**Interview 18**

**(family member)**

**F:** It was very easy to log on, very easy instructions. Very, very easy to look at the web page. I've done quite a bit on the computer so you know it's, you know a good and bad website when you see one, but it was very very intuitive and it lead you through the process very easily. So I thought that was really good. And it was, it was quite obvious where you were going with the process, the different sections, so that made sense as well. I just went through it logically as opposed to jumping in and jumping out. And I did that a couple of times just to remind myself. The only thing, the only sort of time I thought ‘am I going mad or have I seen this before?’, is sometimes you go into an area and it's got the same, the same sessions. So I just thought I might have I gone wrong here, but it's actually linking to something I've done previously.

**I:** Yeah, I think also some of the activities, say for example a particular mindfulness exercise or something like that might have been recommended for one emotion as well, but also recommended for another one. So if you went to both of those, it would look like you're seeing it twice.

**F:** Yes, that makes sense because obviously, the different emotions or activities you know that they do lend themselves quite a lot to similar sort of, I suppose tasks and outcomes. But yeah, it's good.

**I:** I guess, have you looked at any other websites like this before or looked for help?

**F:** I'll just interrupt you for a second because you probably haven’t seen [name of patient], bless her, so she brought me coffee because I was so behind the drag curve.

**I:** I was just gonna say yes, yes. Nice to finally meet you. Thank you so much for helping out with everything. (waves to patient)

**F:** (talks to patient) Do you want me to take it for you? You're alright? (back to interviewer) She’s got this little tray that she carries around on her walker, which is great and we don't have many spillages. We've got quite a flat floor, so it's that's quite good.

**I:** I was meaning to tell you, if there was any chance I could see [name of patient]

**F:** (smiles) No, she's very positive and it's umm… it's great obviously she's been involved in it as well. And I suppose the only… I’ll come back to it, I haven't forgotten what I was talking about. But I suppose from our perspective [name of patient] having PLS as opposed to ALS, things are much slower burn. So it's given us time to think a lot and to act I suppose which is, you know, when we see other people who have got ALS I mean, it's just so sad to see the speed of the act, you know things, and how they are sort of, constantly trying to catch up. So we're in a… I suppose a fairly lucky position in that we have a lot of time to think about things.

**I:** Yeah but I think that was the idea as well, I don't know if you felt a similar thing I was trying to through the website... some of the tips were kind of more immediate things to do rather than yeah, deeper things…

**F:** Yeah, your question you asked before our interruption was have I seen many other websites. And the one I suppose, the one thing that I sort of immediately thought when I saw your website I thought, ‘well this looks nothing like the MND website’ and I kind of had in my mind that they would be linked, specifically for the look and feel about it. And so… 'cause I went into some of the activities that are already on the MND websites, and whilst there are… they've got I think 3 different people doing different exercises… so things like breathing and some you know, sort of physical exercises. Yeah, there was a sort of, not a complete disconnect, but it was noticeable how you approach it from a different angle using different specialists presumably. And I kind of thought, ‘why haven't you actually gone and spoken to the…’ or you might have done, you might have gone to speak to those people on that MND website.

**I:** I was actually just gonna ask, I don't think I've seen the specific thing that you're talking about..

**F:** Oh this could be difficult, it’s whether I can find them again or not… (tries to search on computer)

**I:** Or you can just send it to me at the end as well, that's… it would be really useful to know if they've done something similar.

**F:** Sure. Yeah, I mean sure is that I'm teaching you to suck eggs here now, but is that not part of your literary review you should be doing?

**I:** Um, no. So, in terms of the support that the MNDA offered, I looked at… like there were certain booklets about coping with emotions and things like that, for patients and also for family members. But I haven't come across the videos.

**F:** Well, I should send you a link to that, 'cause there are there are videos, three different ones I remember. It was for people you know, obviously with mobility issues so they could sit and do some exercises. And yeah, so it's was just a thought there.

**I:** OK

**F:** So I think other than I think one typo I saw which was a really minor thing and some sort of signposting I thought… where you know, where you've got the forward and back buttons and then sometimes when it comes to the end of the activity, it just goes back to the main page. Sometimes I thought that some signposting… I haven't got a particular example of that, or have I? I did take some notes, but I can write those back to you if there's anything particular, but I just thought, yeah, it was a little bit of signposting could be better.

