**Interview 5**

**(person with MND)**

**I:** OK it should be starting now. I'll just tell you how to log in as well. Um, so if you click the login button, I've just got a specific email address. So it's test 5 at calm.com all small letters.

**P:** Calm.com

**I:** Yep, Yep, and the password is C for cat. P for pencil test. Yep. Hopefully they should work. You can say not yeah (responding to an error message). So, this initial bit is an introduction to what the website is about. I'll let you have read.

**P:** OK, Yep

**I:** Yep, any particular thoughts about this page?

**P:** No, I think it's straightforward language. Makes sense to explains the purpose, yeah.

**I:** OK, if you going to the next. It just tells you who it's for.

**P:** OK, so you are doing, it's the same website both for patients and their carers.

**I:** Yes. Any thoughts about that?

**P:** Then so when you say you may, you may find it useful to include a family member. Are you more thinking as they may be able to help you with some of the activities? Is that because of the physical, you know, if you're thinking that that patients or you know users can't manage some of the website activities? Or is it because you think that that's important for the utility of the questionnaire?

**I:** Yeah, it's both actually. It could be to help out with activities physically, but some people have also said they like going through things together, so it's just to say that it's not, you don't only have to do it alone, you could do it with someone else, if you wanted too.

**P:** OK, that's just your own choice. Yeah that’s fine, that makes sense.

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

**P:** OK, yeah.

**I:** All good? OK.

**P:** Yeah, it seems like, ah now I've just tracked, I don’t know what the difference is. I see the patient and public involvement team, but what is the patient and public involvement team? Is that who you did your interviews with?

**I:** Um, no, that's a slightly different team, but those two are buttons, if you could click on them, it takes you to…

**P:** Yeah. So is it, is it only three people, the PPI team?

**I:** Yes, um. I think what the PPI team are, people advising on the project. But I did interviews with more people to get information about this and have added this on the website, but it sounds like that's probably not coming across. Um, too clearly well.

**P:** Yeah, I mean, I think if, if... for me when I when I see these teams and when, I'm sure that you have done lots of interviews but, you know, (clears throat) excuse me. It helps me to kind of think that you've got something robust and relevant. If you've got a good number of people who've been involved in it. And if I click on these two things, I just see there's four people in the CALM team, which is great, that’s your researchers, that makes sense, I don't expect that team to be big. But that PPI team, but maybe it's not in the PPI team, but by talking with, when you say talking with people with MND and their family members, but just give us some idea scale…

**I:** how many? Yeah no, that's a good idea, yeah. I'll add that to the description on this page I guess. Um, yeah. Was there anything else about this page or any of the buttons?

**P:** No, that's for people, for people who can't, I mean, I can use my fingers still, but for people who can’t use their fingers, is there going to be some kind of assisted way to navigate?

**I:** So, I'm trying to, I'm trying to see how this works really. I'm relying on, to a large extent, if people have some adapted mouse or an adapted keyboard in some way. But yeah…

**P:** I think that’s fair to be honest, because if it's an issue for the individual, they should have dealt with it at their side. Yeah, OK.

**I:** We are also doing things like um, just trying to make it disability friendly so if someone wants to, um, you know, like screen reading and that sort of thing, have it easier for people to use.

**P:** Yeah, I mean the thing is… I would also say like we’re what we’re three, four pages in now. Yeah and you got some nice calming visuals there, but I think maybe a good way to kind of capture people, and you know, it would be to have some, some like the short video playing or something you know, maybe somebody from your CALM team or a PPI team. Just a quick little, it needs only, needs to be like 5 or 10 seconds talking about…

**I:** Yeah

**P:** Just, just to make it more engaging. Yeah it feels a bit static at the moment.

**I:** OK. Yeah, I'm just writing these notes down. Yeah. I think this is probably quite straightforward (why use nature images). We can go on to the next page. Yeah, this is more specifically how to use it.

**P:** The building positivity and meaning…

**I:** Do you think? (interrupts) Sorry…

**P:** I'm just, I'm just trying to work on my own interpretation of those sections. So positivity and meaning, the way I’m reading now, I'm thinking, right, I'm this is just, this is just a statement so make sure it plays back with what you want it to mean. And so I interpret that as trying, if you're feeling very negative about, there's no point in the future, so that is trying to give you some kind of reason to carry on if you'd like, so that's what that means to me. Adjusting to changes is, yeah, that's quite that's, that's your life is turned upside down. So how do you cope with that? Everything that you used to be able not, well for me, everything that I used to be able to do I can't do anymore. And dealing with worry and stress is yeah, that concern about just that whole overwhelming feeling, that everything is too much and you’re just worried and stressed in the moment. Yeah, so that's what those mean to me.

