**Interview 11**

**(family member)**

**I:** Shouldn't it be saying it started?

**F:** Yes, it says it’s about to start. Yep.

**I:** Yeah, yeah. Brilliant yeah. I guess in general I just wanted to know how you got on with using the website?

**F:** Yes, I found it quite useful, quite a lot of the sections. I mean, I've looked through all of it. Um, the one that I particularly liked was the positivity section and the values and goals I thought was quite interesting as well, cause I hadn't really thought about that, so that was quite interesting. And the adjusting to change as well, because I think that's one of the hardest things that I've found is adjusting to the change, and I think I'm still finding that quite hard. I suppose because [name of person with MND’s] condition’s changing, not quickly because he's got the very slow ALS, but it's just, you know, trying to adapt to the change as it happens, and you’re thinking ahead. So I found the adjusting to change section quite useful for that. So those three really. Some of the others... Yes, I think are useful, but I think because I'm quite a positive person anyway, and I'm trying to do quite a lot of exercise and have a little bit of time to myself, that quite a lot of… one or two of the sections are good, but I found that I'm already doing those sorts of things. But you know, if somebody is not doing it then it's a useful thing to have to make them think about it really.

**I:** OK, OK, can you just remind me which bits were things that you felt you already do in some way?

**F:** I can’t remember without looking at the actual sections.

**I:** OK, was it the positivity stuff like doing pleasant activities or?

**F:** Yeah, I’m not sure the positive, positivity I put a tick by it, so I thought that was very, very useful. And I can't remember the other sections. Probably like, I think there’s one for activities I think is there activities?

**I:** Yeah.

**F:** So, I thought that I looked at that one and thought yes, I'm doing most of those things anyway. Yeah, so that was one of the sections.

**I:** OK, OK, that's OK. We can go through each section. I'll give you a sort of brief of what was in that section. But can I just ask, did you use it by yourself or with your husband?

**F:** I have used it by myself. I have suggested it to my husband two or three times that he should look at it because I think you... I think it would help him because he's, he's quite a negative person. And so, I think some of the sections would be particularly helpful for him, but I haven't managed to get him to have a look at it yet. He's actually been quite poorly for the last two or three weeks,’ cause he had an infection over Easter, so he's been quite poorly, but… Yeah, in fact this morning I did say to him you should have a look at the website, so I'll try and get him to have a look at it after this if I can.

**I:** That’s alright. I just want to sort of see how people normally would use something like this. And I guess linked to that as well. Did you find that you used it, say when you were encountering any difficulty, or was it more because I'm taking part in the study, I guess?

**F:** (laughs) Yes, partly that I think, yes. Yes, partly that really [because taking part in a study]. I haven't felt that I've needed to look at a particular section at a particular time. I’ve just looked through it basically when I've had the time, or I thought about it and then gone through and sort of thought what might be appropriate and what might be useful really.

**I:** OK, OK, so almost like an overview. And then…

**F:** Yes

**I:** yeah, OK. Uhm, yeah, let's go through the specific sections if that's OK. So, you mentioned the positivity one. I think I'll go through each of them because there were three activities there. One was pleasant activities, which I think you said you already do. [**F: Yes**] as a way of coping. So, it was similar to what you're already doing. Uhm, any other sort of comments about that activity and how it was relevant for you?

**F:** No, not really. Just remind me what's in the positivity section.

**I:** So, one of the activities was basically thinking of doing more things that you enjoy.

**F:** Yes

**I:** But also, maybe finding new ways to do this because I guess with MND if it affects how you would have normally gone about doing certain things yes, then finding new ways to adapt that.

**F:** I mean, I think for me, one of the things, the lockdown in a sense has helped me, because before I was struggling to find time or be able to actually leave the house to go out to an exercise class to travel to it to do the class, to travel back because of the time it takes. Whereas during lock down all the classes have gone on to zoom and all I've got to do is just go into another room for an hour or half an hour, do the class and then come back out again. So, that's a way of adapting doing something that I enjoy. Not quite sure what's going to happen after lockdown, but there is a carers hub for [name of county] that I belong to, and they do free exercise classes, yoga and Pilates and all sorts of things, so I can continue to do that. And I'm hoping I can talk to my Pilates teacher and see if she can record classes for me and send them to me to do so I could do them at home because it's going to be more difficult for me to get out now than it was, say, this time last year really.