**I:** More like a return to homepage or something like that.

**F:** Yeah, but by and large it worked really really well and was very easy to do. But I did actually every time I went on to something, I didn't write down where I've been, just so I could from a navigation point of view I could see where I've been. And I did that the second time around because the first time I did it, I thought, ‘have I been here before’ about the activities. So it was just a tick list for myself really.

**I:** Yeah, someone else also mentioned that. It was slightly tricky to remember where you were at and what you'd finished.

**F:** Actually, when I was in, I worked for the civil service for a while, and we had to do a lot of computer-based training courses which were incredibly dull, but the one good thing about them was you could flip through them very very quickly and then do the test at the end. But it also gave you a little tick when it told you that you've been through it, so you actually knew you'd… what activities you'd done.

**I:** Yeah, I know that's easily done. It's just sort of my limited technical ability so I can easily fix that. So yes, I did see that you looked at quite a lot of the sections as well, so I was wondering if I could go through them. I think the first one was about building positivity and there were three activities to help you do that. I just wondered if you felt like they were relevant to you and your situation, or was it something you already do?

**F:** Um, again I think, probably because of [name of patient’s] primary lateral sclerosis, and the fact that it's been 10 years now since we started the journey, and because [name of patient] is so positive in her outlook anyway, it makes my life very much easier and it makes… it's easier to be positive. So whilst I sort of look at all those things like the STOP process that we talked about, what was the other one, yeah, there are various techniques. They were all ones which I suppose, I don't necessarily personally feel I need to use, but I recognize that they are there. And I think in a way that, in some way I probably do them in some respects, even though [name of patient] probably, if she's here listening will say ‘no, you don't, and actually you react completely differently.’ Because I do, there is an element of anger at times and frustration and that I suppose, it is borne out in different emotions at times, and checking yourself is all well and good, but sometimes you do need to have that at release.

**I:** Yeah and yeah, you likely to kind of do similar activities like this as well or have similar approach and that's also completely fine..

**F:** For example, you know I'm very lucky in that we, when we bought this place I suppose, about four years after [name of patient] was started on the process of diagnosing, it took four years for that diagnosis. But we knew it was progressing, so we knew we needed to get a bungalow, and we bought this bungalow. And then we put an extension on with a… it's a sort of swimming pool, but it's a small swimming pool, it's more like a hydrotherapy pool. So it's got very hot water in it, but it's also got a current machine so that I can swim in there. So, so basically [name of patient] can use it every other day for just sort of waking up in the morning and getting her body moving. But it also means that you know if I'm really frustrated, I can just go into the pool, switch the current machine on Olympic Standard, and I have to swim very, very fast. Looks like a bit of a personal washing machines honestly, lots of arms flapping around, but it's a good way of getting the frustrations out. So it's you know I've got different physical means to get rid of some of my frustrations I suppose.

**I:** Yeah, yeah, and I was aware as well that you know some people like using techniques like this, but other people are also more sort of practical people, doing things to… either approach is fine. It's just I guess in the sections as well, where there were there were bits that I offered in terms of practical tips did you follow them or again with the things you already do?

**F:** Yeah, pretty much. I mean you know, I mentioned the STOP, so you know, where… when something's not quite as you know, just stop, take a breath, observe and then look at the perspective you know, and all that is makes absolute sense. And I think you know in general, we do that as a matter of course, but there are times clearly when you don't stop me, you say something that you perhaps could retract at times, and then you gotta think, ‘well, actually now I think I need to build bridges’, rather than you know, had I just stopped and used that technique first of all. Yeah, so I think yeah, I think yeah that I could see the usefulness in all of those things. And the fact that you have obviously tailored those for both people with the condition and also the carers. You know, some… obviously some things are perhaps more relevant to people with less mobility and people with mobility have other ways of dealing with it, I suppose.

**I:** Yeah, uhm, yeah, I was conscious about trying to make it applicable for both. Did anything strike you that maybe was not as relevant for someone with less mobility or…

**F:** To be honest, I was looking at it with more openness rather than just a carer’s perspective. So I was just thinking, ‘well, like I understand that, but actually that's not relevant to me,’ but I understand that could be useful for somebody with the condition. So I thought they were all useful and relevant. And you know, there's nothing I just thought that was a waste of time.

