**Interview 20**

**(family member)**

**I:** That's completely fine. It was just more for me to just understand the background, I guess.

**F:** Yeah, that will be my mainstay because [name of person with MND] is now totally nonverbal and uses a machine to talk. She’s steadily gone downhill that… we as a family, we just generally all try to pitch in where we can and help her where we can. Sometimes it's… you feel like you’re beating your head against a brick wall, which was hence why I got CALMs. It did help you know, why I find it very good, I'm a very slow learner, it takes me forever to even get it. I'm technologically inept [name of interviewer] so it took me some time while, I couldn't come to terms with it, I'm better at transcribing and writing I'm just… It's just old fashioned that way, but I did find it useful.

**I:** Oh, that's really good though because our aim was to try and make it as user-friendly even for people who don't use technology as often so...

**F:** Yeah, yeah, I returned it when probably near the time I was speaking to yourself and I did find it useful and I will employ techniques that I had found and let you know what. Just generally will, even aside from that, even within my own life and situation with the family and speaking about Motor Neuron, you know what. It has been helpful.

**I:** OK, OK, can I just ask you a little bit more about how you used it. For example, did you, how did you like choose the different areas or when did you go on the website?

**F:** I am naturally [name of interviewer] as I say I'm totally inept and I find that I was a bit harum-scarum at the beginning and I just chose as a it came to me, say sadness or frustration or anger once, it would depend on how I felt at that stage. But then I found nearly [name of interviewer] was probably it's the way, maybe because I'm 68, and maybe rote learning, it's an easy way for me to do different things systematically, that's what I did do. And I find by making notes as I went through systematically, I find that more beneficial, just than randomly going through it.

**I:** OK, OK, so you almost just repeated the different sections and made notes as you went along.

**F:** I did, I made notes that sort of an aide memoire. I noted that down and would…then I can refer to it rather than going to the internet every time I needed to be reminded of something. Allbeit I found you know, the breathing and then those mindfulness exercises, they were lovely, you know. So obviously I used them, I would have just done today, and I found them very good.

**I:** OK, OK. Can I just ask in general which ones did you find most useful for you particularly?

**F:** Probably, the ones… I did find the ones useful that…for negativity and positivity, you know. Basically, you know the thing about just saying ‘never’ and you know, everything being the glass half empty. That, I found that you know facing up and putting a different slant on things or reverting back to being or doing things that you would find pleasurable etc. to maybe pick yourself up of a certain scenario [name of interviewer].

**I:** Yeah yeah, so the one where it said thinking about positives and trying to do more enjoyable things.

**F:** Enjoyable things basically, and then you know, [name of interviewer] when I was reading them too then, you know Celeste [example quote from website] and basically you know people talking about their MND, and I thought ‘God, I’m seeing [person with MND]’. My MS is minimal compared it,’ you know, I just thought… It's a bit overwhelming at times [name of interviewer], but at the same time it’s uplifting that people could get on with things that are so devastating.

**I:** Yeah yeah, it's hard to see positive sometimes when it can be that bad.

**F:** Yeah, it is. Particularly, I saw I actually did see [name of person with MND] on Monday. 'cause it’s such a rapid decline it was very daunting [name of interviewer]. So it was… you're trying to find positivity but I don't, sometimes it’s so overwhelming.

**I:** Yeah. Did you find that I guess the information that was given was it was that kind of presented sensitively to capture this difficulty as well that people experience?

**F:** No, I find it fine. There was only one thing, I couldn't access that forum group. I tried to register on that and you see when I try to log in my phones are sort of like, a bit ancient as well [name of interviewer], maybe that's part of it. I'll get my husband to look at it. I find it wouldn't even let me get past and fill my date of birth in. And I was anxious to you know, participate in the forum because I thought you know more information as, is what you do need in scenarios like that, particularly as [name of person with MND]’s health, deteriorates. You know that like-minded, that is always a help, you know, information is always a help.

**I:** Yeah, yeah, oh I'll have a look at the link but I basically got it from the Motor Neuron Disease Association website.

**F:** It let me get as far as forum, but then when I try to type in to register my data birth it wouldn’t let me get any further. Whether it's a problem with my phone, which it could be because this thing is ancient so it could be just that [name of interviewer].

