**Interview 9**

**(family member)**

I: You should get a notification. Yeah. Yeah, I think it's recording now.

F: Yeah, say something yes.

I: OK. Yeah, so thank you for agreeing to be interviewed today. I guess before we started I wanted to know what your impressions were about the title, ‘coping and living well with MND’.

F: Um? OK, I suppose that the question I need to throw it back to you and I will answer your question then is who am I in answering these questions, right? Because I am not an MND patient, I am a carer for an MND patient.

I: Yeah, so the website is meant for both people who have MND and also family members. Um, 'cause it's meant to deal with the emotional side of things which as you can imagine, would affect both as well. Um? So I guess it's also tricky thing to know whether it comes across in the same way for someone who has MND versus a family member, and people will see it differently. So like if at some point you you find something is phrased in a way that, sounds like it's not targeted at a family member or it's more for the patient say, then just let me know. But the aim is to (unintelligible)

F: OK, so you so you ask for my comments on this thing. Yeah, I think my first comment was I thought the layout was a bit unexciting. Having said that, of course, given that the whole point is to make people calm and relaxed and so on. Yeah, maybe my comment is too sudden. You know I came to that conclusion, so I do find it quite a calming layout that's that's that's good. I’ll now move onto the headline ‘what is coping and living well with MND calm about’. Um. If it's if it's intended to, as you say, cover patients and carers that headline to me sounds 90% towards patients and 10% towards carers. And then there's a, there's a risk that I would have said ‘oh no look this is not for me, it is for people with MND’ 'cause we all read these things too quickly and we don't actually analyse every word. When I read it slowly I can see what you're getting at, but when I really quickly It sounded to me like this is something primarily for patients, not for carers. In your next first paragraph you actually go and tidy that up, and you you explain what you know that it is for both I it's um. But that's my comments. I don't think the headline actually gets it quite right.

I: Yeah.

F: You could sneak the way ‘caring’ or something in there… somehow. I guess you you've done here, there we are. So I'm going through going through difficult thoughts and feelings is completely normal with that's fine. Right. OK, that's fine, that's great. Yeah.

I: Yeah yeah. OK if we go to the next page. I’ll just click next on my screen too.

F: Oh I know [name of PPI member] I should say that.

I: Oh do you, OK.

F: It's interesting for me here that in terms of the four people who work with you, you don't have an active carer. What you actually have, are I think 2 carers. Who do a sterling job.

I: Yeah.

F: Sadly their relation has died. Um, and so that that's what strikes me. So I need to tell you I'm an academic, so I'll be making comments

I: no, no, this is fine. This is fine. Does that come across like like it may be different from your experience? I guess for someone who's gone through it and is looking at it retrospectively.

F: I think… the thought it puts in my head going through that I see that is, like everything else, the technology and the process is for caring for MND patients, which is what this is all about, evolves.

I: Yeah.

F: And new techniques emerge, and sadly not very many new drugs emerged. But new thinking emerges etc. Here new ways of um supporting patients come. And so when I look at those numbers, I thought ‘interesting survey. It's all a bit dated now, isn't it?’.

I: Which bit, sorry, the interview?

F: I'm on page. ‘Who created this website’.

I: Right, OK.

F: And the bottom bit there just gave me the impression again. Remember I'm just talking about what hits me when I look at it. Not when I think about it. Thinking ‘Oh yeah, then OK so but all this may be a bit sort of two or three years out of date’.

I: Oh, I see. Because of the 2015, 16, that kind of thing.

F: Yeah you're throwing… I see why you're doing it. You're throwing 15,16 and you're telling me about two carers, whose family member sadly died.

I: OK, OK.

F: So it's sort of left me with the impression ‘is it bit out of date?’ I don't know how even relevant even that point is, but that's what hit me.

I: Oh, that's interesting. Um, I didn't see it like that. I meant to kind of, um, just give a description, but maybe that's coming across as confusing.

F: Um, maybe all you need to do is to have in the earlier bit. This work is being was initiated in 2019 or whatever.

I: OK, OK.

F: Yeah and that's told me and then you can leave the rest as it is.

I: That it’s recent. OK OK, yeah that's a good idea. Yeah if there is a button about the research team, yeah, if you can click the research team button.

F: Oh sorry did I, I pressed the wrong, I press next (unintelligible)

I: You can go back.

F: (unintelligible) …use the website.

I: Yep, that's fine. This is how to use the website. Right.

F: Right? OK yeah, so I think is this telling me? Is this meant to tell me that actually, I could click on one of those. Say I had a problem with adjusting to changes. Yeah, and that I actually am quite positive and all that stuff and I don't wanna go through all that stuff. I just want to go and look at the adjusting to changes. I could do that.

I: Yes. yes it is saying that, not on this page. This is more um. So The thing is, I guess this is also kind of. My… some of my descriptions are quite new, but., this is what the menu page would look like without the descriptions. Um so you could click the buttons and go to whichever section you wanted. The descriptions are so people can kind of, get a sense of what's in the section without having to go through the whole section. So I don't know if the descriptions come across as clear about what to expect maybe.

F: I so I would suggest, that when the first sentence above the bar charts...

I: Yeah yeah.

F: …the columns, If you had a simple sentence saying ‘you will be able to go’. Don’t use these words right, but I'll correct. ‘You will be able to go to any one of these functions’, right? Or if you want to see them all, you can do that too. Just something that just introduces.

