next page. Hopefully this gives you a bit more of what’s actually in the website.

**F:** But it wouldn't it. Would it be designed like this as well? It's just 'cause the navigation is quite… You would be going through each page would you, to get to this stuff? Or would you be?

**I:** As in this section, we've just gone through… or?

**F:** yeah, 'cause I… if I… if this was like the final website say I would… I would assume they would be a menu at the beginning and I could get directly to some of these things. Or is it that it’s the whole way that it's done? You would design to go through all these steps.

**I:** Right, I don't know… so… (\*noise disturbance\*) Something else started playing. Sorry about that. Yeah. I’ll close that down. Sorry, were you saying about that?

**F:** No, I was saying about the navigation so… so will the navigation be like this so you go through certain pages to get to this? Or is there a way of? There'll be a menu and you'll be able to get to pages directly. Or is this how you be navigated through it? If you were trying to use the website,

**I:** Yeah, so we're going through the introduction section because it's the first time that you're logging into the website, so it's a bit a bit of a background about you know what to expect and how to use it. But if you log in the second time, you come directly to this menu page, and then you can choose as you like. Whichever section you want to OK go to.

**F:** Yeah, I just think if you were going on for the first time, you might not get this far 'cause you've had to get to quite a few pages before you got here, so would people be… I know people are probably quite engaged in the topic, but I think… you know… you’re also time… you haven’t got much time and probably in a rush to get to some of these things. So would people have clicked all the way through the introduction to get this far. I don't know.

**I:** OK, OK, yeah, make it shorter in some way. Yeah.

**F:** Yeah, because a lot of the things I've gone through or optional really. You know you might not always want to know all those things, but… you know… you need to have it for people who need to know I guess. But and also, I've never till I've got to here. I'm not really sure what… what this website is going to be providing for me, so I would have wanted that a bit earlier on as well.

**I:** Yeah, yeah. OK.

**F:** Should I click on something or…?

**I:** If you go on to the next page? Sorry, this is just to tell you about it and this is the last of the introduction pages.

**F:** Yeah, I mean I would probably have that. That's… that's probably that's probably one of the first things you want to know, wasn't it? What it is and how to use it. I would say it's probably something I would have wanted before now.

**I:** OK. Yeah. That's there. Um, yeah, if we click next. Yeah, so this is the... The home page. I was just wondering from the different options, does any particular options stand out to you? In terms of where you are at.

**F:** Can I just say one more thing as well? If I was just looking at this page, I have no idea that this was… I mean, I know I see I would have had to had to read things before, but... Motor neuron disease doesn't jump out anywhere to make sure that I've got the to the right place, you know to mean.

**I:** So say… mention MND somewhere?

**F:** well yeah or even… even there should be something running through the bottom or something.

**I:** Yep, as in… linking it to MND?

**F:** Could be for anybody. I mean it doesn't have to be for anyone related to MND. There's nothing on here a lot of the pages are a bit like that as well, and that if you've missed out what the CALM definition is at the beginning.

**I:** Oh, I see.

**F:** Even if it's the Association logo on the page somewhere or something, so there's always some sort of reference to it, you know?

**I:** From any of those options, does anyone stand out or would you like to look at maybe all the techniques?

Um, either I'm I'm trying to be led by whichever you would typically use that, that sort of thing.

**F:** Well, I don't like well, I mean I am in my job. I have to look at things I said. I'm quite critical of this. 'cause it's grey (\*gesturing to a dark grey button\*). It looks as though it looks as if it doesn't work 'cause it's not coloured. It looks as if the box isn't going to work. It doesn't… it doesn't match with any of the other colours, so that would just be one comment so I might not press that.

Um, all techniques. I wouldn't know what that meant without looking, so I wouldn't all coping techniques or or what techniques. So I think that that's a bit ambiguous. I think that would be better having a bit of a explanation.

**I:** OK.

**F:** (\*reading aloud\*) “Dealing with worry and stress. Adjusting to changes”. Adjusting to what changes? Doesn't say enough there. “Building positivity and meaning”. In my life, or is positivity and meaning in… what I don't know.

Dealing with worry and stress is the only one I can understand exactly what that might say. The other three… I'm not quite sure what I'd expect to see.

**I:** OK. Maybe let's click dealing with worry and stress then?

**F:** Yeah again, so this would make me feel that it was again, maybe the patient. “With MND you sometimes feel yourself feeling worried and stressed”. Kind of.