**I:** Yeah, it might have too also do it. I don't know if the forum has certain rules or something like that.

**F:** Might have to do sorry with what [name of interviewer]?

**I:** With whether like the forum has specific criteria or something.

**F:** Possibly or maybe because the option I chose to look at I don't know. But anyway I couldn't access it and I will have another look at it. I think a thing like that it is very useful, and you know practicalities, they, they are important. [name of person with MND]’s presently going through having physical problems obviously, and she's having a wet room built and we've had innumerable problems with that. So I would say she's really availed of all of the techniques, etc. that you’ve advocated in it [name of interviewer]. Because she has had such an awful, awful time.

**I:** Yeah, she gave me some really helpful feedback as well about how it applied to her situation. And yeah, I guess we spoke about the positivity section. I was just wondering… you mentioned about the mindfulness activities. Yeah, when did you use them? Or how did you use them in in your situation?

**F:** I find them… I love the talking sessions, you know the meditative states and the awareness of the breath, etc. I find that calming.

**I:** OK, yeah. And this was the three-minute breathing space was, was it that?

**F:** Sorry, I didn't catch up that.

**I:** The three-minute breathing space or a different one? Sorry I'm putting you on the spot to remember the name.

**F:** It's not that [name of interviewer] I can't actually hear what you're saying. As I say my phone is protected as per the reception at the border area I’ve had this problems with friends.

**I:** I just yeah, I was wondering if that was the three-minute breathing space or a different activity?

**F:** I can't recall now.

**I:** Yeah. But it was one to just focus on the breathing, was it?

**F:** The focusing on the breathing was lovely actually, it was very helpful and very… it’s possibly difficult to roll out in stages the day…so it brought me back to the day, it was very grounding.

**I:** OK, did you try any of the other ones which said, you know, think of a safe place where you're comfortable and to kind of get those feelings of safety and comfort? I think it described it in terms, like to have an image in your mind of a place you like.

**F:** Yeah, yeah. That would have come easily now that… you know I find it wasn't a problem at all that.

**I:** OK, OK. And I did want to ask you about the one where it asked you to pay attention to different parts of your body, the body scan?

**F:** The body scan that was interesting actually, let me see with the notes I made about the body scan. Uhm… Can you just remind me about it, where was it, towards the synopsis wasn’t it?

**I:** Yeah, it was in the all activity section, and in the mindfulness row, I think it was like the last one…

**F:** Sorry [name of interviewer] what’s the question on that one?

**I:** I just wondered what your thoughts are about that particular activity.

**F:** About the body scan?

**I:** Yes, that one.

**F:** The body scan?

**I:** The body scan.

**F:** [name of interviewer] I would need reminding...

**I:** Yeah, I'll tell you about it some. It asks you to pay attention to different parts of your body and then almost breathe into those different parts and kind of have feelings of warmth and comfort as you do that.

**F:** Oh yes, from your toes up to your heart.

**I:** Correct, yeah, yeah.

**F:** Oh, that was lovely! I liked that and you reminded me from the toes there on to the heart and that was each thing in the warmth, etc. But that really was lovely.

**I:** I was… I was just wondering as well 'cause you said you're in a wheelchair and I don't know in terms of symptoms and MS symptoms and things like that, but was that difficult to do to think of your body?

**F:** [name of interviewer] I use a wheelchair for exterior use, I use a rollator normally about the house for a balance and performance, but I'm actually not mobile, I’m very immobile, but I can move so that wasn't a difficulty at all. The wheelchair is for… I can't walk outside the house because I make sure… with things like rough terrain, etc. balance would be an impediment to my movement.

**I:** Ok. Yeah, I see now.

**F:** But as far as sitting or something that has never been problematic. And in fact I don’t find it uncomfortable this scenario, where I normally do sit, and I don't go out a lot anyway. So knowing that, that was easily achievable that.

**I:** OK, I'm glad. Yeah, I guess. I just wanted to ask you about the kind of information about the different emotions, sadness, frustration, anger.

**F:** They fluctuate now and… you see [name of interviewer] when I first looked at the site, I find that maybe on the day… maybe that's isn’t the proper way to do it, but then it just didn't perhaps suit me at that early stage. But when I went on it initially, I didn't pick the sequence of, you know, the anger, sadness, frustration. I probably picked, maybe on the day I picked frustration, but I just went through them systematically because that's the way I find it easier for something to sink in. But it actually was helpful in like dealing with your particular… your mood changes probably from day to day, never mind week to week.