**I:** Yeah, no, that's really useful. Would you, based on where you're at, where would you gravitate towards? Do you think?

**P:** Um? I'll probably look at all of them to be quite honest, because they’re all, they're all relevant to me at the moment. I mean, it's because it's a fresh diagnosis. The adjusting to changes is, is obviously relevant. I'm still fighting with that and it, I think it's always going to be relevant because it you soon as you got, you got your head around one thing that's changed, then another thing changes in you physically, that means you’ve got to change what you do. So, the positivity and meaning, to me the positivity and meaning and worry and stress are quite closely linked to each other because the lack of positivity and meaning is, it causes worry and stress or the worry and stress causes the lack of positivity in… that’s quite close to one another.

**I:** OK, we'll try and hopefully give you a flavour of a little bit of each of them. Um, yeah, if you go onto the next…

**P:** Sorry when it says techniques, if you'd like to look at the available techniques and choose one that suits you best. What does technique mean? (referring to the all techniques description)

**I:** So the techniques are… maybe I should say they’re more like activities rather, or psychological techniques… But it's, so for each of the buttons above, it's providing information as well and guiding people through which techniques to use or not.

**P:** So I think techniques means something to you from your research background, but maybe you talked about it before as being tools and hints and tips. Maybe it would it, maybe you need to use a bit more of that language because I think that's what you’re referring to really, isn't it?

**I:** Yeah, that's correct. Yeah, I think I'll probably use that on a couple of pages, so I'll change them on the respective ones. Yeah, but that section has everything together in case you want to just jump into something directly. OK. Um, if we go on to the next page, I think there's one last intro page.

**P:** OK, so we've had quite a few pages now, haven't we? Yeah, I just, I think if you could get someone talking some of this content and maybe have fewer pages, that would be better. 'cause I feel like I've spent a few, a little bit of time navigating my way to this point, whereas if I just clicked the video and someone just told me this. Yeah, if I'm struggling with using my fingers or my concentration isn't great. I'm not too bad at the moment 'cause I'm fairly early on, but if I'm not and I'm coming across this for the first time, I may lose a bit of energy by that stage.

**I:** Yeah, that's an important point. Um… yeah the one good thing I guess is that you don't have to go through this all the time. It's just the first time you log in. Um, and then if you click the next… The second time you log in, just takes you directly here

**P:** Oh OK, right.

**I:** Yeah. So maybe let's start with the top I guess and try one activity in each section. Would that be OK?

[Positivity and meaning section - intro]

**P:** OK. So I think these are really important because you want, so you hear like, you feel like you hit, I just feel like I'm reading a lot of things and I just think it be a lot more impactful if you actually had someone saying how they feel, it's stating these things, you know talk… If you could get, I mean I don't know whether you could get patient or you’d need to get somebody to just say the words from a patient to actually make it real.

**I:** Yeah. Yeah, there is a lot.

**P:** Yeah maybe that’s coming up on the next screens but it just every page is looking a bit the same at the moment.

**I:** OK, OK

**P:** Text on the left, picture on the right is all about the same at the moment

**I:** I'm sorry it doesn't change too much. Yeah, but that's more like a lack of technical skills on our part.

**P:** Well, embedding a video instead of your graphic, I don't know how hard it is to do actually. I just think if you get someone to say these things is a lot more meaningful than reading it, you know you could get some real emote.. through some real empathy to what is that you're trying to convey, if you got the patient talking about this…

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

**P:** Sorry, I'm now gonna read it, sorry so. (reads) Yeah, OK.

**I:** I guess… sorry if I can just ask you quick question reading that from the perspective of being recently diagnosed, does that come across as empathic, in terms of language, really?

