**Interview 2**

**(family member)**

**I:** Yes. It's recording. Yeah, so um, this is the first page that you would typically see if you clicked on the website. But I guess you saw the page before this as well, which said what the name of the website was: “Coping and living well with MND or CALM”. Um, and I just wanted to know what you thought of the title?

**F:** Uh, yeah, no I like the title. Makes you feel calm.

**I:** Does it kind of give you any hints about what to expect?

**F:** Uh… That it’s gonna make you feel a bit better.

**I:** OK. OK, that's good. And then this- the page you're looking at right now is the first page. Um, so I’ll just give you a little bit of time if you haven't read it, just maybe go through some bits of the information and just tell me your first thoughts about it.

**F:** Uh, I suppose if I read the things it says it doesn't mention things that are too upsetting then I think “Oh is it trying to hide things from me?”

**I:** OK. OK yeah, no that's fair.

**F:** Otherwise, it’s- otherwise I think it sounds like it's gonna be quite a useful positive thing.

**I:** OK. If you click the “next” button. Great, so this is the next page about who it's for.

**F:** I suppose 'cause I'm quite a solitary person. I just read it and think “oh, I'll just want to look at it by myself.” I don’t think I’d particularly wanna sit and look with it with someone without knowing what it was but that's me.

**I:** Um. Does it, does it say that-Um. Does it come across to you that it's open for family members as well?

**F:** Yeah, so you can look at it together with a family member or a friend.

**I:** OK. Um. If you click the “next” button. Maybe click it again. I don't know if that will- oh, there we go. Uh, so, this is just a little bit about who built it. I'm not-if you have any comments, but I think it’s probably quite straightforward.

**F:** Yeah, no that’s fine.

**I:** Um, yeah. If you go “next”. I think there’s just a little delay. Has the page changed for you?

**F:** Yeah.

**I:** There we go, yep. Oh, one person’s picture is missing. Um Yeah, this is just a little bit about the team.

**F:** OK.

**I:** And if you click “next”. It’s OK, I think it's just a little slow. You get to stare at our faces for longer. Ah. Has it changed for you?

**F:** Yes, yeah.

**I:** Oh, OK. Yeah, it's just changed for me. Um, so these are some of the people who helped us as well. So just a little bit about them. Um- Don't know if you had any thoughts on this page?

**F:** Um, I suppose I look at the picture of [name of PPI member] and just think “Well, yeah, that's what I've got coming at some point but- or my husband’s gonna be like, at some point, I suppose.

**I:** Yeah, it's a bit of a stark contrast to the others, I guess.

**F:** Mm-hm.

**I:** Um. Does that kind of put you off going further or anything like that or?

**F:** No, it wouldn’t put me off. Sort of just makes-it just hits- it makes it hit home again, I suppose with you know what the condition’s like, I suppose. 'Cause we're still early on, you know, it's different, isn’t it, depending where you are I guess.

**I:** Yeah. OK, no, that's- that's also good feedback. I'm just making a note of a couple of things as I speak to you. Uh yep, if you click the next page. Don't worry, it gets more interesting. This is just the introduction.

**F:** OK.

**I:** Is- is it- the information clear on this page? [what can you expect]

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

**I:** OK, if we move on to the next. Any first thoughts on this kind of- [why nature images]

**F:** Uh. Well, I live right- I live in [name of place] so I'm just thinking I'm lucky 'cause actually I can go out and look at things like that all the time. I’m quite- we’re like outdoor people so I don’t need to look at pictures, I can go outside and look at it for real. Yeah that's true. It does improve your- it does improve your mood, I just think well I'm lucky 'cause actually I don't need to look at a picture, I can just go and see the real thing.

**I:** Oh, that's good. I wish I did, live in [name of place]. Um, yeah, if you move on to the next page. Yeah, so this is probably a bit more about how to actually use the website.

**F:** OK.

**I:** I'm just wondering if the level of instruction or guidance is OK, like would you know where to go based on what your situation is, etc.?

**F:** Uh, yeah. I think if I would look at it, it would just depend on what mood I was in, I think. When I looked at it, I think I would know which one I wanted to click on, yeah. It's quite clear.