**I:** In general though, did it come across that it was relevant for carer or family member as well?

**F:** I think so, yeah.

**I:** That's good.

**F:** Yeah no, there's nothing I would put into room 101.

**I:** Yeah, I'm also aware like a lot of these techniques when I've studied or read up about them tend to be for people who have the condition, but I thought it could equally be applicable to family members as well…

**F:** Yeah. I also thought the examples that the people, the real people who gave little anecdotes of their life, I think that was also a good example of how that could manifest itself, and therefore how that that activity could help to resolve it, release it, push it back.

**I:** Yeah, you mentioned the anger, sadness and frustration section and things like this STOP technique were helpful. Did you try any of the kind of mindfulness stuff, where you could listen to an audio?

**F:** Again I, well I went onto every activity but I read those activities rather than listening to them and I just went through it again. You know, we're lucky in that we've got, well actually I might say too big a garden 'cause it takes up a lot of time, but we went in to it with eyes open and we spend a lot of time in the garden. And so things for me, like you know we have a lot of animals, birds in the garden and things, so there's always a lot where you can just sort of, take a breath and just listen or will just be happy and in a bit of space that's… I mean obviously through the lock down I feel desperately sorry for people who live in flats for example, because there's no escape you know, to get to the outdoors unless they leave their house. Whereas we can just… I'll just show you from where I'm sitting (turns camera and directs at garden). Sometimes it's quite frustrating on a Zoom call for other people 'cause they just see where, what you're looking out on, and if you're not looking at the TV screen or the camera, it's pretty obvious what I'm looking at. Have to focus (gestures tunnel vision and laughs)

**I:** You’ll have to have a mirror behind you or something like that (laughs)

**F:** Yeah, so we're very lucky with the with the garden and there's lots of lots of things that just are pleasing to the eye and you just… it automatically makes you feel more relaxed.

**I:** OK, OK I see. So some of those activities actually make more sense and just like spending time in the garden and you can kind of be mindful in that way, is…

**F:** Exactly, you know whether we you know, we're lucky 'cause we have a garden, you know, sometimes we have coffee here. But if it's nice we can go out somewhere and have a coffee and just look at something different and it's great with [name of patient’s] scooter because she can always sit on the scooter in a different place rather than actually on her…. you know, as a chair or bench or something like that. So you know we can always find something different to look at and just be able to talk about I suppose. But I also thought that the photos that you had on the website were good because it just… it takes you to a place where you can actually take yourself away from your immediate surroundings. But we were able to do that pretty much from our garden, which is good.

**I:** Yeah, that was the aim of trying to use photos like that. I'm glad it helped. Yeah, I guess just going to the other sections as well. There was anxiety and stress and did you feel that the information there as well was relevant to you and your situation?

**F:** I think it's all relevant, it's how much you feel you need. And again, it's something you can always come back to if you want to. But I mean [name of patient] bless her, she's a mind of information, she's been doing mindfulness for years now. So she can, she always has a sleep at lunch time and so she can take herself off to a, you know, even if she's not tired, she can take herself into a place where she feels relaxed and so wakes up or comes back into the world, she’s refreshed. So obviously a lot of that rubs off onto myself, although she again should probably disagree that I'm a bit of a... can't sit still for very long and I'm always doing things, so I'm not quite as relaxing to be around as perhaps I could be. There's lots to do, you know and I did try and relax sometimes, but my relaxation is by doing things to be honest and that takes my mind off things.

**I:** Yeah, and that was something I was wondering as well because typically the carers are kind of run off their feet trying to do different things. And yeah, just having… were the suggestions kind of practical enough that you know, you could find space and time to do within a hectic schedule or something like that?

**F:** Yeah, and again, I think I've got to put it into context that my life is relatively easy in comparison to other people that we meet and see who got the condition or a more severe form of it. [name of patient] managed to, she's still walking with a walker and she’s still managing to do things by herself. So yes, I need to be around, so she doesn't drive anymore, so putting her walker into the car or scooter into the car. So there are things that I do and I do most of the washing and you know, dishwasher and a lot of the cooking now. Although she's… I'm still the sous chef, she's still the main chef and she still tells me what to do so, I'm happy with that. But I think we're still in a place where there's… I don't feel run off my feet all the time looking after [name of patient] or her needs. I think there's still... we still got a huge amount we do together so I don't feel that. Actually I mean I was, I had the grandchildren today, I had to take them to school. So I am run off my feet in other ways, looking after grandchildren and grandparents or parents. So yeah, I do have other things where I feel I'm run off my feet at times, but actually they're so different, all those different activities that that it's not doesn't feel a burden.