“If you’re struggling with these feelings. In this section we suggest some ways to deal with these feelings. You can try… self kindness and mindfulness exercises from the all techniques section. If you're looking for more information to deal with worry and stress.”

So maybe it would just say… maybe that would be something to make sure when you explain what's in all techniques then that was fair.

Worry and anxiety, stress and feeling good. Yeah, so those are two options and they take you to different sections.

**I:** Um? Any particular one you'd like to click?

**F:** Yeah, I mean I think. Well, is this “being burdened with worry”? Or if you're a carer you burdened by the overload of work you've got 'cause you suddenly become a carer rather than a partner or a you know carer rather than a daughter?

**I:** Yeah, it's meant to sort of appeal to both, so if you… If you have MND, it's being burdened with just carrying out daily tasks. But if you're a carer then it's being burdened with caring.

**F:** Yeah, quite negative word though right? 'Cause you know if you have them (\*inaudible\*). You don't want to think of your carer as being burdened by you do so I don't know if I like that word. “Feeling overwhelmed” might be better than “burdened”.

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

**F:** (\*reading aloud\*) “There is a lot going on… Feel that everything is difficult... These fears are common… give ourselves a break”. Yeah, I don't like doing that, I think it's quite negative. Shall I go into tips.

**I:** Yeah… I don't know why that's not a line (\*referring to a formatting error on screen\*). I had made it a line, but it seems to have come...

**F:** It looks like it's a bullet point. (\*pause while reading\*) I don't think there's anything sort of rocket science. The picture... I can see the picture again. It's just that I just see that the picture is a bit of a like filling in the gap.

**I:** OK. Um, yeah. Next This one, yeah.

**F:** (\*Reading aloud\*) “Here is some advice for the people with MND from other people with MND and their family members. Why other people? Oh, *from* other people. Yeah, sorry.

Why? Why would you separate the two then? Why have you got the ones before and then this one is from other (people with MND)…. Shouldn't they both be integrated? It should be the same advice. You know what I mean? The same advice really. Give yourself a break.

**I:** Uh, yeah, yeah I guess I was coming from it more as like…This is what healthcare professionals would say and this is some more like peer to peer advice…

**F:** I don’t like that distinction. Does it matter who says what? Do you just want the advice, don’t you? Doesn’t matter who is coming out with it. And now I've got to read two pages rather than one. Especially when some of it is repetitive. I'm not sure it's helpful.

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

**F:** Because you've already told me I'm going to go into practical tips, but I've now had to wait. I've got to wait… you know what I mean? I need to come in to another page now. There's a lot of clicking through. Especially when you know that the people that using this haven't got much time and having small breaks, it kind of the practical tips are kind of eating up on your time.

**I:** Does this sound relatable as well? Even for a family member?

**F:** Well, I do, I mean, I mean… I don't live with my dad, it is my mom that is the main carer. I think my dad needs help with absolutely everything, so it's alright to say, you know, take some time for yourself. But if my dad needs to go to toilet or something, you can't, you can't. It's… you're always on call, so I think it's quite a difficult and with covid as well, probably makes it more difficult. You can't miss… get support as much you need so... It is, it is more difficult I think, and I think as well for someone with MND, it's such an adoption for them to be asking for help as well. When the person has reached out to you for help, you don't really want to let them down and say you're busy doing. You know you can't, so yeah, so there's a bit of a everyone is trying to adapt to a new way of working. You know my dad was completely well as everybody is and they're all completely independent and everything until this happened, so he's having to adapt in losing his independence. And my mom is having to adapt too. (\*background noise and interruption\*)

**I:** Yeah we can. We can go on to the next. Maybe um, maybe look at this. Yep. You can click the suggested technique button.

**F:** Oh yeah, they were back to the one we were on before. Yeah, there's a lot of “give yourself a break”. I mean… that was on before… so we are repeating a bit.

(\*Reading aloud\*) “Safe place meditation”. Well, it's not just stress, it’s stress and anxiety, isn't it?

So do next?

**I:** Yep.

**F:** Ah, there's no picture here. (\*laughs\*).

**I:** I think there was just a lot of information to cover.

**F:** I guess as well… on the usual websites you scroll down to see the information and you're not really always having it all presented on one screen. So that would make things… you wouldn't be doing as much clicking through then maybe.

Yeah, I mean I don't know whether you can say people with MND often say they find mindfulness helps. You could always… could you not just have one of the quotes from one of those people like you know, the picture of whoever is one of the three people you had saying, you know? Yeah, maybe if it was a person saying I found this really helpful?