I: Yeah, I see what you mean. Yeah, that can be done. Are you on the next page, or?

F: (unintelligible)… nature images? (pause) OK.

I: Yeah. Fairly straightforward I guess.

F: So when you say the good news is you don't have to go there, what were you trying to convey with that? That we don't have to go to the places.

I: Not the specific places that people may feel like, um. They need to be in nature in order to feel better. I just say that that's not to put any pressure on..

F: OK. That's OK, nice picture. Move on?

I: Yeah. I think this is the last in the introduction, so.

F: OK. So. I'll make a comment as if I was making a comment to any one of the people, I was here. Where did you tell me? Or maybe you did and I've just gone through it, what the purpose of this for me was? What should I, not me in this interview, but if I’m a user. Yeah. What is it purpose? What should I expect out of it?

I: OK, almost why to use it.

F: Yeah, yeah?

I: I see what you mean. Yeah. OK, I think I should. Yeah put, that may be really early on. 'Cause it will help you understand why you need to go through the how to, you need to know the why first, I guess.

F: Yeah, you jumped into the how corner. So and please I'm not being critical. I get embarrassed that I’m making all these remarks to you, I’m making you look worried, it's not. I'm just trying to be helpful.

I: Yeah no, I'm I'm just trying to think of ways to correct this, but I want this kind of feedback. It's fine.

F: OK.

I: OK um.

F: So if I just deal with, yeah, sure.

I: I can stop the recording if you want.

(interruption)

F: No its fine. I just I feel just let me just type one thing. (pause) What is this teams, isn't it?

I: Yeah.

F: Yeah. I'm sorry about this. OK, OK. (pause) I'm all yours OK.

I: OK? Um? Yeah, I think if you go into the next. Unless you had any comment about…

F: I again, I'm being pedantic here. Yeah. Yeah, I find you say that. Um, that's actually what I was, you know, when we saw the different coloured blocks. Yeah yeah, so the second paragraph here? You know whose activities that you prefer. Maybe what I was saying is maybe, that's in the wrong place and you should be saying that earlier on, before I saw that diagram.

I: Yeah, yeah.

F: Once that's fine. When you say so, the thing that throws me a little bit on here is when you say this is your website.

I: Yeah. Yeah.

F: it isn't really is it is your website?

I: Yeah, I I think I'm yeah I'm trying to say more it. How? Feel free to use it as you want to. You don't have to. Maybe I should just say that.

F: Again, don't use my words. Yeah, 'cause English is a is a foreign language to me right? Which it is. I have to say right here. So it's. it’s um. It's my usage of this site that is particular to me. Yeah yeah, it's a general purpose site.

I: Yes.

F: I don't get specific use of it.

I: Yeah.

F: Or something like that yeah, so anyway look, I'm being pedantic on word just (unintelligible)… my website.

I: Yeah no that that's fine. 'cause other people might read it as the same thing. So yeah. Um, yeah, yeah we going to.

F: Next?

I: Yeah, if we go onto next. So typically if you, if you're logging into the website for the first time, it takes you through an introduction that we just went through, but if you came back for the second time, you jump straight to this main homepage and can just use the techniques from there.

F: Yeah?

I: Yeah, so I guess from the ones that are shown on the screen. You did mention adjusting to changes. Does that particularly jump out to you?

F: Yeah, again, maybe you could consider, you know, at the very top ‘welcome to the CALM website’ Yeah yeah, you select select a block most appropriate or select the block. Just what to do. It is amazing how people don't figure out what is supposedly obvious.

I: Yeah, OK

F: So what you're asking me to do here is I come to this page 'cause I've done it before and come back in here and you want me to select the most appropriate box?

I: Yeah.

F: Should I do that?

I: Yeah, you can go ahead and do that.

F: OK I’ll select the blue one.

I: OK.

F: Is it OK, I'll do something else if you prefer?

I: No that's fine, that's fine. I would like to see how you would typically use it as well, so this.

F: OK.

F: OK. Um? (pause) OK, I think my next comment is. A biggish one, I think, right? What's striking me at the moment, but maybe I'm asking this too early, is you haven’t an ask me what is it that's worrying me? What you've done is you've categorized five groups of worry. And just if you're saying pick one of them and I'll tell you all about that.

I: Right, yeah.

F: I wonder if you considered yeah.. I don’t know, inviting somebody to put some selective keywords or something in. Yeah, that helps navigate there. I maybe come back to say more about that later, so. So my 'cause my thoughts at the moment is, you know how can this help me. She hasn't even asked me how I feel. OK, you haven’t asked me what's worrying me. Because that heading you gave me dealing with change, is quite a, broad heading, so at which point are you gonna ask me ‘what bits of dealing with change worry me’, and maybe you do later on. Then I should shut up if you do.

I: Uh, no, actually. Yeah, you're right I. I do discuss the feelings, but it's still categorized in a sense so. Yeah, I agree a more personal approach would be helpful. I’m slightly limited with this specific technology and how to do that, but I agree that that is a useful way to do it. And probably better than, providing like generic information.

F: OK this [mumble] Shall I press on?

I: I guess I wanted to ask you one more thing. Before you went on to this page, um through the title adjusting to changes I guess. Did you know that or did you expect that I was going to be talking about the emotional side rather than adjusting to physical or practical changes.