**I:** Yeah, they're not sort of caring tasks those kinds of things…

**F:** Exactly, yeah, it's not the mundane or the… just the drudgery of life. It's, you know, most of them are enjoyable activities I think.

**I:** OK. There was just one section I wanted to ask you about, it was the activities about self-kindness and I just wondered what you thought about that kind of approach? 'cause it's something new that I'm testing as well.

**F:** Yeah, and I… again I… So there's been a lot in in the news in the last period of time you know, probably last 12 months, specially with the Prince Harry and so on, the football is doing mental awareness, Prince William is involved in that. So there's actually been quite a lot, and certainly as an engineer, they've had a mental awareness week as well recently. And a lot of it is about making sure that you're, you know you're looking at yourself. And I'm quite often telling my mother-in-law who's 93 to look after herself, rather than just think about her husband. Because she was in… had to get to a hospital on Friday, and it's basically because of anxiety. It’s made her ill, looking after her husband and I said, look, we've got carers in, who should do the caring for your husband so you can carry on being the wife. So you need to look after yourself because if you're ill then I've got to do more work. And I don't want to do anymore work for you too. Yeah, so you look after yourself by being kind to yourself and taking time out. So actually I'm using some of the stuff that you've shown, to try and tell my mother-in-law to just relax a little and do less and take more care of yourself. So yeah, it's really relevant actually. But I'm using ways to find those things and you know, it's a good checklist, I think, just to remind yourself actually, that you are important as well because you know you have to… You know, if I'm ill then [name of patient's] parents and the grandchildren and [name of patient] you know, are not in trouble but they’ll be less well supported.

**I:** Yeah yeah. I see what you mean. It's almost like just a helpful reminder to just have in the background.

**F:** You know, in all of it you know, whatever you said, whether it's talking about anger, sadness and frustrations, and therefore you know, thinking about yourself you know, I recognize all of those things in myself. And generally you can keep them in check and you've got mechanisms with which to keep them in check. You know, [name of patient] would be the first to say that you know, I’m maybe not as controlled as I should be or would want to be. And I agree with her in that.

**I:** Yeah, yeah, but it's also we don't always get it right every time, and it's something you can dip in and out of whenever.

**F:** But you need that knowledge to be able to check yourself. Just say you know I, I come back to that STOP, you know, it's just such a simple acronym. Say STOP, you know, you're going down a rabbit hole here or you're just digging yourself a deeper hole, which you'll never get out of because you know that's how anger and frustration works sometimes. And sometimes you know [name of patient] will take herself away from situation or indeed I will because you know that you have to reset your brain to just say stop. This isn't going in the direction I want it to and it's born out of frustration with the situation you find yourself in, which you know none of us expected or clearly wanted this at the outset.

**I:** I wondered if you felt that there were other areas that perhaps either you are struggling with now or in the past that we've not covered or not spoken about in the website?

**F:** Yeah, that's a really difficult one. Because if I just take myself back to when [name of patient] was going to [name of hospital] in [name of place] and we were going on a fairly regular basis to have tests done. And then we went up to [name of another place] to get the final diagnosis. So [name of patient] spent a week in hospital there going through all the tests again, that's after four years. And then we had a consultation in [name of another hospital] and that was the first time, well no, that wasn't, the first time was in the [name of another hospital] where [name of patient] was met by somebody from the motor neuron disease Association. But that was one of the first times, really, where we've been, sort of I suppose, counselled about the condition and what it might entail, and then we went to… My first time meeting somebody from the MND was in [name of hospital] in [name of place], and there was just a person with a T shirt with MND put on it, handing out leaflets. And you know, just being there… and it was a time when you just thought, ‘blimey, all this is just…’ although you knew it was on the horizon something… the awareness that the condition has been diagnosed and this is actually happening now. Now for us there again, there was time where you could, you can read all this information or you can have time to talk to people. We have a very good support group here as well who have got the Association visitors so and it's literally a 5 minute walk to the coffee shop where we go and meet on a monthly basis or we did before lockdown. So we had the time to hear and see and read all of the things that were going to happen to us. And that doesn't happen with people who have ALS, you know from the diagnosis, from initially the first symptoms to being diagnosed is generally quite short, and then the decline thereafter is so quick and there's a huge amount for them to do so you know from getting changes done to the house to you know that.