**P:** Well, yeah, one of the things I say to people is absolute, everything is absolutely hopeless. Everything! and… Sorry (cries)

**I:** It's OK.

**P:** Yeah, you know you're used to, like interactions with health care being constructive (says this while crying).

**I:** Yeah. Maybe acknowledging, I guess that it's difficult because I guess, if it sounds too upbeat…

**P:** Well, I don't, I don't think, you don't need to go too negative because you're trying to. You're trying to build positivity and meaning here. Here (reads) here ‘like you feel you hear a lot of bad news… (continues reading) think of something positive... I'm struggling to think of anything positive, or well no, there are some things positive related to my MND because it's changed other things, in other areas of my life, relationships with family, etc. I guess you could say that it's turned positive, but if I guess when people think about MND, they think about what the disease has done to them, and there's nothing positive physically or emotionally that the disease directly has done to them,

**I:** yeah.

**P:** Yeah, No I think it's, I think it's fair. I don't think you need to, you don't wanna be too negative here? I, I get very down every time I have a health care interaction, to be honest, because everything feels so hopeless so I don't, I don't need to hear anymore of that, especially if you're in a positivity and meaning section I think. So I think you've acknowledged that there's a lot of bad news. You've acknowledged it, but then you're trying to move on.

**I:** Yeah, Um, yeah, I didn't actually see it that way, like this also being a health care interaction in a sense. Yeah, if you go into the next page I think. Yeah, these are some examples.

**P:** OK

**I:** So this is like taken from interviews with people…

**P:** So should I play one of them?

**I:** Yeah apologies, it's gonna be more reading than playing.

**P:** Yeah, OK. Yeah, I think if you could make them talking about that so. OK, I mean that they seem fairly obvious things to me.

**I:** OK.

**P:** OK. I'm going to the next.

**I:** This takes you to three different activities in this section. I don't know if you have a

preference?

[participant clicks on pleasant activities]

**I:** That's OK.

**P:** So when you say keeping track of pleasant activities, do you mean just being aware of what makes you feel better and trying to do it more? What do you mean by keeping track of pleasant activities?

**I:** Yeah, exactly that. I think I tried to explain it in the next couple of pages, but it is basically what you said.

**P:** Oh, I will just simplify the language there and saying like something like being aware of what activities make you feel better

**I:** OK, yeah

**P:** It’s just that when you say keeping track, it makes me feel that I've got to tick a box and say I've done this like so many times in a week. That's not what you're saying, I don't think..

**I:** It kind of is…

**P:** Oh ok (laughs)

**I:** No, but it’s good to see it can be potentially confusing as well. Maybe let's look at the actual activity and then, um, we’ll try and see if it's less confusing.

[Pleasant activities – list of activities]

**P:** I guess you're saying, you got a typo there, have you? It says ‘you examples of pleasant activities below.’ That right?

**I:** OK, thank you. Thanks for that. So OK. When you're looking at these activities as well, if you feel that say some would not be relevant to people or difficult to do, or something like that as well. Yeah, let me know.

**P:** Yeah. Well, I understand what this is trying to do. I'm kind of, for me maybe it's because I'm relatively early in the journey, I would like an acknowledgement earlier on in this, that the pleasant things have changed massively. So like if I had been doing this pre MND obviously some of these things may be on my list, but there's many, many things that wouldn’t be on that list, that can't be on that list. So there’s a big sense of loss for me when I think about pleasant activities. So I feel like, I say to people, I feel like my world's got a lot smaller. And in terms of what I can do and that's, I'm still grieving for that now. Maybe with somebody further on wouldn't, would be more in the kind of adaptation phase I don't know, but for me, I feel a bit sad when I look at this list. And I'm there thinking is this what my world is now then, that I just have to take pleasure that I've eaten a good meal. And I understand that I have to, because in a few months time, or whenever I might not be able to do that, so I get it, but I still I feel a sense of loss when I look at this list and I think is this it? Is this, is this is my list of pleasant activities now. So is it's not, this isn’t you doing the website wrong, that's just you know my outlook when I'm looking at this. I'm trying to… you’re trying to take me to a happy place by looking at this list, but I feel a sense of loss. Because I think… I can't, well I can’t wear clothes I like because I have to, every time I open my wardrobe in the morning I have to think what can I put on. So, so that one is… I struggle with that 'cause I know is I feel permanently like, can't self care the way they used to in terms of styling my hair, putting makeup on blah blah blah. So the whole thing about looking the best that you can look, wearing clothes that you want to look, to wear. I'm just referring back to my pre MND stage now I'm thinking well, that one absolutely gives me lack of pleasure. So let me just have a look down the… so that's not your website…that’s a reaction that my phase that maybe that needs to get acknowledged that that would be a feeling that some people could have.