F: Yeah, I've assumed and the reason I volunteered for this is that this is about emotional stuff.

I: Yeah.

F: yeah. Um?

[screen frozen]

I: I don’t know what happened there? (pause) Maybe refresh?

**PART 2**

I: How are you fine? I'm trying to think what I last heard, I think it was more. Um, yeah you joined because you assumed...

F: (overlapping voices) yes this was about emotions rather than about physical changes…

I: Yeah.

F: ...and yes, and that's precisely the reason 'cause um I've said to quite a few of the bodies that I sit on, that there's enormous focus on physical parts of the (cut out). But there is so little about the psychological aspects and certainly the psychological aspects for carers, so it's the emotional stuff that's really interesting for me.

I: OK, OK, I'm glad that came across. Um. Yeah. We are on the ‘changes in how you feel’ page aren’t we?

F: We are yeah.

I: Yeah. OK, let's go to the next page and you can tell me if that's what, do you still feel like I'm asking you how you feel? Or that I've kind of, just assumed.

F: Um? (pause) Yeah um. I, so if we look talk about the emotions that I vary and they vary with time, you know and they go back and it's constantly going round here. The frustration, I, not not a great, not a great one, OK? It does happen from time to time.

I: Yeah.

F: Is that? Is that intended to convey frustration with the person I'm caring for, or frustration with the system?

I: You're right that the solution would, I guess, be different for both. Um? Is, yeah it was not meant to, it could be frustration with the kinds of tasks, maybe, for caring or just the amount of things you have to do, stuff like that. Um I guess the way it is, to manage it emotionally would sort of be similar, unless it's to do with, as you say, the system, because that's probably a more practical route.

F: Let me give you an example here, to help you right? I do get really frustrated and that leads towards anger, with the system, yeah where we live is 100 miles away from the nearest authorized MND Centre which is in [name of place].

I: OK, OK.

F: And because of that, it is and because my wife is quadriplegic, it's very, it's nigh on impossible to take her there. So the system doesn't really have any MND specialist advice.

I: OK, yeah.

F: So it all gets delegated to the palliative care team. They are beautiful, wonderful people, but they are not specialists.

I: Yeah.

F: Now, you know, I think, but there's a way of dealing with this. We could have some sort of telemedicine. I could actually speak to the consultant.

I: Yeah.

F: And I get the answer ‘oh the system does not allow us to do that, we're not allowed to do this’. So I'm using that as an example, not not just specific.

I: Yeah, yeah.

F: I get really frustrated with some bureaucratic rule somewhere that prevents doing what is thoroughly doable, i.e. have a telemedicine consultation.

I: Yeah.

F: So that frustration is different to when I've done something for my wife, two, three times and I still, she still wants me to do it again.

I: I see, yeah

F: So I'll give you an example of that. You know that by the time it gets to like 10:00 o'clock at night, I am really tired. And so I can see my wife's as you would expect here, and she will ask me to do something. And I'm saying ‘look, but it doesn't need doing now I can, you can tell me this tomorrow’. But every day she will say something when I go in at 10:00 o'clock to say goodnight, she says ‘do this for me’. Yeah?

I: Yeah.

F: And so I get frustrated that, A- I am tired by that time and B- I have asked her ‘don't do this’, but she still does. So that's a different kind of frustration…

I: Yeah, yeah.

F: … to the frustration against the system. Right?

I: I see what you mean, yeah. Um.

F: Um, things I get from time to time.

I: OK .

F: Anger, I do get anger. Not when I'm with her, at all. But I get I get angry, um that because my wife has had MND for six years and I've been a carer for six years, and I'd never planned to be a carer, nobody does. In many ways, six years of my life have gone by. You know I had to give up my work, I had a heart attack and had a brain haemorrhage. The strain of doing all this, I'm not saying it was just the caring, but all that came up and I get angry about the effect it's had on me and my life. And then I feel guilty because I had those feelings. So that's how those three play out with me.

I: No, that that makes sense, um. And that would be, that would be a typical thing as well that people will have bits of both and different ones at different times I guess. Um? Yeah. No, you just got me thinking about different solutions as well to that and I’d like to see your impressions about some of the techniques that we have suggested within that. Maybe I'm trying to think which one. Uh, does any one particularly stick out to you?

F: Let me try anger. That seems to be the worst one… (unintelligible)

I: Yeah, OK yeah.

F: Yeah, I’ll click on anger, yeah?

I: Yeah OK.

F: Now those as I read those, they tend they come across to me as slanted towards patient centric rather than carer centric.

I: OK OK yeah.

F: So I'm not quite sure. I mean I can have a look at the rest of it, but I'm not sure. What would you like me to do now?

I: So we've suggested one technique. This is of course not the only technique, but, it's just one of the suggestions…

F: OK, shall I click?

I: And yeah, you can go through that.

F: Kay.

I: Any thoughts about this page or?

F: By, when you say 3 minute breathing space? Does it mean take 3 minutes out and go do something else? Or does it mean spend 3 minutes doing, you know the often quoted ‘deep breaths out deep breaths out’, mean how literal do you mean breathing?

I: Yeah, so um, I mentioned it on the next pages, but I think it probably needs to come earlier 'cause. It is, it basically means it's a 3 minute mindfulness sort of exercise, which involves breathing as well.