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

**F:** It was good basically, the suggested activities are, you know, the self-kindness and compassion breaks and then, I find they all were, you know they were useful in helping with the certain emotions.

**I:** The self-kindness ones helped with the emotions? In what way could you tell me a little bit more?

**F:** I found it useful because it gives me techniques to actually remove myself from the say for example, frustration, which was a difficult one to overcome I think. And it’s been particularly apparent, probably since [name of person with MND] has become weaker. That I need to sort of… rage nearly developed frustration with the system that allowed her not to progress with certain things that she needs done. And then the stepping away and the removal and using techniques like uh...

**I:** Oh uhm, was it thought distancing, was it that one?

**F:** Sorry?

**I:** Was it thought distancing, where you take a step back from your thoughts and…

**F:** Thought distancing seemed to be part of it, yeah, and then activities that sort of, I found that would be more pleasurable. And stand back from it, you know the things that… maybe to sit down and read or something for a while and then centre myself before I would return to…

**I:** OK

**F:** Makes you more open minded.

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

**F:** Like I, I just thought I'd get nowhere with this. In fact, you tie yourself open circles so maybe I would knit or something you know, I would go to bed and then return to it with a more centred approach, perhaps [name of interviewer].

**I:** OK, OK, so I see it like the self-kindness activities almost help you step back and just take a break from it and then you could see it differently maybe?

**F:** Yeah, and the stop technique. You know the stop, then breathe and then observe. It's...as a matter of fact I was going to ask you [name of interviewer], the CALM, the one we’ve done will that stay online, or can I return to that when I want for example?

**I:** Yeah, since you sort of signed up for this study, you can continue to use it. I know for sure it'll be there till September this year. I don't know whether we'll sort of renew it after that, because it's just all linked to my PhD, and what stage I'm at, so I know for certain it's there till September.

**F:** Right, right. Just to, nearly as our memory aide, I’ve written most of it down. But I do find the talking scenarios, I found them lovely, so I would like to reuse them.

**I:** OK, OK, I'll see if I'll just speak to my supervisors and see if there's a way I can send that to you. Did you mean the audio of like the mindfulness exercises?

**F:** Right, that would be lovely.

**I:** OK, OK. Yeah, I, I will just speak to them and get back to you with that. Uhm, I'm glad you found it helpful though.

**F:** I did find it very useful actually. It was a sort of focused me a lot.

**I:** OK, OK, and when you say focused also, does that mean just kind of not get caught up in your thoughts and then look at it slightly differently?

**F:** It perhaps helped to look at things differently, when I employed techniques that when I return to them I address it with a clearer, more open mind on it, that wasn't... For example, say the sadness or the anger, it was useful to return to some of those without those emotions.

**I:** OK, OK, so it didn't sort of get rid of them, but you could deal with the emotion sort of better?

**F:** Sorry [name of interviewer]?

**I:** Yeah, no it was not like the emotion went away, but you could approach it with a fresher perspective.

**F:** Yeah, yeah.

**I:** OK. Yeah, I guess I've asked you about a lot of the different sections… Oh yes, the anxiety and stress section as well, was that relevant to your situation as well?

**F:** That, that would be anxious about… you couldn't basically go through anything like this without I suppose anxiety being there, you know with [name of person with MND] I’m just worried constantly about her. So yeah, the anxiety I think is pervasive isn’t it?

**I:** Yeah, definitely.

**F:** And the thought distancing lets you, you know, step back and basically the unhelpful thoughts or whatever, breathing techniques, are all probably helpful in that respect.

**I:** Yeah, yeah, I see.

**F:** And I also find even though you know, the tips that you probably think should come naturally to you like talk with someone or write it down. You know, talking is like very therapeutic and [name of person with MND] and I, albeit she can’t talk, we would contact each other daily and we would attempt to lift each other spirits or attempt the harder things, you know which you also have to figure out, you know..