**I:** Yeah, I…no this is really important because especially you don't know how this reaches people as well. And if they're on their own and read this and it upsets them um, yeah, that's definitely not what we want to happen. So um, yes, something maybe pre this page about acknowledging that it will be different or not look the same…

**P:** Yeah

**I:** I guess would it also help if, um it was mentioned somewhere that this isn't, this is not the only list, like that it's not a finite list?

**P:** Oh yeah. That it would be impossible to give us a finite list anyway, wouldn't it? Because people are so different in their outlooks in their lifestyles it would be impossible to give it all, so you're just trying to start them thinking, things that, get them thinking about things that give them pleasure. Um so yeah, I look at this and I feel quite depressed because I just feel like my worlds got so much smaller. Like before when you say ‘do exercise’, when I say do exercise, I think right before I used to be playing tennis I used to be out walking my dogs, I would walk like 10 miles a day, I can't do that anymore so exercise is a real big negative to me. Whereas I know that actually what, what I need to adapt to and feel pleasant about is the exercise that I can do, which is just like a stretching thing. But it's like what does that word mean to you? Is a difficult thing with exercise and also in this in the same sort of way ‘taking a walk’, maybe it's like rather than taking a walk it's like being outside or something like that. So it's not about the physical, the physical activity, it’s more about what they're achieving in it. I don't know….

**I:** No that’s really important, though…

**P:** It’s like ‘exercise’ oh don't like it… that's not taking me to a happy place, those words. Whereas I know, I know in myself that is one of the things that I need to be doing. I need to be getting outside and… so I talk about when I say to my husband ‘Oh what should we do today’ and I say ‘I've got to go outside’ yeah, I don't say ‘I've got to take a walk’ because the walking causes me distress because I can't walk like I used to. So I just say I've got to go outside.

**I:** Yeah, get some fresh air or spend time with nature, that kind of thing.

**P:** OK, so go to a meeting. What does that mean?

**I:** Um, I guess I was probably referring to like coffee mornings or those sorts of MNDA meetings that help some people.

**P:** Yeah, I look at that and think what does that mean? Does it mean for people working? Does it mean… it just sounds a bit formal to me, yeah. ‘Interacting with other people, a group of people’ you know, ‘attending some group something’ just sounds a bit worky. Yeah? (Reads) Oh gosh, right!

**I:** Which one did you say ‘Oh gosh’, to?

**P:** Make a new friend because. Um because of this sensation I have that my world is getting so much smaller. I can't imagine how to make a new friend at the moment. But maybe that's worse as well, because I've got this diagnosis and this happened in lockdown.

**I:** Yeah, yeah.

**P:** I can see that maybe in normal times I would be meeting more people related to having MND like I know you get Association visitors from in the MNDA and I think, the ethos behind that is to try to get new friends who can help through this time, because I can't actually meet them. That's, that's not very good for me at the moment, but I think that's probably a lockdown thing as well.

**I:** Yeah, it's tricky. No, that that's a fair point as well… some of them, now that I look at it probably won’t work in lockdown…

**P:** Yeah. But we will come out of lockdown, so we shouldn't, we shouldn't… Yeah, getting haircut, some of these things actually, I know that they should be pleasurable normally, but I just see them as complications I think getting my hair done would cause me more distress. And it wouldn’t actually give me pleasure because it would be like all the logistics of trying to get there, and explaining what's going on with me and trying to have... Maybe it's… I don't know… some of these things don't. So yeah, but it's impossible for you to actually give a list that that is good things for everybody, so you know.

**I:** Yeah, but I think it's also worth something maybe in the lead up to that about these being suggestions, but you can, you know, think of other ones as well more relevant to your situation. I think 'cause then people will look at this list almost quite literally I guess.

**P:** Yeah, OK.

**I:** OK. And then the next page, I guess just…

**P:** OK, so you just trying to create discipline whereby you do less things that make you feel good every day?

**I:** Yeah, and I guess it's also about noticing it. Um just trying to sort of direct attention also to the positive.

**P:** OK

**I:** Does this make it more clear what the ‘keeping track’ of? I meant.

**P:** Yes, I think you are literally keeping track of. Yeah, and trying to get people to make sure that they do those activities and don't spend days on the negative. I mean, the other thing that strikes me about this is that if you start to keep track of this in this way, depends on what's on your list you know, things are going to change with how your disease progresses. And it may also, if you start to see it, you keeping track of it and you seeing that you're losing them. How do you, how do you deal with that sensation?