F: Yeah, yeah.

I: Yeah, so it's it's a guided guided exercise. I should probably just say that, because it does sound confusing.

F: Should I go on?

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

F: OK so I get that. I mentioned how where we go from there, because if I'm angry and I try and do this every everybody is, you know, a lot of people talk about mindfulness here and they say basically ‘look shut everything out of your mind, focus on your breathing, come in and out and in and out’. The trouble is 'cause you're angry, very difficult to do that for three minutes because in 30 seconds my mind is filling up with all that stuff. And what I struggle with when I'm doing it is how do I get that stuff out of my head, 'cause it comes back and I gotta get it out again right here. So I'm interested what you say further on here.

I: Yeah.

F: I mean, it's ridiculous. They tell me you know what you do it, count the number of breaths that you focus on counting, and I don't think I've ever got further than 7. Yep, that by that point my heads imploded with all the other stuff that's going round again, so I'm a pretty poor example of good mindfulness.

I: No that that's fine. It works for some people and doesn't as well like, but..

F: It does. It does work. Don't let me say it, It doesn't work. It does work and I do do it, but I find it hard to last three minutes. Is what I'm saying.

I: OK, OK. No but this is this is feedback that is really useful because I think, and correct me if I'm wrong as well, but like some of these techniques make sense like if just for daily situations or that kind of thing, but I think when it's with MND and the intensity of the situation, sometimes I feel like we may need different things for the mindfulness exercises. So this kind of feedback is really useful.

F: OK, yeah. So shall I go and...

I: Yeah, if you go on to the next page. Um, so this is. You could listen to the audio, but I guess in this interview it might be, It might not really, get through the whole thing. Maybe we could click the written instructions.

F: I've gone, so I go back yeah?

I: Yeah.

F: Click for written instructions OK.

I: I mean, typically you would listen to the audio, but, yeah, this is just so we can comment on it.

F: OK, I'm clicking to the next one ‘Step 3’.

I: Yep. Just to get a general idea of the kind of exercise.

F: I, this is good, I actually think this is, this is good here and all my earlier comments I say is that I find it hard to last three minutes doing this, OK?

I: Can I just sort of unpick that a bit more, um so? Is it because, um, there's just lots of thoughts going on, so just the length of the exercise is too much or, the kind of the mindfulness exercise.

F: I'm talking during. And this is not a reason not to do it. But I start doing it almost exactly as you describe here, and it's my intention to last the full course, which in this case is 3 minutes.

I: Yeah.

F: And I do start and I do that OK, I empty my head then I start and I breathe and I focus on the breathing and so on. But for me, within the first minute, other thoughts come back in. Now I think that's quite normal.

I: Yeah.

F: It's quite normal here, and so what is useful for me, and maybe you do it there if I read it properly, is to say ‘look, that is that happens and what you've gotta do is push them out again’.

I: OK OK yeah.

F: Bare with me it’s just my other phone. (on the phone) Hello. Yeah. Yeah. Please. Yeah. [name of person] look, I'm on an interview with University Southampton at the moment. If you could call on later on this morning is that OK? Yeah. Hi, I'm back. Uh.

I: Yeah that’s ok. Yeah, I think you're saying it's difficult to do, because the thoughts come in.

F: Yeah, and does your, maybe your text covers that I haven't really ready it in detail.

I: It, it does. It does say it briefly. But I'm getting a sense that it probably needs to be a bit more. Because I heard this from another person as well, who was talking about it in the context of anxiety. Um, and said almost like they prefer things that were more guided. Um, you know, like almost where there's more talking, so prevents your mind from, going in all those different directions.

F: My constructive comment here right is, what you don't want to happen, is that I get to here, I start doing this and after 40 seconds my head is full of stuff again and I say ‘I'm a failure’.

I: Yeah, yeah.

F: Yeah? I failed in this technique. It doesn't work for me and then I go ‘this technique is rubbish, it's no good’. Yeah?

I: Yeah, OK.

F: Yeah, you know? And I go down down that path, whereas in fact what happened is actually quite normal and I just needed somebody to tell me ‘so what you gotta do is just push them all out again’.

I: Yeah, yeah.

F: So my comments are aimed at just making sure the person doesn't feel a failure.

I: I see yeah, no that that's really good point. Um, if you just go on to the next page I think I want, I say something. I think this might be the space to say something like that as well. Um? I haven't done it to the extent that you suggested. I feel like…

F: You could say you could, if you could say something there, my feeling is that it would be helpful.

I: Yeah, yeah, I agree. Yeah. Um, yeah, I've tried mindfulness myself and had the similar concerns, so that is really normal. Um, OK. If we go on to the next page, I think it takes you back to the menu.

F: The next page? Yeah?

I: Yeah.

F: I've got anger.

I: Yeah.

F: Yeah.

I: And could you click the practical tips?

F: Yeah.

I: I just wanna see as a, as a family member as well with your situation, does this does this make sense or? Yeah.

F: (reading out loud) Time to think. Okay. Yeah, so so what is your question to me?

I: Whether it seems appropriate to you and your situation as well.

F: All those are. I, when I feel, that anger, which doesn't happen often, um and the anger, is. As they say, it's not with my wife because she's ill, the anger is almost some sort of self-pity. That my life, you know, five years of my life. I've spent the last five years doing something I never intended to do and have been prevented from doing things I did want to do.