**I:** OK, and I think that's just next- the last page of the introduction.

**F:** OK, yeah, that's fair enough.

**I:** OK. If you go onto the next. So, this is the home page which you’ve seen. And I guess from here on I'll kind of be led by, say, if you were using it how you would use, it rather than me kind of tell you where to go. Um. So just say this was the first time you were looking at it and, is there any particular section you feel drawn to at the moment?

**F:** Uh, yeah, I would go to “Adjusting to changes”. Uh, 'cause I'm quite a positive person anyway, at the moment, so I wouldn't particularly do that and uh, “Worry and stress” I think well, maybe that's a bit further down the line. I would say sort of things changing at this point would be the one that would draw me in more.

**I:** OK. Yeah, let's go ahead and click that section then. Um, has it changed? Ah, there we go. Um, yeah, I'll let you have a read. [changes and how you feel]

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

**I:** Does it kind of feel relevant to you as well?

**F:** Uh, yeah probably, I suppose, yeah. At times, I suppose, you think, you know-you’ve- everything’s changing and uh, how you see yourself a bit. Yeah no I would- that would - yeah I would - it would be enough to make me think “Oh I’ll look a bit more, I'll carry on looking”, it wouldn't make me think “Oh I'm switching it off”.

**I:** OK, um. Also, at any point, um, let me know if, like from a family member's point of view, if you feel like it's more oriented to the person who has MND and not to your situation, ‘cause then I'll know if I’ve worded something correctly. [audio cuts out] But if this is fine, then we can go “next”. Think that takes you to “menu”.

**F:** I’m back on the menu again.

**I:** Oh, uh, sorry, can you click “adjusting to changes” again? I don't know why that happened.

**F:** Next?

**I:** Yeah, it should go to a different menu.

**F:** Yeah it is, mine is.

**I:** Ah, OK. Yep. So, because this is more about the emotional side of things, um, rather than, say, physically adjusting to stuff. We put these three options in terms of emotions. Um, ‘cause, typically, that- that is what people feel, but would you be drawn to any particular one or do you-would like another emotion in there or something like that?

**F:** Uh. No, I would look at all of them. To be honest, this morning I've been out on a three hour cycle ride and it's been lovely and sunny and I've had a lovely morning so I'm kind of feeling quite happy and positive. I would look at that and think, yeah, perhaps over the last few months I've felt all of those, so if I'm not feeling- if I've looked at this when I'm not feeling in a particularly low mood, I just think I would look at all of them out of interest, probably. But that probably ticks all the- ticks all the boxes I suppose. But yeah, today there wouldn't be a particular one that I'd be drawn to. I suppose... if I was to pick-uh- frustration, probably would be the one that would more draw me in and the anger would be the least likely one, 'cause I don't really get angry.

**I:** OK, OK, let's go ahead with frustration then. Um, yeah, it can even be- it doesn't have to sort of be right now. It could be you’re exploring it to see if you've had any of these emotions in the past or future, that sort of thing as well.

**F:** Yeah OK.

**I:** Um, so we have these two, kind of, options. One is more a technique, it's just sort of, one technique that we suggest, but there are more if you’d like to explore some more and also some people are more- uh, cope better by actually doing things rather than maybe doing these sorts of techniques. So, there is the practical tips section so we can explore both and-and you can let me know what you think of them.

**F:** OK. So, should I go on technique first?

**I:** Yeah, we can do technique first.

**F:** OK. Yeah, I’m quite good at self-kindness. Hence my three-hour cycle-ride this morning.

**I:** Um, yeah, I guess it's just a reminder then.

**F:** Yeah, no that's good. I think “oh yeah that’s good, I'm doing the right thing by going off on my cycle ride” so that- I’d like that.

**I:** That's-that's good to know, I'm on the right track.

**F:** Uh, shall I go “next”?

**I:** Next, yeah. So, yeah, this is an audio. You can either listen to or you can read the instructions. Um. We- if we’re listening, we probably won't listen to the whole thing, but just a little bit just to give you an idea of what it sounds like.