**I:** OK So it's actually given more opportunity. Ok.

**F:** yeah. So that’s one way of adapting

**I:** And I guess linked to that as well you mentioned the values and goals section that you found useful. Could you tell me a little bit more about how that was applied to your life and your situation?

**F:** Well, I think I just hadn't thought about thinking of my situation in terms of… well, I do in terms of value, because obviously I appreciate what we've got and 'cause we've got a nice house, because we have bigish garden and I've got a very supportive family. So, you know, those are all values that I've already got, but I hadn't really thought about you know, goals, really. So that was, you know, something to think about.

**I:** Yeah, OK, OK and still relevant as a family member in terms of the examples and all of that as well that were given on the website? Did you find that you related to that section?

**F:** Yes, yes, yeah.

**I:** The other one was finding positives, which I guess you may have already done because you said you were a positive person. But like looking at your situation and also paying attention to the positive things, not to say that negative things on there, but just also giving equal attention to both. Did you try that activity or was it something you already do?

**F:** It's something I already do.

**I:** Yeah, OK, OK. Uhm Yeah, I guess any other comments about the positivity section before we go onto another one?

**F:** No, I don't think so. No.

**I:** OK. Yes, so the other section was adjusting to changes and that had anger, frustration, sadness. Uhm did you have to look at any of these or how did you use these actions?

**F:** Yes, 'cause the anger is… I think it's more frustration rather than anger really, I think it is. Frustration is a big part of it I think for me and obviously my husband as well, 'cause he's not been able to do things that he wants to do and I'm quite an impatient person. So, I've had to try and learn to be patient and to do things more slowly 'cause I'm normally just right, if I've got a job to do, I’ve just gone, get on and do it and then… But with my husband because, you know, we've had to take a slower pace, I know that is something I've had to adjust to, still haven't fully conquered that one, I'm not sure I ever will actually. But that's you know something that I got to try and do and things like that.

**I:** OK yeah, uhm in the frustration section as well, I think there was like a suggested activity which was a kind of a mindfulness exercise, but there were also practical tips. I wonder if he used any one of those or you had to look at all of it?

**F:** I have, but it's sort of probably a few weeks since I… or week or two since I've looked at that, these particular ones that I can't remember what was in them at the time. I know there was one where it was sort of basically saying, I don't know where that was in the adjusting to change or not, but it was just, you know, taking your time and sort of almost taking a deep breath and I have. I have practiced mindfulness before and I do yoga as well. So that makes you think about your breathing and things like that. So yeah, certainly all that does definitely help.

**I:** OK, OK, so you are familiar with mindfulness and those things.

**F:** Yep

**I:** OK. Do you, do you practice mindfulness or? any specific...

**F:** I haven’t practiced it recently, I did when I was going through a bit of a depression and I actually went on a course for mindfulness where I went once a week and practiced it. And I have got a book of mindfulness as well, so I'm aware of it. And I think that's why I like the yoga as well, really, because that's sort of almost part of it really. So that, yeah, that does help.

**I:** I was just keen to understand how people would use it in a daily life situation. Is it more of a habit that you kind of do regularly or like when you're really upset?

**F:** Yes, it's not, it's not a habit I do regularly, although I probably should do. But, but I don't. It's probably just when I feel I need to do it, that I do it. Whereas if I did it more regularly it would probably help.

**I:** OK, it's a tricky thing to do even with all your other responsibilities as well.

**F:** Yeah (laughs)

**I:** I find it hard myself. Yeah, and I guess linked to that as well, did you find something like mindfulness helpful, even in terms of dealing with specific MND situations or problems like frustrations related to that?

**F:** Yes, yeah. Also, I think the anger as well really, because I do occasionally get quite angry, but that's partly through frustration. But it… you know, it comes out as anger. Yes, I think just to sort of take a deep breath and just sort of probably count to 10 or something like that, just to calm down a little bit. Yeah, certainly does help.