I: OK, OK.

F: So I and I get sort of angry about that. And so it's not specifically something that my wife has done to make me angry, it is the whole circumstances taken in the round is ‘how did I get caught up in a mess like this’. And you know this is just terrible and it's it's never going to end and all this stuff here which you know is the opposite of what many people say about MND. So so for me the most essential thing is when I feel like that I may not be in the room. So what do I do? And the relaxation and meditation exercises help me calm down. That could be it. Go for a walk. Yeah I can do that. Yeah it's do something different, isn't it really?

I: Yeah.

F: You're saying yeah? Yeah, so yeah that's fine.

I: OK OK. Yeah, if we go to the next page.

F: Oh gosh, sorry let me just get rid of this (answers phone)

I: Yeah.

F: Hello. Hey [name of person], hi? Is it? I'm on a on a conference call with the University of Southampton. Is there something urgent you need? Do you want me to get them now? 'Cause I'm really I'm on the screen with the University now. No, but I'm sorry. I'm really being rude. I'm sorry, but I need to go back. OK fine. Sorry, that was the palliative care team.

I: OK. Can I just check with you as well? Do you have a specific time you need to get back? Um, I can make sure I finish before then.

F: No no, I’m fine. Don’t worry I’m fine, thanks yeah.

I: OK. Yeah, so this is just a quote to um. Yeah.

F: OK, so the first bit of the quote. Again, it's patient centric, isn't it?

I: Yeah yeah.

F: I suppose, what's coming up in my mind, is that even though you say this is for carers and for patients, there are bits that come up when it's clearly patients.

I: Yeah, OK, yeah.

F: And I just wonder, it's easy for me to say this, if that's the right architecture, just to have one path for everybody going through it. Or at some point, do you need to have a divergence? Depending on whether you're a carer or a patient.

I: Yeah, yeah. Um? The answers really, I don't know which is why I'm doing some of these interviews to see how people react to them so it, it, it makes sense that not all of it would be relevant and then trying to work out a solution based on that. Yeah, I just think if I presumed beforehand, that that was also not appropriate, which is why, i'm kind of asking people if it's relevant or no.

F: So the second paragraph is valid.

I: Yeah.

F: Yeah, it's the first one that isn't.

I: Yeah.

F: So, so I'm saying that 'cause one time in my life I was a computer scientist here right here. So I know a little bit about what I'm talking about. You know, if if at some point it if it did make sense to have a divergence point depending you’re a carer or a patient, much of the architecture of the slides could be the same. It's just that you’d have slightly different text on.

I: OK.

F: Yeah? So if I’d gone and chosen the carer bit down here, you could take me you could take me to here (points to screen), but instead of that example at the top, you’d have a different example.

I: Oh, I see I see, yeah.

F: Yeah. So so I'm not talking that you have to completely reinvent the whole thing.

I: OK, OK.

F: You basically have two copies of your slide, if I call them slides, two copies of the slides but with slightly different text on one route, depending on which route people go down.

I: OK, I I didn't know you could do that. OK yeah, that's handy.

F: Should I press on?

I: Yes. Um, I'm trying to think if we could go back from the anger page, if you click back.

F: Ok click back OK.

I: So I'd like you to look at the sadness technique if that's OK. See what you thought 'cause it's slightly different.

F: You want me to suggest a technique?

I: Yup, if you don't have any more comments on this page. I guess it's, yeah.

F: No OK, I got a suggested technique. (pause to read) OK, so I've read that.

I: Yeah.

F: So I so, I'm pretending I'm a complete novice at this now then, so I stopped for a moment, i've got a negative thought.

I: Yeah.

F: I stopped for a moment. I can feel the negative thought in my head. What does it mean: ‘Put some distance between you and the unhelpful thought’?

I: Yeah, I I go on to explain in the next few pages 'cause you can do this in different ways.

F: OK. Next?

I: Yeah, if we go to the next I guess this first step is to notice the unhelpful thought. Um, yeah, I’ll let you read.

F: Yeah, that's a really good slide.

I: Did these did these sound like similar thoughts you might have as well? Is it relatable?

F: Yes.

I: Yeah, okay. Yep, so if we go into the next.

F: (pause to read) OK, and actually this terminology of stepping back that that cracks it.

I: Yeah.

F: It was putting the distance. Yeah.

I: Oh I see OK. OK, no I'm glad that's helpful. I'll use more of that then

F: So this this is really helpful. This is a good one, so I'm going on just that?

I: Yep.

F: Right thought distancing metaphors. (pause to read) OK.

I: I guess this is just this this similar concept, just different ways of thinking about it and

doing it.

F: Yeah, this is good.

I: Yeah if we go on to the next page I think it's more of a technique.

F: (pause to read) OK. OK. Hum. I have comments, but I’ve gotta keep, do you want me to keep going?

I: No, let me know the comments, yeah.

F: OK, what um. And this is just out of my experience, this. Um, so what, I’ve forgotten what the box was called. What did you call it? The first one was anger, which one, which box are we in now?

I: Sadness.

F: Sorry?

I: Sadness.

F: Sadness.

I: Yeah.

F: The sadness is worse in the middle of the night.

I: Okay.

F: So you lie in bed, because all this stuff is going on around you. You know, you're listening for any unusual sounds and so on. You quite often don't sleep very deeply.