**F:** OK. And do I press on the ah- the triangle?

**I:** Yes, and I'll keep my fingers crossed this works. Can you hear anything? [compassion break audio]

**F:** Yeah, I can hear him.

**I:** OK. [after a few minutes] Uh, yeah, we can stop if you want to or we can go ahead. Just to kind of, give you a flavour, is this the sort of thing you would- you would be happy to listen to or…just your immediate thoughts?

**F:** Uh, no, his voice is too slow and boring for me. I'd like someone a bit more upbeat. I'd switch off. So no, his- for me personally, he’s- no he’s, he’s too um…too calm.

**I:** OK. Um, would you- would you want to, sort of, read the instructions for this kind of exercise? Or would you…

**F:** Yeah, I’d probably switch- I’d think “oh his voice is getting on my nerves”, so then I'd switch on and read it and- switch him off and read it instead. Should I click on that?

**I:** Uh, yeah. That's fine, don't worry. I know like meditation is also not a thing for everyone, so it's perfectly fine. [after a long pause reading] Can you re- Oh, OK. Yeah, just generally what your thoughts are on that kind of exercise?

**F:** It’s not really my thing, I would rather go out for a walk or a run or something. I’m not really one for sitting, so I’d think “no can't be bothered with, uh, I'm too busy”.

**I:** OK.

**F:** So, no it wouldn't make me wanna try it. No.

**I:** OK. Um, let's go to “next” and just see if the practical tips are a bit more...Uh, yeah. Has your screen changed?

**F:** Yeah.

**I:** OK. Oh yes, sorry. I will adjust the spacing. I can see that now. Um.

**F:** Yeah, I prefer that. I think it just reminds you not to be so hard on yourself. And it would remind me, you know, the person who got it, you know how they might be struggling as well, you know I may be frustrated but it’s more frustrating for them. So, I’d find that more useful than the meditation technique.

**I:** OK, no, that-that's really good to know. Does it-does it come across is useful for, uh- for you as a person taking care of someone with MND?

**F:** Uh. Well, yeah, obviously, we're not quite at this point yet, but I suppose it would in that it would um… It would remind me more, you know, of what they’re thinking, I think, rather than myself. Think it's more aimed at the person who's got it than the person who’s caring. Although some of it is OK, like asking for help- Well no, no it does. I suppose when you first read it, you think it's more aimed at the person who's got MND. But then if you read it again, it does apply to the carer as well, actually.

**I:** OK. Anyone that- I guess it's OK to ask for help? No, I'll let you answer rather than jumping in there.

**F:** Yeah, that would probably- that would be a big thing for me 'cause that's something I wouldn't generally do. It would remind me- it would just make me think “oh actually it is OK”.

**I:** Um…Is there any one that seems more for the person with MND rather than yourself?

**F:** Um… Pacing your activities, I would say.

**I:** OK. OK. Yeah. Yeah no, it's important for me to see also how people read it because I could frame things slightly differently and then make it a bit more relevant to… OK. Anything more about this page? Or should we-

**F:** No, that’s fine.

**I:** OK. Do you find quotes like this helpful or? [page with quotes]

**F:** Uh, yeah. Yeah, no, I quite like quotes from people.

**I:** OK. Um, yeah if you had no other comments, we can go to the next page.

**F:** Yeah.

**I:** Uh, maybe go back? Um. I'm just trying to see, you probably don't want to do anger or sadness today. Maybe let's- let's go to the home page.

**F:** OK.

**I:** And, if you could go to “building positivity and meaning”? Um. I just want to try a different kind of task and get your thoughts about that. [positivity and meaning intro]

**F:** Do you want me to go on the next page?

**I:** Uh, yeah, if you had-This was all OK, yeah?

**F:** Yeah, it’s all good so far.

**I:** Right so, yeah you- if you wanted to click any of the buttons you could or you could go on to the next page, either. [buttons with quotes]

**F:** So, do you want me to listen to one of those?

**I:** It's quotes rather than the listening, but you could have a look if you wanted.

**F:** No, I like both of those.

**I:** Do you feel it, sort of, adds to it or is it a bit of a repetition?

**F:** No, I quite- no, I like things like that. I think it's useful when it's someone who's got it, what they’ve, uh, said. [moves to next menu page]

**I:** Yeah, so there are three sorts of activities in this section. Um. Would you like to pick any particular one or...

**F:** Um… “Pleasant” sounds a bit dull for me. “Benefit finding” now sounds more intriguing, so I’d probably click on that.