I think a lot of people we have spoken to have said not just enough time for any of that, I didn't have time to you know, scratch my head, let alone read or look at websites or do things. The other difficulty with the MND Association is, whilst it’s, I think it's a great resource and charity, people with the condition and their carers aren't obliged to let you know, they're not, it's not forced on them and nor should it be. But there probably needs to be a slightly better engagement process between them, the medical elements, and the association to identify those people who are in greatest need. So to answer your question, I've rambled on probably too much, but I think it's those people where your, the resources, the support you're trying to offer need to get to, the carers and those people at the start. But how you do that when so much else is going on in their lives is a really difficult one to try and resolve…

**I:** It may be too… if it's too early in the process, it's too much information to process at that point or just to have something handy for when people feel ready or something like that?

**F:** Yeah, I mean, I would suggest you, I'm sure you have done, but if you just go to the MND website, I think it's a really good website, but there's a huge amount of information in there. And you know, to try and go there and still find the right information you want, at the right time for people who are a time limited is probably a tall order.

**I:** Yeah, that's really important, kind of how… either how you direct people to a resource like this or how you kind of describe it, and how you tell them it may help for them to use, that sort of thing.

**F:** Yeah, I think the Association visitors (AV) are of the, is the right sort of support network to point people in the directions and give them advice on what the priorities they might need to be thinking about. But if that AV hasn't been engaged or hasn't had the ability to engage with the carer or the person with MND at the earliest point, then it's a… it's doomed to fail in a way because you know things ramp up so quickly with people with a serious condition that it's.. yeah, it's just difficult I think. Good luck with that (laughs)

**I:** Yeah. I think I agree with you earlier is kind of better, even if not this specific resource, to establish that kind of trust and… yeah.

**F:** There was a particular well, there are two people we know that their both their wives have sadly died now and they died very very quickly after diagnosis. But both of them were naturally angry at the whole situation. Generally because the you know, the diagnosis isn't detected or that the initial symptoms aren't detected and directed to the right area like neurology, then they're on the backfoot right from the start. So they’re, both of those, were very angry that their diagnosis hadn't been sorry, the symptoms hadn't been properly directed to the right resource in the first place. So they're angry at that, then they were angry at the ridiculous system we have in place for trying to get the NHS and the councils to do the right, to provide the right services at the right time. So there's pretty much anger all the way through their journey to, to death ultimately. And so all they’re left with when you talk to them is the anger and the frustration they've had right through the process. And unfortunately, I think something like the thing you're providing will probably help them to put their frustrations and their anger in the right direction. But actually it, it's the systems that they need to have in place to help them, and then maybe it helps them after the event to channel again their frustrations and their anger towards the systems that failed them ultimately.

**I:** Yeah, I agree that it's like a tiny intervention in the bigger…

**F:** It is, but for us, I think you know, it has made me think, so it's been worthwhile just from that perspective.

**I:** Thank you. Did you feel that, say since having a look at the website, that anything has changed in terms of your perspective or attitude or anything like that?

**F:** Oh, that's a difficult one. Again, I think the things that I um… when we talk about the anxiety, well being and anxiety again, you have the metaphors and STOP process I think you know, it keeps coming up because they are just so easy to think about. So definitely it has lodged itself in there, which I think is really important. I didn't notice that in any of the other MND stuff that I've seen before. So yeah, I think you’ve hit the nail on the head with some of those aspects and some of the activities.

**I:** Yeah, it's probably too short a time as well 'cause you should look at it, read it, remember, practice it…

**F:** Yeah, you know, my brain’s like a sieve, so actually I looked at your website on two occasions. So I went through on one occasion, none of it stuck, so I went back to again a week later. In fact, I went, I had a look at it last Thursday 'cause I thought our meeting was last Friday stupidly. So I looked at it on Thursday again and it helped again to reinforce what I've seen before so. And the fact that I still remember some of the things with or without my notes, and I haven't looked at it since, is a good sign.

**I:** That's good, I'm glad. I think I've asked you most of my questions. I was just wondering if there was anything else you wanted to add?

**F:** Yes, my mother's got a picture just like yours on the wall. Hers is in colour, yours is black and white.

**I:** Yeah, it's just sort of like a black and beige or gold.

**F:** And no, yeah the question I do have is really about how you intend or is there an intention to link it more in line with the MND website?

**I:** Yeah, if you don't mind, can I stop the recording and then I can just explain about the project etc.