I: Yeah.

F: And that is my case, so I will wake up two or three times in the night. Yeah, um, largely because of the stress and things that that's that's, I live in that that day on day. Um, and when that happens, that's when sadness is worst I think.

I: Okay.

F: So all those are on on the play, so techniques that work, then…

I: Yeah.

F: …are much more useful. And this ‘stop technique’, maybe one of those.

I: OK.

F: So all I'm pointing out there's a recognition with sadness that you know you tend to be in bed alone …it’s dark, you're looking at the clock.

I: OK, OK yeah.

F: And it's a real, that's the sort of, difficult time to get together to get the sadness.

I: OK OK. (overlapping voices) That that's the context rather than just like when you're busy in your day.

F: And you know, maybe maybe it's worth mentioning that just as an example of when you might feel sad.

I: Yeah. No, that's really useful 'cause I do give an example on the next page, but I don't think it's, I don't think I've got the context right, I think. But I’ll let you, I’ll let you tell me. (pause to read) Right, yeah, I also realize this is more a patient...

F: It is, that’s patient centric…

I: Yeah.

F: …and I'm looking at the context of my wife, so my wife, yeah it's that. You know my wife is much more advanced than that, so she lies in bed all the time. So when she wakes up in the middle of the night…

I: Mmm.

F: …she feels everything is incredibly hopeless. Um. So I'm not sure what you're asking me about this, It's um.

I: Whether, whether., this context, I guess a carer would need a different example, really. Yeah. No, I I'm sorry, I answered my own question there. Uh. I may be if we go on to the next page and you tell me if the, how it's applied, whether it's it's done so appropriately.

F: (Pause to read) I'm afraid that reads like a Disney script.

I: OK, it's unrealistic.

F: Yeah, it's, all, yeah

I: OK. No, that's that's fair. Is it, can you tell me which, is it mainly the last bit?

F: Yeah the third paragraph, sorry it was second, the one that she asked herself.

I: OK.

F: Yeah, but that whole paragraph there, sounds a bit sort of sugar, sugar coated. God, you know it's that easy...

I: Yeah.

F: …it isn't.

I: Yep. Um, I guess. Yeah, the put ‘put some perspective…’ one was the one I was kinda struggling with. Um. And I want, did you have any examples or something that that you use in a similar way?

F: um. I think. So first of all we have this we, you know I'm doing it again from a carer point of view.

I: Yeah.

F: I'm saying here, so some of the things that Nina [example] would be worried about, I don't for me here, so I'm just dealing with this sadness. Um, yeah, as a carer.

I: Yeah.

F: I think paragraphs one, two and three are fine. I think my comment is that the outcome in paragraph four, is that's the bit that’s too sugar-coated Disney, it’s Disney-esque.

I: Yeah, yeah.

F: And I think he expectation to get to there is too high. Uh, and and that even diverting the thought if you ended up with the thought diverted or well whatever, then that's a win.

I: OK.

F: Yeah, you know, but deciding to make the most of her life right now and not think about what might be there, I think you know that… (voices overlapping)

I: That's not even needed, yeah.

F: …it's all a bit sort of platitude really I think there.

I: Okay, yeah. Yeah. No, that's fair. Um, OK. So even if it stops at the diversion stage that's also

helpful.

F: It’s is incredibly helpful, and I think it's about as much as you can aspire to. I don't think this kind of technique is going to in, you know, involve allow you to completely reinvent your thinking for the next three months, it's, that comes from somewhere else, and the whole point to this for me is to stop it when it got off track into depression territory.

I: Yeah, yeah, exactly yeah. Um, now that that's exactly what we were aiming to do, so good. I wondered in the context that you were explaining, when the sadness comes, would you, would you do a technique like this? Or would you do some of the other techniques that we've seen maybe?

F: Um. I think, when that happens, I would yes I would. I'm a sort of 1 trick pony really, I do the mindfulness stuff.

I: OK.

F: I start by doing the breathing, ‘OK stop thinking like this’. Now to help me stop think, let me start breathing deeply. Um, I remember it could be like 5:00 AM I'm talking about here.

I: Yeah.

F: Yeah, 'cause in the day it's much easier to handle, much easier to handle. For me, it's much easier to handle. It's more difficult if it's 4:00 AM or 5:00 AM. And so what I do, this is so this is just me is I'll either I bought I put two things in my bedroom here, one is a Nespresso coffee machine. Yeah so I might just go and take a cup of coffee, now that doesn't help my sleep.

I: Yeah, yeah.

F: But yeah, the caffeine helps.

I: Yeah.

F: Um, the other thing that I do is I'll put the radio on. Yeah, and there's always some news program and I can always listen to the news and that takes my mind away. Yeah, so I do two physical things rather than just…

I: Yeah.

F: …(overlapping voices) things.

I: Yeah.

F: And I do the psychological as well, so I’ll kick off with that. And then when I get to the point, OK then it's sort of moving away a bit now, but I know if I stop it'll come rushing back. So I have one, I've had one of these, be careful saying it, you know these devices where you mention the name and it switches itself on. I've got one next to me here, would you mind not saying it. I don’t get out of bed for that I just shout out, you know and say ‘play BBC Radio 4’ or something and stuff comes on. And interestingly, I may then fall asleep.

I: OK.