**I:** OK yeah, let's go there. What are your thoughts about how things are worded in this section?

**F:** Uh, no I- no I like that, 'cause that's sort of the way I think about things I suppose it's just, uh, I suppose I would just read it and think “oh yeah, I agree with that so far”.

**I:** OK, that's good. Um, yeah, if we go into the next. I guess these are just examples of how. [quotes]

**F:** Yeah, no I think that’s very true in life.

**I:** OK. Oh, that looks- not like how I designed it. Sorry. Oh, there we go. It jumped. Can I ask what you think about an exercise like this?

**F:** Uh, yeah, I would- I would more... I would find that- Uh I’d prefer doing that than sitting and meditating in silence. I think it's quite a good way to think. It’s kind of, what I tend to do a bit anyway, so it would perhaps just remind me to do it and it doesn’t take very long and can just, sort of, pick you back up again, I think.

**I:** OK. Do you feel any more guidance or examples or things like that are needed?

**F:** Uh, no. I reckon that’s good.

**I:** Um. Yeah, if anything sounds, as well, like a phrase that, you know, puts you off or that you wouldn't use something like that, um, just let me know.

**F:** No. It’s fine I like that.

**I:** OK. If we go to the next page.

**F:** OK.

**I:** OK. I'm gonna see if this works, did you- if you could click- do you know the home button on the top? Um…

**F:** Yeah, OK, yeah. Back on another home page, yeah.

**I:** Um, could you go to “all techniques”?

**F:** Yeah.

**I:** Um just- what are your first impressions about this page? [all techniques menu]

**F:** Yeah, I just think it’s quite useful, sort of gives you a couple of things to look about and have a think about. It sort of makes you think about you know what -uh- you might be needing, I suppose. If you’re feeling a bit- whether you…it makes you think whether, you know, you do just need to make yourself feel a bit more positive, whether you just need to relax a bit more I suppose. It makes you perhaps think about how you are actually feeling, as in what you might need to do to help yourself, I suppose.

**I:** And…I guess there's-there’s two ways of really using it. One is to kind of go through the different sections, how we first got directed through that path, or come to a section like this where there’s everything. Um…

**F:** Yeah, it’s quite useful- I think it's quite useful to be able to look at it altogether. Might help narrow it down a bit as to what you think you need in that particular moment in time.

**I:** OK, so is there any- I know this is sort of hypothetical- but is there any way you could see yourself using it? Would you prefer, say, this section or how would you use it?

**F:** Uh, yeah, possibly. Probably prefer looking at this, you never know, you know, having to make a decision whether I needed to, in the first instance where I needed self-kindness, so I prefer looking at it all together and then taking it from there, what jumped out at me, I think.

**I:** OK, and just assuming you were- you did it that way…Just based on, 'cause I've given sort of minimal information on this page with what to use, when that kind of thing, but do you still feel, like, confident that you can make a decision about where to go?

**F:** Uh, yeah. Yes.

**I:** That's good, as long as it's not confusing or…

**F:** No.

**I:** OK. Is there any particular one you wanted to try out? Or not, that's also OK.

**F:** I suppose I- well, I suppose in the mood I was in today ‘cause I know we’ve just been- I would probably click on all of them today actually, if I was just sitting around doing nothing and was just curious. I might even click on “pleasant activities” if I was just sat, thinking of something to do. Well, I suppose the ones that would more jump out with me is not- is less the self-kindness things, wouldn't really be my thing. Uh. Probably more the “values and goals”, I’d probably look at “body scan” out of interest or maybe even “three-minute breathing space” 'cause I just think “Oh well, it’s only three minutes. “Safe Place meditation” would- I’d probably be like no. So, if I was looking at them, thinking what ones would I click on to do, I’d probably say the three minutes, body scan values and goals, I probably would put thought distancing if I was looking at it and I was feeling, um, weren't feeling so good. I’d look at that.