**I:** Yeah yeah. I'm glad then the practical tips were also quite handy.

**F:** Sorry [name of interviewer]?

**I:** Did you find the practical tips also useful?

**F:** Yeah, I basically, you know, if you need help, I’m a proponent of this anyway, but I think because [name of person with MND] has seen me and has been such a help to me that she knows that I do ask for help when I need it. 'cause I could have this for 22 years, so we've... [name of person with MND] has been with me every step of that. So it's probably she's learning from myself, but it's alright to ask for help on what you know, give her… it'll basically you know, things like getting used to the equipment [name of interviewer]. Because I've been in a wheelchair for X amount of years, I have had adaptations done, [name of person with MND] has watched this and been so helpful to me that its [a well worth?] passed by now, and maybe that's herself, she's presently waiting for a wheelchair. So she's used one of my other ones, which will suffice after a while. But it's not as you know, some people think ‘Oh God, I'm getting older, I need hearing aids. I'll never wear them because of the pride.’ I think [name of person with MND], because she seen me like that for so long, that she’s alright with it.

**I:** Yeah, so you've almost helped each other out I guess by going through…

**F:** Yeah well, because she has been so good through all of my 22 years, that she knows or has seen it happen and basically I nearly don't have to ask for help because they know what to provide. They've known, my sisters, what to provide and [name of person with MND] probably sees that now, it's not a shame to ask for help, if you need it ask for it.

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

**F:** You just need reminding of this. What was good about this too is reminding you of things that are alright to do, you know…

**I:** Yeah, it's useful to just have a reminder 'cause you could forget things...

**F:** Yeah, you probably take a lot of things for granted, or I think that's natural. But some things just need to prompt for you to realize that, ‘Oh this isn’t so daunting,’ that people are there later to lessen or to provide physical assistance.

**I:** Yeah, yeah and sometimes if you're stressed or worried then you don't think of these things automatically.

**F:** You actually don’t. You can't see the wood from the trees I suppose.

**I:** Yeah yeah, OK. I guess I also wanted to ask you whether, as a sister and family member, did you find that just how things were presented on the website was relevant to you as well, or did it seem like it was focusing on the patient?

**F:** [name of interviewer] It totally did. Because of maybe what [name of person with MND] is going through. I actually found I could divide it up between what were [name of person with MND]’s and where I am. I found it very useful in that respect, it was nearly… maybe because [name of person with MND]’s so swift, what happened and so galloping that mine’s a slow progress, time to come to terms with things. Whereas [name of person with MND]’s was thrown on her and was so daunting. But I got to relate some of it to myself. But then [name of person with MND]’s overwhelming, I mean you have to to work yourself halfway through it and think, well, you know, calm down or leave it and come back to it.

**I:** Yeah yeah, OK. So yeah, some of it made you think of her situation and some of it is more relevant for you.

**F:** Aye, yeah.

**I:** OK, OK. I just wonder if since using the website as well, how do you know feel about just dealing with emotions and if anything comes up in the future?

**F:** Probably. They've been very useful tools [name of interviewer] but I'm just probably, and you’ve dealt with this too, about how you deal with day to day, but we as a family we probably all of us can't help being scared of the what the future will bring. And nothing presently can maybe stop us with thinking that. But it'll be a matter of training ourselves to seize the day today and look into the day today, but the future’s obviously, because of the nature of MND is quite scary. We just have to ground ourselves to deal with each minute as it happens.

**I:** Yeah, yeah.

**F:** By the same token we have, we really do you have to think ahead of ourselves because [name of person with MND]’s not going to get better. So we have to, we have to put things in situ that will help. so it's very…it’s odd 'cause you are in the mindfulness zone and then all of a sudden you think ‘Gosh, I really do have to think of this because it's not, it's not fair for [name of person with MND] having to think of things and look after herself. It’s done… [name of interviewer] I don't know like explain it properly, but it's a bit overwhelming in stages.

**I:** Yeah, yeah I understand what you mean. It's when you think of the big picture it can just all be too much and just taking the approach of once one day at a time.

**F:** Yeah, that's… I haven't, but you do really need to plan ahead for this illness. Because things like even physically [name of person with MND] moving. As I say, I saw the other day up at my mother's house and she had to bring her feed tube, she uses her RIG feed, but because she was comfortable up at my mother's home that it was awful because then she needed her suction thing, which she didn’t have with her 'cause she's needing to physically transport too. It’s one of those machines, and because of her not having her suction thing with her she became… she couldn't deal with the physicality of being in the house and that was very rough to watch [name of interviewer].