**I:** Yeah, I think I may have mentioned it on one of the coming pages. Um?

**F:** So I go forward then?

**I:** Click next, yeah.

**F:** Yeah, yeah, I think this is the thing… you having to click all the time? It would be nice if that was with the bit before.

I think I understand mindfulness, 'cause we do it no, but I think with MND I think it's a difficult one because. Yes, you have to think of the moment and you don't want to think of too much into the future. But because it's a constant changing situation and to a degree you have to be a little bit forward thinking so that you don't. You know… you don't get lost, so that one you need to get your stairlift fitted so you can make it up the stairs. Otherwise there's no point waiting until the day you can't get up the stairs to get your chair lift. Because it might take a month. So you might need to get a ramp fitted before you get your wheelchair.

**I:** Yeah.

**F:** It's a common. It's a difficult balance, isn't it? I think but, but I guess I understand mindfulness works for lots of people, so… so that's fair enough. Yeah, I think it's… it's a different thing for different people.

**I:** Some people like the opposite approach where you know your plan and get stuff ready and that actually helps with anxiety and stuff so I've kind of given options, but it's completely fine if, say, mindfulness is not helping or like this is not the only strategy or technique,

**F:** yeah, I probably would have liked maybe that one going back to that page where I had three lists or four options. One was the other techniques. I might have liked, rather than having it done like that, I might have just wanted to see mindfulness. And the things up front. 'cause then I know what's there. 'cause I do find them having to click through…

**I:** Ah, OK.

**I:** I find all these things and you want them upfront, really. Especially… especially when the practical tips are taking time out for you and you're telling someone that their time is precious, but then actually it is taking quite a lot of time to get the information they want from your website, I would say.

**I:** OK, OK,

**F:** And you don't see many websites that... Why don't… you don't see many websites that have just got two quotes on the screen, you would normally have the quotes embedded in part of the earlier screen, you know what I mean?

**I:** Err… yes you can click through to get to a quote or something like that.

**F:** Well, you don't need to. I mean… there’s not much information, this is more like a power point presentation that I would be giving to an audience that is a website. I would say, do you know what I mean? That's maybe what I'm struggling with.

**I:** OK.

**F:** 'cause when… when I'm on a website I'm used to scrolling down or having a drop down menu or having information that I can get to quite easily, it's quite easy to navigate. Whereas with this it’s quite a… it's more like a PowerPoint presentation where I’m having to click through, click through to get to the information I want, whereas a website… is normally a bit more interactive.

**I:** Right, right. If we could click the written instructions, actually I just because it's easier to comment on. Sorry though, it would be a fair amount of reading, but in that's just for the interview purpose I guess in reality you would listen to the audio cassettes.

So I'm just trying to make sure I phrase things correctly.

**F:** Yeah, in this activity… I don't know. I don't, maybe… I don't like the word exercise. People think of exercise as going for a run.

**I:** OK.

**F:** So this… how long would this be then? If it was the audio?

**I:** About 6 minutes.

**F:** So that would be your that be your session of meditation.

**I:** But yes, I think there's one more page. And in total it takes 6 minutes.

**F:** Yeah, that’s fine. I mean, I guess, could people just say different things that they were guided meditations… so it's… it's what you what I would expect to see just going back… Does it say here anywhere how long it's going to be? I would say if I was going to do this I wouldn't know whether it's the five minutes, 20 minutes, half an hour, you know what I mean? How long I was going to be there for?

**I:** Yeah, yeah, that's really important. Um, I don't think I've done that on the other, so it's a good point. OK, yeah. If you can't, then next I think there's just one more page.

**F:** Yeah, I mean that could be with that. I mean, I think you're only saying like 4 lines there that could be here somewhere couldn't it.

**I:** Yep. Next Um, this actually I wanted to show you maybe go to home on the top where… the all techniques section is. Yeah, so was this something like what you were talking about? A place where you can see it at a glance… everything.

**F:** Yeah, so I would rather have like everything like this, so even including the other bits before rather than, I've gotta click through to find what this one is. I'd rather this if this was all. If everything you've got is in one place you can just use what you want then I think that would be for me that would be better.

**I:** OK, OK. Um, yeah, so this… this option is if people would prefer that kind of approach. Um? Does it offer a correct level of instruction? Is it clear for you to know where to go?

**F:** Well, I would just have a click and see what's there I suppose. OK, compassionate break. I don't know what that would be. Would it just be a break? Befriending yourself? Not quite sure I know what that would be. Compassionate letter writing to who were suppose is up to a friend. Three minute breathing space. I don't if that’s mindfulness again. That’s 3 minutes there, but before it was six.