**I:** OK. No, that-that's really useful to know. Yeah, 'cause, yeah- people are so different so I'm glad there's at least, you know, some bits that you'd like to look at. Um… I just wanted to ask you a couple of questions, having, sort of, broadly looked at the different sections. Would this be something you would even consider looking at or using?

**F:** Uh, possibly further down the line, probably not at the moment, no, 'cause I feel, um, OK, I think. I think further down the line if I'm finding life more difficult or I’m not able to get out as much. At the moment- if I’m more tied down to being a carer then- and I’m at home more, then I probably would. But, at the moment while I can- while [name of person with MND]’s still independent in looking after himself and I'm not really changing my life that much, then no, not at the moment.

**I:** OK, that's good. And, I guess this is thinking back at the introduction as well. Having seen it, do you think it's clear that you could use something like- you don't have to use this, like regularly or something, but dip in and out whenever?

**F:** Yeah, definitely. Definitely. Yeah, yeah.

**I:** Do you feel like that comes across?

**F:** I think it could be a personal thing- I think some people might find something they wanted to look at and others, other people it would just be.. Yeah, you get the impression that you can, it would be, you might look at it and think “that’s not for me today” but it would sit in my mind, that it was something that was there that I might return to when I was feeling differently, I think.

**I:** OK. OK, and um… overall, just in terms of the way things are presented or the style in which they are presented, is there anything you generally either liked or disliked?

**F:** Uh, I think it is a lot you need to read. I quite like having the pictures of nature there actually. Um, it's all very easy to follow. No, I think the presentation is very good.

**I:** OK. Just gonna look at my questions if I missed anything out. Um… I guess, is there something you would have liked that maybe we didn't talk about or didn't include?

**F:** Um…Not that I can think of at the moment, but as I say that's 'cause it's still quite early on, but whether that would change in a year’s time, whether there might be- I might feel differently, I could imagine I might feel differently in a year’s time but at the moment… uh, no.

**I:** OK.

**F:** I think it probably depends very much where you are, um… Where you are on the journey with- with MND, I suppose. It’s different for everyone, isn't it?

**I:** Yeah, yeah, I think yeah, speaking to [name of person with MND] yesterday as well it’s fairly recent for you as well so, it's good to know that… maybe for a family member this early on this is not the kind of information or techniques that people would like? I don't know.

**F:** Uh, well other people might, but I think ‘cause I'm… ‘cause I’m quite a positive person anyway and I like, and I do a lot of, spend a lot of time outside and exercising, that's kind of alright at the moment. But I can imagine if in a couple years’ time I'm not able to do that, then I would be looking at things like this. Whereas, perhaps other people who, uh, don't do that, are gonna… would find something like this useful early on 'cause I think it can be difficult when you first get the diagnosis. I'm perhaps, yeah, we're perhaps over, slightly over the like the initial very early shock. We are sort of at this stage, where we’ve accepted it a bit more but aren't really having to deal with, uh, quite how bad it’s gonna be yet.

**I:** OK no, that's really- everyone’s at different stages as well. So this is useful information. Um…What else did I want…Anything else you want to say about the website?

**F:** Uh, no I think it’s- I think it’s really well laid out and easy to use. And it's- but it's the kind of thing, you know, we're all different, but some people are going to really- find- are going to find different things useful from it and at different times. But for me at the moment, I’d probably look at it and think; yeah, there were things- there were things I looked at that made me feel a bit better about, you know, being positive and seeing the pleasure in the simple everyday things and that would make me feel good 'cause I just think “oh, that's what I tend to do.” So we always feel good, don't we? when someone says we’re doing what we should be doing, I suppose. Yeah, so then it will probably stick in my mind, I think. So maybe in the future if I wasn't feeling quite so positive, I might think “oh, actually I'll look at that again” and it might just give me a prompt to be more positive and just pick your thoughts up again. Sometimes it just takes something little, doesn’t it? To push you in the right direction again. Whereas, perhaps, I don't know, I suppose other people who are perhaps in a more negative place in life when they receive the diagnosis and they find it more useful from the start. It all depends where you are in life, when you get bad news, isn't it?

**I:** That’s true, yeah. Um… OK, I- I will stop the recording if that's OK with you?

**F:** OK, yeah.