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

**P:** So I guess it's just about, you know, at the moment I don't particularly enjoy cooking a good meal, cooking isn’t my passion, but I can't, I can't cook I haven’t got sufficient strength. So you know things will change for people as they as they go along. And if this, if they start tracking this, does it, does it also have the potential to become like a chart of their decline?

**I:** Yeah, yeah, no I I didn't see it like that. That's really good point. Yeah, I'm gonna have to take that back to the team and think about that… Yep. I think it's nearly over… I guess these are just tips about how to restructure it, but the same thing really.

[last page in the pleasant activities section – motivational message with cherry blossoms]

**P:** OK.

**I:** Did you have any thoughts about this page?

**P:** Just finding the format all a bit it's not very engaging, text on one side and the photograph on the other is… I just I'm getting a bit fatigued reading through it all.

**I:** OK

**P:** So that's just a format thing, so right. So what we're trying to do here is just plan make sure that you've got the ability to do things that you want to do. OK.

[Next page – asking people to go at their own pace]

**I:** I guess this is some kind of acknowledgement of the fact that it is difficult, but maybe a bit more early on would be useful.

**P:** Yeah. Alright. Yeah, and like I say this is maybe this is a place where you could also bring in that, the sense of, you know, things are going to change, things are going to get physically... You don't want to make it negative 'cause you're trying to be pleasant here and positive, but the adaptation that's required as your disease progresses. So the nature of your pleasant activity may become different, but you still striving to achieve a different pleasant activity.

**I:** Yeah, yeah. That's true, yeah OK. Can you go to the home page if that's OK? We may not have time to go through all of it, but I want to at least give you flavour of each section. So if we go to the adjusting to changes. Yeah. Yeah, I just wondered in terms of relevance… [referring to the options anger, frustration, sadness] Oh you clicked that, there’s a bit of a lag for me… Do these options feel relevant to you?

**P:** Well, yeah, I often say to people I don't think, I've not felt anger. I know that, that is one of the things that you can feel, so I mean. I guess you've got this from your interviews with people, so they must be relevant. So I know that some people will feel anger. I've never felt that because my, you know, nobody's chosen to have this, and you know, somebody has to get it so there's no point getting angry about getting it. But yeah, sadness and frustration. And yeah, the sadness is loss as well. (starts to cry)

**I:** Yeah. We can go through that option then.

[Thought distancing intro – from suggested technique]

**I:** Yeah, sorry, I’ll wait till you finish..

**P:** ‘Put some distance between you and the unhelpful thought’. Well, I think how are you

supposed to do that?

**I:** I do explain in the next couple of pages, but this is more to give you a flavor of the kind of thing I don't know if you may have tried something like this before…

[Next page – step 1 recognising unhelpful thoughts]

**P:** I think your content is really good. I'm just struggling with reading everything all the time.

**I:** Yeah, sorry.

**P:** Maybe I don't know whether it's just me, I'm just used to having a lot more variability in terms of how things are presented. 'Cause I think got the content is good and there are those questions are they are resonating with me. You know, predicting the future, any negative outcomes da..da..da Yeah, that's all relevant, but I'm just losing my energy because I'm just reading so much text all the time.

**I:** No, that's, that's more I guess from my side, yeah.

**P:** OK (sighs) So I think these are potentially really useful things that you are trying, the techniques that you're trying to pass on. I can see this as being something that I would want to try.

**I:** Just in a more engaging format I guess, yeah.

**P:** Can I go onto the next button because it was..

**I:** Yeah, and don't worry if you're tired of reading also, that's fine, we can skip some pages.

[Thought distancing – metaphors]

**P:** Yes, no I’m interested in this now. Right when I like, I like these metaphors. Again, it's just you could actually do something better with them rather than writing about them, maybe to help people use some imagination. But yeah, I like, I like the content.