**I:** Yeah.

**F:** Changed place meditation is that the same as that three minute one or not? I don't know body scan. How long does that take? I don't know. I mean, maybe… maybe it would be useful to have “this is your one” if you just need a 3 minute break. If you need a whatever break this is it. And if you've got more time… or to help you go to sleep at night. This might be the one to do. I don't know if that would be maybe?

**I:** OK, OK.

**F:** 'cause I don't know what the difference between the three are. Yeah, and then pleasant activities. Is that just a list of things? Nice things to do? Which is obviously different for everyone. Benefits finding: that sounds to me as if you're trying to get benefits as in social services, kind of.

Benefit finding rather than… benefit finding of *what* 'cause there's a lot of talking in MND isn't there, about disability benefits… so I wouldn't… wouldn't be sure what that was. Values and goals again not sure and then thought distancing. I don't know whether that would be linked to mindfulness and relaxation really. 'cause all these are all about quieting your thoughts a little bit at least. I'm not sure why that would be different, I don't know.

**I:** Um, did you want? Did you want to try any one of these?

**F:** (\*Clicks on “Benefits finding”\*) I have no idea what that is.

**I:** It's not about social care benefits.

**F:** I guessed that, because it wouldn’t have fitted, but they still didn't know better. “Trying to find some positives”. Well, that's more about positive thinking or positive mindset, isn't it? I would have said not benefit finding. Don't know. Or gratitude or something. Keep a gratitude diary or whatever they call it, yeah?

**I:** Yeah.

**F:** I think the other quotes you gave me. They didn't have any name underneath did they? The ones we saw before. I think I prefer to see a quote, so I prefer this when it says who it's from. And I also maybe would be quite nice to see a face, if that would be possible.

**I:** OK, about that, um, I guess, um. What do you think about the the label of “person with MND or family member of person with MND”?

**F:** Well, I think that's quite useful because then you might. It relates to the two ways you're coming after, I suppose. 'cause it's for both people, isn't it so?

**I:** But it doesn't sound like too impersonal or something like that.

**F:** No, I mean you could put “Ian, Living with MND for X amount of Time” or even maybe, that would be another way to make it more personalized was “Ian, Diagnosed X well...”, but yeah.

**I:** OK. Uh, if you go to the next page. This is the actual exercise.

**F:** Yeah, I just think I'm on Page 3 of benefit finding, so I would have still wanted to know this before now.

**I:** What do you think about this kind of exercise?

**F:** Well, I mean, I still think it is better. It’s finding the positive, isn't it, in a bad situation? So although this has happened well, I don't know why... I mean, although this has happened as if you're trying to cover it up as well. Do you mean although I have MND, I feel lucky that… or although I fell today I feel lucky that… I don't know? Maybe that's why.

An unexpected good thing that happened was… I don't know. I am surprised that… something I learned was… I'm not sure I would personally find it useful. I would find someone thinking of… what do they say before you go to bed? Think of five good things that happened in your day. You'll be grateful for them. I find that better. I think you're being quite prescriptive, and sometimes you might... People might... If they can't think of anything, might feel a bit disappointed in themselves if they can't answer this.

**I:** So… more like give people... An option like you could do it this way, but also you could... You don't have to complete one of these sentences.

**F:** Yeah, 'cause I mean I don't know what this is. I mean I get it, is this the benefit of here then? Is this what you're saying? So even though the person is really all upset that someone's got MND, if all this together? So that's the benefit, yeah?

Yeah, I'm not sure I mean. Personally it’s probably brought me closer to my auntie, but on the other hand I'm not sure I would think of that as an amazing positive compared to the awfulness of the situation. It does not outweigh it, you know to mean so I don't know whether...

**I:** Yeah, I think the idea was not… 'cause you're right. There is that negative component and it's not trying to like, ignore it or pretend it didn't happen, but just kind of acknowledging that there is positive but it's not to say that you know one stronger than the other. Yeah, I don't know whether that comes across.

Yeah, if you go to the next page.

**F:** Maybe it's the first one: “although this is happened, I feel lucky that” is probably not… I don't know, that's probably kind of a bit of a “oh really!?”. You could have someone going on here and thinking “I don't think so”. Maybe if it was at the bottom, but because you start with that it’s a bit difficult.