**I:** OK, OK. The sadness one, but it may have come across come up in some other techniques as well, there was an exercise called thought distancing. I don't know if you had a look at it. It was basically to take a step back from negative thoughts and if they're bothering you, if you're anxious, that kind of thing, a couple of visualizations to kind of put them aside and then give yourself space to think about them slightly differently. I wondered if you saw that one or tried it out?

**F:** I did see that one. Yes, I did see it. I don't think I've consciously done that one, partly because at the moment I'm not feeling sad, I suppose. So uhm, but I think you know, if I get to that point then it would certainly be useful to look at it and try and as you say, step back and sort of look at it in a different way, yeah.

**I:** That’s absolutely fine. Uhm, yeah I'm just trying to go through the activities. And there was also the anxiety and worry section. Again, with similar sort of mindfulness exercises, but I wondered if you had any other comments on anxiety or stress?

**F:** No, I don't, at the moment don't feel anxious. I mean, I worry a little bit in the background as to what's going to happen in the future. But I'm not, I'm generally not a person that worries. So, although I might be thinking you know, ‘oh wonder what's going to happen in a few months’ time’ I'm not worrying about it. I mean, it's there because it's something I've got to face in the future, but I'm not actually worrying about it, and I don't feel at the moment that I'm getting anxious about things as well, really.

**I:** OK, so it was mainly some of the positivity stuff dealing with anger and frustration and more of I guess the mindfulness exercises that were useful.

**F:** Yeah.

**I:** OK, uhm did you also look at any of the practical tips? I'm just wondering if you came across something that you either applied in your life or something you read and you thought this is just not relevant to me?

**F:** Well, I think with quite a lot of the sections I thought they were relevant for people in my situation. But because I suppose at the moment I just feel as though I'm coping alright with things, I look at it, and I think, ‘yes, well, that's OK 'cause I'm already doing that’, or ‘I feel OK about that at the moment.’ But I mean it may be the fact that there's, you know, it's lovely weather at the moment and you know it all helps, doesn't it? Now we've got through the winter and things like that, you feel better in yourself. So yes, I think possibly I'm just feeling alright at the moment about things. So, but I know that they're there if I, you know start to feel sad or anxious or worried, then at least I know they're there and I can dip back into them then and have a look really.

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

**F:** I think. I think possibly this study for me would have probably been more useful from your point of view, if I'd been part of it, possibly say two years ago or a year ago or something. I just feel as though I'm sort of a bit more on a calmer level at the moment, so it might not be particularly useful from your point of view.

**I:** No, that's really interesting, actually. 'cause I'm, I don't actually know at what point it would be useful for people, so I’d like to hear why you think it would have been useful earlier, because at the moment for the study I'm asking people who say have recently been diagnosed and also those who have had it for a while. So yeah, I'm keen to hear why..

**F:** I think as a carer, it would have been useful for me earlier on in the diagnosis. Because my husband was diagnosed with…it would be almost six years in July. And obviously to begin with, it didn't cause too many problems. But then obviously it's got worse you know, over the years. So I think possibly about two years ago, it would… it affected me more than it's affecting me now. I think because obviously, I am obviously getting used to it or got used to it and are learning to deal with it. So, from my point of view as a carer I think I would have found it more useful earlier on in the diagnosis.

**I:** OK, OK, you've already sort of developed ways to cope and yeah.

**F:** Yes, I’ve tried.

**I:** I guess even looking back though, would at that point when you were struggling, would the kind of topics that I presented the relevant in that situation as well, or were there some problems that I haven't covered on the website?

**F:** Uhm, no, I think that probably I think they're probably all there really, because it would be sort of, you know, anxiety and worry, frustration, anger, sadness. All of those things really and to be able to sort of look at one of the sections and think ‘well, yes, if I do that, that will help me to cope with either the anger, the frustration, or the sadness.’ Yeah, I think most of them would have been would have been useful.

**I:** OK, OK. And I guess even before starting the study and having a look at the website, was this the sort of thing you were expecting to find?