F: Because that, sadness is gone and then fall back asleep, and then when I hear the news at 8:00 o'clock, I'm sort of saying to myself, ‘but I knew bits of that story’. How did I do that? 'Cause I've been sleeping in and out of it.

I: OK, OK yeah I guess, these are techniques as well, but there is lots of, I mean, you can use the same concept and do be mindful of, practically or distract yourself which is like distracting yourself from your thoughts, but in a more, um, in a way that's adapted to your setting and just easier to do rather than like stop and do a technique.

F: Yeah, um. Yeah, you know, I think you really said, the techniques vary from person to person. So the best technique for me is, part technique as you describe, part one of these two physical endings. That really, that really took my mind off.

I: OK.

F: So it’s either coffee or the radio.

I: Yeah. Um. Yeah, no that that's really useful. Um I just I wanna show you something quickly if we, if you're on the website, maybe could you see the home button right at the top?

F: Yeah.

I: Yeah, if you click that, it takes you to the main page.

F: Yeah.

I: And if you go to the ‘all activity’ section.

F: Yeah. OK.

I: Um? Yes, so this has, all the different techniques in one place.

F: OK, she looks quite interesting.

I: Which bit is interesting?

F: All of it actually seeing it.

I: OK.

F: So I just wonder. You know at the outset. Again, for me and my style of thinking, when I'm trying to decide, am I really gonna invest in doing this or is this just another one of these ‘doing good’ things that, um. You know something saying ‘look there are there are a whole host of different techniques’, and if I saw those and then ‘the purpose of this is to help you decide which are the best ones that are appropriate to you’.

I: Yeah.

F: I would have found that really quite helpful at the start.

I: OK.

F: That, this site is not yet another one trick pony that only goes to mindfulness.

I: OK, OK. That's really useful, ‘cause I think this is the bit I was wondering as well. And that's why there's this whole process of testing it out where the, you know, sometimes you go into a website with more ‘this is how I'm feeling and I'm looking for information about how to deal with this’, versus if just all the techniques are there and I just pick something that I know I would find useful. Do you see what I'm saying?

F: No, I didn't quite, describe that again.

I: So I’m wondering which approach people prefer. Whether you would come to the website going ‘I'm struggling with anger’, say and wanting guidance about that or wanting to know the different steps and techniques that you could do. Versus ‘it doesn't actually matter I could be feeling a number of things’, but, these are the techniques, these are all the techniques and then I choose what suits me best.

F: Yeah, that’s interesting. So when I made the comment I would have found it useful to at the start is when I'm trying to decide do I really invest in this or...

I: Yeah.

F: …give it cursory attention. I'm going to find this slide useful in the introduction bit. Yeah, so when you told me you know, you see the introduction once the next time you log on you go to some space. You go, you go straight to one of the three boxes there. Oh you, I'm not sure if you had all activities as a false/fourth box. You know the re-entry, yeah?

I: Yeah, yeah.

F: So you could have the three buttons and I could go straight there and not have to navigate through things I don't want to go to, would be one argument. The second the counter argument, I suppose, is that I might think I've got an anger issue. But actually it was something else that's making me angry. So I might be constantly pressing the wrong button or not enough buttons.

I: Okay.

F: But I'm looking at the way it manifests itself. I'm angry, but actually you know why am I angry? And it's because I'm stressed or because of something else yeah. So so I think if I was making a suggestion I would include this screen early on on the introduction part of the website…

I: Yeah.

F: …just to show this is not a one trick pony, there are loads of different things that you can try, yeah?

I: Yeah.

F: And my purpose is to get you to the right ones. And then when, when you have the re-entry path coming in, you know I've gone for the second, third, fourth, fifth time and we cut out the introduction and we come through it into which of these boxes. I probably, I think I'd argue that there is space for pulling the ‘all activities’ as a fourth box on that sheet. I can't remember if it's there already or not.

I: I think it was there but a very brief description saying it contains all activities, but I could say it contains mindfulness, self kindness, all these different, like list some of the activity.

F: What I’m getting at, if the intention is that people keep coming back and using this…

I: Yeah.

F: Yeah, um, and so when we do that we go straight to the let's get on with it list, the three buttons. There’s a temptation that you just go to the same one? Because I'm angry again, I'm angry again and you're gonna end up getting the same techniques that we got when we did the same thing last week and the week before.

I: Yeah.

F: By having access to this screen…

I: Yeah.

F: …here, in so you've got the button saying ‘all activities’ and I could click on that and this screen comes out if I click on that, it then tells me, well, actually, maybe I should try something different.

I: Yeah, yeah. I agree, and it's it's even as as a suggested technique that's not the only technique to deal with anger, it there are all these techniques so you you don't want someone thinking ‘I tried this, it didn't work’. So now..

F: Sure.

I: Yeah.

F: OK, OK.

I: OK, I'm glad you like this page. Yeah, I guess from this list of techniques as well, do you feel like on this page I've given enough description or Guidance? So does it need anymore?

F: So what happens if I click on these now? I'm not going to, so I can click on that.

I: You could if you wanted to. So it takes you directly to the technique, not the information about, something like that.

F: So ‘compassionate breaks’, yeah there that that is there, yeah? I think do something physical. Um, may not come out clearly enough in all of this.

I: Something physical, sorry. I don't know where.

F: I go for a walk, if it's the daytime. (incoherent) night-time.