**I:** Yeah, there is going to be more writing…

**P:** With the beach ball it could you know, yeah, you could get it moving around just so you’ve got a bit of a change from that static picture on the right hand side 'cause it's always text left, picture right. You know, even if you just move, move them around a bit in terms of the layout, that would give some variety. But you could, all you need to do there would be to have the beach ball bobbing around in the water, if you just wanted a low tech solution and you know, click on the beach ball and have somebody talking the text right. You know, just little simple things like that may make it just a bit more… and I know you gotta be careful not to make it too fiddly, a format that people who haven't got lots of… who may be struggling to navigate can still look at it. So yeah, I appreciate that there's some limitations to what you can do, but I think we know we also do struggle with concentration. Yeah, too much reading you just. It's difficult to keep people on board and you…I like this content so it seems a shame that it's not really, you know, I've got to this point. I will have to read it all. I like it, but I just think it I could catch it could capture me more…

**I:** Yeah, yeah, if this was not an interview or something you'd switch off at that point I see. [Next page] This is essentially the similar technique, it's just different ways of doing it so people can choose if they prefer to use a metaphor visualization or the Stop technique.

[phone rings]

**P:** So I'm just gonna take this call.

**I:** We'll just stop the recording.

[recording stopped]

Part 2 starts

[Thought distancing – STOP technique description]

**I:** Yeah, I can see it now. Yeah, does this sound like something you would use?

**P:** I like the idea of this, I would. Yeah I would like to do this and I think I probably will give this a go.

**I:** Yeah, on the next page just to sort of help people along, I've given an example.

**P:** Um, yeah. (laughs) ‘Try to carry on with her normal routine as best she could.’ I'm amazed you could try to do that. OK, right? (starts reading) Yes, this would be this sort of thing where you could actually get somebody just talking, saying, being Nina doesn't need to be Nina, obviously, but just saying this would be a lot more impactful, the text yeah. And then you could get Nina actually doing this. (continues reading) OK, yeah.

**I:** Does this example seem relatable?

**P:** Yeah, I don't like, I just said the text I'm just fighting my way down it all the time. Just a shame because I like this content. Um so the ‘put some perspective and proceed’, I think is the bit that I'm kind of looking at that, so ‘my best friend…’ I get fed up with people tell him to take things one day at a time to be quite honest, but maybe that's just me. The ‘putting it into perspective’ bit isn't very strong. I don't know what other perspectives you could put on it. Because just somebody telling me to take one day at a time and saying you’re a lovely and strong person is not necessarily going to get me out of a negative mindset, I'm afraid. What would it take for me? But I think for me it would take something of like, the perspective I would need would be, maybe you know, everybody needs a different perspective I'm sure, but for me it would need to be probably something about… You can only can only deal with the things that you can change. You know, some things are set and some things you can change. Need to focus on the things that you can change would be this perspective that I would need. And yeah, it's just that and then somebody help. I like the thought of what would my best friend say to me right now. I think that's a good stance or good position for that. But I think yeah, that would be the perspective that I would need. Those two perspectives really, but I've done the technique. I like the technique in general.

**I:** Can I use the example you gave me as well about paying attention to things you can control?

**P:** Of course.

**I:** I think that's it on this section. Um, can we look at the practical tips just to see what you think?

**P:** Yeah right so this OK, this is really interesting now reach out to someone or talk right and talk about how you're feeling. So yeah, this is one of the things I started to do straight away, so I'm on the MND online forum, posted little bit in that and it… For me, finding information was a big part of coping, or trying to cope. But it was… what I found was these forums and other people who are in a similar situation is a real double edged sword. Because it, at one stage you can hear more about it and that prepares you, but yeah, it scares you to death. So I think that you know, there needs to be some acknowledgement of that when you're talking about interacting with forums on MND, so they almost need to come with some kind of I don't know how you, how it gets expressed…

**I:** Almost like if you feel ready go or…

**P:** I have kind of unconsciously started to do what you're talking about here. You know, just recognizing the time when I'm ready to hear a little bit more about it in my own mindset, 'cause I had, I've been going, I've been going through a phase of like going on to these…It's more the Facebook sites to be honest, the MND online forum tends to be quite constructive. I find it's more the Facebook sites, there are Facebook patient sites and I don't know whether you're in them and you see some of the things in them. Um…But then so I was going through a phase when I was quite new into this and wanting to kind of get my head round it by understanding it, looking at the Facebook sites for things like support and information for MND people living with them and stuff like that. And obviously there are people there at all stages of the disease, and when you are newly diagnosed to hear some of the stories and emotions and difficulties that people are having, it was, it was really horrible. So that took me to a more negative place than when I started to be quite honest. Now I don't, I have to start regulating myself in how, how and when I use those sites and so it was almost like I think you said, you know, pick time when you feel good and I needed to do it. I know that I needed to do it. Avoiding it was not going to be a sustainable strategy, but I had to do it at a time when I could cope with it.