**I:** I see. Yeah, do you feel like that about any of the other options?

**F:** Well, I'm not so keen on the first 2, “something I learned” was is quite neutral. Isn't “something I can be proud of” is that my grandchildren or whatever. “I am grateful for” their quite neutral. I think this one I don't like at all. “Although this is happened, I feel lucky that” I'm like, really? You know, I don't expect it. “Good thing that has happened” is, you know, maybe not for the first two. I just don't like it.

**I:** That's good, um, yeah. I think there's just one more page.

**F:** Yeah again, I mean it's a lot... I don't know why we've just got a whole page on this, unless that's the way you... Unless there's some psychology in this in the fact that I'm clicking through. So much is meant to slow you down or take… is that the whole thing, that it's taking time out of your day, so therefore... This is this is meant to provide you with your break.

**I:** Yeah, I guess all these activities, really, um? It is difficult to just jump into, um. And typically you would do if you were doing something like this. With support you be guided through it, so this is also just trying to replicate that. I guess in pages. Yeah.

And I guess also to give you time to maybe do some of the activities and break it up that way. If there was nothing else on this page… We could go to the next one maybe?

I wanted to ask you some questions about the overall. Kind of website, but if there was anything else you wanted to… Any other option you wanted to click on just let me know.

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

**I:** Yep, so I guess what I what I wanted to know was. If you would see yourself using some kind of support like this?

**F:** Well, if I'm honest, I don't know if I would say probably wouldn't. I mean, maybe if there was a link from the motor neuron disease website or something. Association to this, maybe I would.

And I don't think there's. I mean, I mean, maybe we do a lot of Wellness activity and stuff in work, so a lot of this is stuff that I already know to a degree, maybe so I don't really know for me. I don't think my mum would have the time to go through this, to be honest.

**I:** OK, OK. Uh, yeah, I know that's completely fair, um. And yeah, some people also I have (\*inaudible\*).

**F:** I found the navigation a bit frustrating 'cause you know you have to go… It’s just not a lot of information on some pages I do feel as if I'm more being presented with the presentation rather than being on a real website. That's just...

**I:** OK, OK. Yeah. So the overall kind of presentation and. Um, how it guides you through? That's yeah.

**F:** I mean it. Just it looks it seems. I mean, it just looks like a power point presentation, doesn't it, really? But maybe that's I don't know if that's how it ends up. I feel as if I'm in PowerPoint rather than being in a compassionate website. That's kind of… I'm a bit lost. It's not very professional. Maybe makes me feel it's a bit. Quirky maybe? I don't know… I know it's from a student background or whatever, so I guess maybe that's there, but it's just needs a bit of IT support to get it to be better I think.

**I:** Yeah, I know what you mean.

**F:** I suppose it sounds awful, right? And I don't mean this, but like MND as we know is a very underfunded disease. And it just kind of reinforces how… You know, if you went to the Cancer Research website around some of the website you go to all these all singing and dancing bits of things for information.

Do you know what I mean? It's all. Very professional and it's been… it's been there for years and they've been developing it for years. It makes the situation feel a bit sort of. Unprofessional, maybe in a bit sort of like… I can't… It’s hard to express myself, but it just reinforces that whole awfulness of a situation where there's not much… You know that people are trying their best to do something but it just reinforces the need to do more and to be more advanced in this area, I think, but that's just me.

**I:** Yeah, yeah no. I see what you mean. Um? It just also in terms of, like, um, the way the content was. Do you think you use something like this or you already sort of use similar techniques, so stuff like that?

**F:** Yeah, I mean I'm probably lucky with my work. As I said, we do a lot of Wellness activities so we have free access to headspace apps and things like that so. Which are all a bit more professional because they're like designed specifically. So then when I come to something like this when I'm comparing it to that, which is obviously a paid for service, then headspace which I’m fortunate that work has paid for. This is not... It's not there, is it? So I suppose I would... I would then not personally, then I would not be using it because I just think it's not… not as good as what other things that… that are out there unfortunately.

**I:** Yeah, yeah, yeah. Um? Yeah, I think I was there. Anything else about just generally about the website. I think I've probably covered most of my questions.

**F:** Yeah, I mean… Just overall a bit more clarity on what it all is really and being more sort of upfront on what it is and who it's for and… You know… as I said, but I'm not sure after looking… I still wasn't sure. Is CALM a charity, organization, academic institution, PhD project? I still don't know. And then there was a mention of a study on one of the things is it study? I mean, I know this is part of a study, but that's just your evaluation of website. I assume. I don't know.

**I:** Yeah, yeah no. I did present it in slightly confusing way I think I'll just streamline that a bit better.

(\*Recording ends\*)