**F:** Not sure what I expected to find really. I think when you go into each section, it's quite, it covers quite a lot of things. So I thought that, I think it was more depth to it than I was expecting, which is good. Like when you look at the sort of sections, you could even really just sort of flip over them, but then when you go into them and you see the different aspects and things, other things that you can click on. Yeah, I thought that was quite good.

**I:** OK OK uhm I wondered if you also had a look at the other support section. It kind of points you to professional support, peer support and other resources things like that, did you have a look at it?

**F:** Yeah, I mean with these sorts of peer support I've got the carers group that I belong to, so that's obviously other carers as well in [name of county]. And the professionals, we are linked in with all the other professionals, the MND nurse and the occupational therapist, district nurses. Not last year, it must have been the year before, just before we went into lockdown, my husband was going to a local hospice just one day a week to their day-care centre. And through that, it also meant that I could also get support, which I did have. I did have counselling and they did also some therapies and things as well, which I was able to use. And yeah, that was all, that was all very helpful. So that's you know, another thing of support really.

**I:** OK, that's good. I'm actually just learning from people's experiences to develop that section, because support is so different.

**F:** Yes.

**I:** In different parts of the country, so it's good to know you've had some access to support as well.

**F:** Yeah, I mean, one thing that I found is, and this probably isn't anything that you could deal with in your study I don't think, is the actual activity of caring and the physical side of caring. Sort of, you know, just helping someone to get dressed or… and that's one of those things that I found the hardest. Because presumably carers that go into people's homes are obviously trained how to you know, assist them, handle them, how to get them dressed. If you’re just a carer at home, there's nowhere, or there doesn't seem to be anybody who can help you with that. Just simple things to begin with like putting someone else’s socks on, which I found the hardest thing to do initially. And it's just practical things like that and I'm not sure you could bring that into your study, but I think that's a gap for carers really.

**I:** Yeah, and I think it does link to it does link to emotions as well even if you were thinking about like getting frustrated or not sure how to do certain tasks.

**F:** Yes, that's right.

**I:** Yeah, yeah it does link, and I have heard this from other people as well. Like some kind of carer training would be useful.

**F:** I think it would definitely yeah.

**I:** OK. Uhm, but I guess even if from the website and the emotional side of things, I don't know if I mentioned enough about the emotions about dealing with caring and caring tasks. Do you think that might have needed a bit more examples or explanation or something like that?

**F:** I think emotion is difficult, isn't it really? Because everybody's different in their emotions as to how they how they cope with things really. So, I'm not sure that there's anything else really that you could put in there. I think you've just got to sort of guide people just to the right way to sort of deal with it or think about it, haven't you really?

**I:** Yeah, that's true, just making a note of that.

**F:** OK.

**I:** Yeah, I guess you did mention that you're coping with things fairly well or now compared to what you used to. But I just wondered if you felt after using the website whether anything had either changed for you emotionally, or any techniques you felt were useful and you might use in the future?

**F:** I think the… certainly the values and goals I think is something that I'm more likely to use that I haven't sort of thought of before really.

**I:** OK.

**F:** I think everything else, and… I think that's probably the main one really for me to think about.

**I:** OK, that's good. I guess you've kind of answered this throughout different questions, but did you feel it was relevant to you as a family member or at certain points that you felt maybe this is more for the person with MND or this technique would not apply to a caring situation or something like?

**F:** No, I think, I thought I mean, I don't know what my husband will think of it, but he's not very amenable to these sorts of studies and things either, so I'm not quite sure what his view of it will be. I mean, it may be completely different to mine, could well be, because we do seem to see these things quite differently. But from my point of view, as a family member, I thought it was, I thought it was relevant.

**I:** OK, OK that's good 'cause I was trying to accommodate both people, but I was… I just wanted to be conscious that it was not like leaving anyone out or not representing experiences enough.

**F:** No, I don't, I don't think so. I think it would be relevant to you know, family members, carers and the person, obviously whose got the disease.

**I:** Yeah, OK, yeah, I think I’ve asked most of my questions. I wondered if there was anything else you wanted to comment on.

**F:** No, I don't think so. I mean, what happens with the study now?

**I:** Uh, yeah, I'll tell you about it. I’ll just stop the recording, so it stops transcribing all of it.