**I:** Did she get there in the end with sorting out the food tube?

**F:** Once I brought her home and she was able to use it, but I think it will actually probably frighten her and she thought, can I with ease leave my own home or what? You know, probably… I just think her confidence was a bit shaken.

**I:** Has she kind of adjusted now into using the tube and things like that?

**F:** I think it's like everybody is, their comfort zone is where they are more used to being and if you remove people from their comfort zone, it is more difficult. I just think everything like that takes a, takes a sort of a brick out of your wall doesn't it, it is daunting. So, like when I did text her later that evening, she actually says when she got back she was able to deal with this stuff and the other and felt better. So possibly [name of person with MND]’s used the techniques that she has, you know, via your CALMs course.

**I:** Yeah.

**F:** She said she was. She was feeling grand.

**I:** But it's completely understandable as well when something like that happens, at that moment you don't really think of the techniques, because that's such a big problem.

**F:** No, I think you’d be overwhelmed,I agree with you, yeah.

**I:** And at that time all we can do is really just give ourselves space too just deal with it and thenlater think of maybe trying to help.

**F:** Yeah.

**I:** Uhm you have said a lot of positive things about the website and I'm glad, but I just wondered if there was anything you disliked about it or found difficult to use?

**F:** [name of interviewer], I have to tell you that I find all technology difficult, I even find talking on the phone difficult. I'm very old school and I find having to write things down, just my way of doing it, it’s old fashioned, but it is the only way I can deal with it. So, technology does daunt me, so that was a daunter, yeah. But when I got into the comfort zone with it, I thought what's the worst I can do. I felt alright, and it was very well laid out actually to tell you the truth when I did come to terms with that. But I'm just old fashioned, the way it was presented very good.

**I:** Which part was originally daunting, was it the logging in and?

**F:** The whole, everything. ButI really am, I'm old school smoke signals stage. I really, really am bad technologically. I'm a luddite, I just find any technology daunting. So, the very thought of having to do something online is awful for me but I got there.

**I:** You managed very well. (laughs)

**F: I** got there!

**I:** Yes, that's very good. Yeah, and I think I had a look at sort of, the information that I had, and you looked at pretty much the whole website and yeah, I think almost all the sections in there so you did a really good job of going through each of them.

**F:** [name of interviewer], I have to say that I will return to it, I know I will return to it because it's just the way I need to do it to make something sink in. I just need to be… I need to repeat things, but now I'm more comfortable with how it's laid out and as I say it’s laid out very well that I will return and go into the sites and maybe use it more appropriately. Like watch your emotions is it frustration, anger, sadness, maybe I’ll do less of a linear way and more of this is how I feel way.

**I:** Yeah, yeah I guess now you know what's there you can choose.

**F:** You’ll know, I will know my own emotion at the stage but first, I just had to go through it the way I went through it because that's the way I can deal with things.

**I:** Yeah, yeah, I wondered as well if there was anything else that you are perhaps struggling with emotionally that maybe we haven't spoken about or covered in the website?

**F:** No, I think basically, it generally covers the whole gamut, of what you do feel. Probably the, the emotion that… the positivity of feelings of joy. You see in the middle of anger, frustration, sadness or whatever, joy is also one… like joy, just joy of seeing [name of person with MND] happy and joy and seeing things that are upbeat for us. Because a lot of the time [name of interviewer] in the middle of all we do, we laugh to excess which is good, and I think that positivity is, I forget what I bring to [name of person with MND]’s wellness, that we do have good fun.

**I:** OK OK maybe a bit more focus on the positive stuff too.

**F:** Aye, and those remind to focus on the positives, but we do have a lot of fun. So the joy and I think that has to override the negativity. Or sometimes the use of words are merely negative, the use of anger or whatever, you know, anger is such a horrible terminology isn't it?

**I:** Right, OK,

**F:** It's honest but it’s daunting.

**I:**  Yeah, I see what you mean. Just trying not to be too negative in the words and how things are phrased.

**F:** Yeah.

**I:**  OK, OK. That's most of my questions, I want I don't know if you had anything perhaps to add from your notes?

**F:** The only questions I had [name of interviewer], was about the forum and that I couldn't access the forum details, but we have already chatted about that. And the only other thing I wanted to ask you basically, and you've answered that already, was future scope if I could access the site, but you were going to have a word with that…

**[end of recording]**