I: Oh um. You mean suggest practical tips?

F: Yeah, I'm I'm on this ‘all activities’ menu here.

I: yeah.

F: Alright um I'm so the way I'm interpreting this, I'm saying look actually this site this website is worth persevering with because it's actually got a whole host of different things that could be there. I just notice that there wasn't anything ‘do something physical’ on there and maybe there shouldn't be because it's somewhere else. That's the only point I'm making.

I: Yeah, yeah.

F: And I'm not quite sure what ‘compassionate letter writing is’.

F: OK.

F: It sounds to me like writing 'cause you're person you're caring for has died

I: Oh. OK. I'll find another title. It's meant to be more directing compassion towards yourself. Yeah, I should say that more, yeah. Um, OK. I agree with your practical tips as well. That's a useful coping strategy, but I've not brought it in at this section. Yeah. But yeah, exercising stuff is another very useful coping strategy.

F: So let me sum up just to make sure I made my point clearly here. When a user like me gets encouraged to use this site, the site doesn't necessarily have the level of credibility that you would like it to have on day one, so some of the things you need to do in the introduction, I believe are not only describe how to use the site and what it is…

I: (Doorbell rings) Sorry, that's just my doorbell, that's fine.

F: …but also yeah, you need to bring the user more on site and more invested into it. And that's why I think they're showing this kind of slide and this is the ‘all activities’ menu. That kind of slide early on is basically telling the user ‘yeah, stick with me 'cause we got lots of things here and we're going to find out which ones work for you’. And I would then say ‘OK, then I'm really, am gonna give this a go’. Whereas you can't assume that because I've logged on that I am going to give it a go.

I: I see.

F: 'Cause yeah, nine times out of ten I log on to something and I say ‘this is a load of drivel’ and I switch it and I don't go. Yeah, so so that's why I say in the introduction bit is to get the person really invested in the site. And then um, the use of this slide, which I think you underplay the use of this slide again in the practical usage side of it as the fourth button of ‘where do you wanna go’ really has value. 'Cause I know people will tend to go to the same button and try that because they recognized the problem. But actually occasionally, you just might want to remind yourself or else you could be doing and you might want to try.

I: OK, OK. It's almost like this has to be a bit more, up in the forefront.

F: I think you you use this twice. You use it forefront in the introduction to get the people invested saying: ‘OK then this site has got something about it, it's not just taking me to the same place as everybody else’. Then and then when you come to the actual day-to-day week to week use of it, it has a different purpose. But again a strong purpose, so it appears sort of twice in different places, I would suggest.

I: Yeah, I agree. Yeah. No very useful suggestions.

F: How are we doing? Do we have?

I: Yeah, I just almost like you've answered. My last question was also meant as a kind of a sum up summing up question, just overall things you liked or didn't like about the website.

F: Um? OK um. So first of all I I really like the idea of having it. I find yeah the use in colours and things are quite calming and that and that's good. Um, I think, we could make it clearer the question that you put at the start that this is about dealing with emotions and not dealing with physical stuff.

I: Yeah.

F: I'm just using years of experience of having designed things and then people use them for something they were never intended to do, and then say they’re rubbish. Yeah, and just because they weren't clear that it actually wasn't what they thought it was.

I: Yeah.

F: So in that introduction thing, I think you really do need to make it clear. (unintelligible)… motions and there are various techniques like on this slide etc etc. What I don't like I'm not sure I said I'm repeating the point, I'm not sure if the carer patient divide, if it really works, it's. You know it to me it seems like you, haven’t really differentiated that what you've done is do one that is aimed at patients and you're hoping you'll get away with it with carers.

I: OK. OK.

F: Yeah, there's that and you know, for for every patient there is at least one carer and probably more than one carer, as other members of the family get involved. So you actually I'm just making this hypothesis that have more carers than you have patients.

I: Yeah.

F: And it's those emotional needs of the carers. That's the only thing I'm focused on, I have not looked at this as a…

I: No I think that that's really fair and I kind of had a sense of where I might be doing it better or not, but hearing from you, I think makes more sense also because I can see how it's coming across to people.

F: Listen, you, you know I'm only one person. You're speaking to lots of people and they may well have very different views. Is there. I repeat the fact that you're doing this I think is great. The stuff you've got on there I think is really good.

I: Yeah.

F: I just don't think that the flow is a flow that would have suited me.

I: OK.

F: I would have pressed on with it and I would have got there but it doesn't all my sort of you’ve heard them I'm not going to say them again, that's what my comments are about really then.

I: Yeah no. I I agree there. I think I've got a sense of what you would prefer in terms of flow as well, so. Um, yeah, that's really useful. We do make changes also, based on all these comments and feed that into the next round. So this is all really useful. Um, yeah, I'm done with my questions. I don't know if you had anything else you wanted to add about the website.

F: No I'm done. I hope I haven't dispirited you. As my purpose is entirely the opposite. It is to encourage you.

I: Yeah.

F: And I repeat, these are just the comments of one person and the next person could have very different views and that's your job to sort that out here.

I: Yeah.

F: I'm just trying to avoid this being launched and then it stumbles because the architecture wasn't quite right.

I: Yeah, yeah.

F: Content wise, but the architecture wasn't there.

I: Yeah.

F: So now I'm done. So I hope I said something.

I: I'll just stop recording so I can talk to you.