**I:** Yeah I have heard from other people as well that it's not for everyone. So maybe adding a bit more about that element because you know, just because we're giving the advice doesn't mean you have to do it, if might make you feel worse, that's not good.

**P:** ‘Try new things’ Ooh! I don't know what new things can try, but maybe I'm in a bit of a downwards… I'm in the kind of, I can't do anything that I used to enjoy anymore. Sort of mentality, yeah…

**I:** I guess the reason I added that was some people probably did different things after MND, almost like fundraising or helping out with organizations or MND campaigns or something like that. I guess that's probably where I was going...

**P:** Yeah, yeah, OK. Yeah, yeah, I mean it, it is not an exhaustive list. They're all things I can see would make, could make people feel better. So that's yeah, makes sense.

**I:** OK. If we go actually, if you can click the home button at the top with the little home. Um? Maybe I'm just trying to see you. Worries and stress has quite a similar format actually. Could we just try the stress one because the worry, it's quite a similar technique to the thought distancing when you've tried.

**P:** OK.

[Page introducing stress and feeling burdened]

**I:** What are your thoughts about this page?

**P:** (reads) ‘In this section we talk about mindfulness’. OK, so I need to go into the next section for mindfulness and then there are more ideas in the ‘All techniques’ section. Yeah, OK

[safe place meditation intro]

**P:** OK.

**I:** Have you tried anything like this before?

**P:** I've got the headspace. I've had that before MND happened to me. I have tried to use it but I've struggled a little bit to be honest, 'cause I can't relax enough to get myself to the state and I used to be able to take myself to a happy, relaxed state and I can't get there anymore with some of these techniques. So I haven't been doing it an awful lot. But I'm interested in what other things you have over and above that kind of the standard relaxation meditation things so I will, um, I'll go on and see what else there is.

**I:** I guess the actual exercise is quite similar.

**P:** Mmm-hm

[Introduction to what mindfulness is]

**I:** This is probably for someone who hasn't really tried mindfulness

**P:** Oh

[clicks to next page – quotes about how mindfulness helps]

**P:** Yeah, I think they’re good quotes, I like those.

[next page – actual audio exercise]

**I:** Hum. I think I have a problem with the audio because I tried it this morning and it wasn't working for some reason. But essentially, you can click the play button, or if you wanted to read instructions, you could… it takes you through a guided meditation, to think about a place where you feel safe and happy as a kind of a break from stressful life.

**P:** Hum. Yeah, OK, yeah, I will try that.

**I:** If you click the next…

[last page – safe place meditation]

**I:** I was just wondering actually, with this exercise or with previous mindfulness or meditation based stuff that you may have tried. Um, are there any particular difficulties or say things we need to keep in mind if we're doing something like this for people with MND?

**P:** Well, thinking about the… so I've used that headspace ones. And I personally find the ones that have a lot of guidance in them, so almost virtually constant talking to be honest, very guided, because otherwise I find that my thoughts go back to MND and negativity. So I need someone to be constantly distracting me, and taking me to that place. 'Cause I know some are semi-guided and un-guided and you’re supposed to just take yourself there. And I used to be able to do that, I can't do that anymore. I also I get really irritated, I'm sure you wouldn't do this, but there are some of the headspace ones talk about shutting your muscles down and relaxing. Obviously that's a really bad, really bad association to have for MND. So nothing that talks about shutting your muscles down.

**I:** yeah

**P:** I think the breathing ones are really good because that's uh, that's also one of the exercises that you're given. So with that I feel like ‘Great!’ I'm hopefully dealing with my emotional well being, but I'm also getting a double hit because this is good thing for me to do for my lungs anyway, I should be doing this. So I think they're really, really good. I think that they generally help anyway, at getting you to calm down. They're always part of the exercise, aren't they?

**I:** Yeah, yeah. Have you ever tried a body scan?

**P:** Yeah, yeah

**I:** Was that what you meant by the one where your muscles…

**P:** yes

**I:** OK, no 'cause we have a similar exercise, but it's more pay attention to different parts of your body and how they're feeling, but it's not…. I wondered if even that instruction could potentially be…

**P:** That could potentially be, because you may be feeling like ‘Oh my, my hands felt worse today.’ You know, if things going worse than that. And then if you talk about, if you use that sort of language then that might take you to negative place. The one that I found in terms of kind of like a body scan type one that was quite helpful was one, it talks about a warm feeling going through your body like sunshine or something, and so that one I found quite a good one. Because it takes you to scan across your body, but tries to get a good feeling in each of those parts of your body.

**I:** Yeah, that's a good idea. OK, I'm gonna make a note of that. Yeah, um. Trying to think… Let's just go to the next. How are you feeling in terms of tiredness?

**P:** What right now?

**I:** Yeah, just with going through all the pages.

**P:** I'm good to go for about 10-15 more minutes if you if that works for you.

**I:** OK, I just very briefly wanted to show you the first page of the ‘all techniques’ section. So if you go maybe to home. Alright, now it's changed for me. So this is essentially the first page, so it doesn't give you too much guidance like how we've seen in the other sections. It just says these are the techniques and choose them as you want.

**P:** So if I click one of these, it would tell me more about it, would it?

**I:** Yeah, but it'll take you to the actual technique rather than you know whole bit about stress or sadness or those sorts of things. It just goes to thought distancing or…

**P:** Yeah.

**I:** So overall, do you think you'd use more of this kind of approach or would you prefer more guided section by section?

**P:** I'd like this to be honest. Because I like, I mean you kinda down the left hand side, the self-kindness, mindfulness, relaxation, staying positive, dealing with difficult thoughts. And for me that helps me to understand to navigate which ones might be useful in, in different situations. So that's all the guidance I need to be honest.

**I:** OK

**P:** Especially if I've read through the site once, I could see myself, this would be where I would just go after the first time I've gone through it.

**I:** True, yeah. Um.. I guess, I know it was a lot of reading, but hypothetically, would this be something you would typically use or see yourself using?

**P:** Um, the websites overall? yeah. Yeah, I think I would probably fast forward myself right to this page here to be honest. [All techniques section]

**I:** Yeah

**P:** But like you say, you know, I'll probably, it would probably be useful to go through the first bit, at least for the first time. I'm intrigued now I see this page. I want to read about compassionate letter writing, I want to read about benefit finding. So this is, this has got my imagination more than some of the other things. And I'm also intrigued to know how all of this plays… 'cause one of the things I don't know much about what techniques it's going to lead into, but one of the things I've asked my neuropsychologist to help me with and I think it's an approach that's commonly used is the acceptance and commitment therapy. Are these tools that will be used in acceptance and commitment or does it play against all of that?

**I:** Yeah, so some of them are actually taken from acceptance and commitment therapy. I guess I'm trying to see which ones… things like values and goals. I guess maybe even a little bit of thought distancing, is also linked to that way of thinking. I think um, acceptance and commitment therapy also does some mindfulness, but maybe with a different focus. So it's definitely not, um incompatible..

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

**I:** Yeah, and people can use this as little or as often as they feel like. So if say at a certain point you feel like you'd actually benefit more from seeing an actual therapist face to face and doing those one on one sessions, yeah, that's also fine. This can be, you know, something in the background you dip into.

**P:** Yeah.

**I:** Um, yeah I guess overall, it's tricky to say in the future, but would you see yourself using it more like that with the therapy as the main support and this kind of you dip into whenever you need it?

**P:** Yeah, I suppose I am. I would have used this straightaway, straightaway at diagnosis if someone signposted me to it. It would have been something that I would have gone to straight away. So I think there's definitely a place for it because you know in it's not a perfect world, you never get everything that you want at the time that you want it. So I think it's a useful adjunct to everything else that's going on with patients. Like you say, if it's not, it's not going to be contradicting anything else that they’re hearing in other places, I think there’s, you know, some useful tools here to think about trying. And you've made it clear where they fit in for people. What else would I say? Yeah I would, I would use it I've not gone on to see, we've not got into these specific techniques. I would want to go straight into here and look at what they actually are. But yeah I would, I would definitely give this a go.

**I:** Is there anything else you wanted to mention about just the website overall? Anything we've not covered?

**P:** I don't think so.

**I:** OK. That's alright. I will stop the recording.

[End of interview]