**Interview 1**

**(family member)**

**I:** You should get a message. Yep, it’s started.

**F:** Yeah, Yep.

**I:** Yeah, so I guess first just more of an open question. How did you get on with the website?

**F:** I found it worked well. I think it was fairly easy to use, the jump through the sections, the page backwards and forwards was very easy to use, very clear. And I don't think you know, I would have any problem navigating through it to find it particularly where you wanted to be on it.

**I:** Yeah, OK, that's good. I guess, sort of when did you decide to open it or use it?

**F:** I mean I, initially the first time it came through with the other…I had a quick look through it, really just to see what it was all about and have a look through. And then couple of times since probably would look through it and kind of, kind of look for things not, not specific items as in I need to look and search for this, but if I'm in this situation, where would I look. And on there, and obviously in various places there was advice as to where to go depending on the situation. And if you are anxious or worried, what was possibly the best route to go down to find, potentially find an answer anyway.

**I:** OK, so it was more pre-emptive, I guess, before there was a problem..

**F:** I don't think it. I don't think, personally it would be something I would use a lot. I would see it more as it as a kind of a reference tool to, if there was an issue that I didn't know where to go to look for an answer and then it was somewhere that might be, point me in the right direction.

**I:** OK, OK. I guess similar sort of question. How did you choose which sections to look at?

**F:** I went through all of them (laughs)

**I:** Oh you went through all of them. Is that more because of this study or…

**F:** Well no… I think whatever it is, I would probably have looked through the whole thing. And I think from a personal point of view, maybe you're looking more for a coping strategy, so possibly in that sort of area where, how, you cope with situations. So if I was feeling anxious about how I was handling my care with [name of person with MND] or things like that, then that might be something that I was looking at. If I wasn't feeling in the right mood then I'm not giving the right feelings towards her as well. That becomes a bit of a self developing situation.

**I:** OK, OK.

**F:** So kind of, in one sense, a bit like you're looking for a shoulder to lean on or something like that, just to give you a bit of, a bit of moral support.

**I:** OK, OK, that's that's interesting. And I guess linked to that as well, did you find a lot of the sections were relevant to family members?

**F:** I think most of them were relevant. I think some of them were possibly a bit shallow, there could maybe have been a little bit more detail in there and.. or possibly pointing you again to something with a bit more in depth advice.

**I:** OK, I want to pick up on that, but I might try and do it, sort of section by section if that's OK. I'm just, just so I have examples. I guess the kind of comment will be similar, but just so I understand it a bit more. Yeah, so the first bit was about building positivity so that had I think, pleasant activities and positive thinking and values and goals, that sort of thing. Yeah, your thoughts on that section?

**F:** Yeah, I think, I think the positive thinking one is useful. I think that's actually useful to.. and thinking about the nice things we've come across this before in various other psychological studies that we've done and our meetings that we've had. And I think if you're in a situation where you are under pressure or under stress, it's very difficult to think about the nice things…they don’t spring to mind. So maybe in there somewhere, nudging people into what they should be thinking about. Tropical sandy beach and things like that is maybe the nice thing you should be thinking about, but it doesn't spring to mind, certainly after the last 12 minutes.

**I:** Yeah, I was so in that you're right that it is very difficult to do in a situation when potentially you're in crisis and yeah, things are not looking good. I tried to do that via examples I don't know if… like quotes from other people or something like I don't know if that that particularly helped?

**F:** I think possibly you know a short, I'm gonna sound educational now, bullet points where if you are in that situation, Mr. Smith thinks, or four… or these are examples of what people are thinking about, so that maybe just triggers the mind to make you think about something in a bit more positive situation.

I: OK, OK..

**F:** Sort of hints, type of thing. You know, well it would say think of a nice situation, then possibly put some hints in or some pictures or something. Trigger people's mind a bit, yeah.

**I:** Yeah, that's really useful and a lot of people seem to like that section, so it's clearly, you know, I mean felt like they needed it and yeah. Yeah, I guess also because in your case it you kind of had a long time to sort of get used to this. In that sense, did it feel familiar or like you been doing similar things that…

**F:** Yes, I think we are fortunate in that you know, we have had time to adjust or sort of over the seven years since [name of person with MND] was diagnosed, we've been able to adjust as time went on. Now you know, we were open minded enough and fully aware that some people instead of seven years might have seven months there. Therefore, their stress and pressure is obviously much higher or much more intense than we feel. So maybe you know they're under more pressure to look and possibly the positivity is harder to find when the when the patients deterioration is much faster, if that makes sense.

**I:** Yeah, yeah.

**F:** We've been fortunate in that we've been able to adjust at each step along the way, although each step becomes progressively harder, we’ve been able to just our life to go along with it and… But if you know, you're in a situation where the MND is almost running away with you, and there is very little you can do, and I would, I would suggest that positivity at that point is very difficult to find.

**I:** Yeah, yeah. I see what you mean. Should we go on to the next section if there weren’t any other comments about this…

**F:** Fine, yeah

**I:** So I guess the other ones, I’ll kind of club it together. But based on emotion, if you are feeling sad or angry or stressed, there was either a suggested technique or practical tips or some examples. How did you get on with that?

**F:** Yeah, the stress one, I think everybody gets stressed. I think yes, you, at some point you need to be able to take a step back and take a deep breath and maybe have a cup of coffee I'll go and potter in the garden or something. Because particularly in a situation where you're [touches wood] you know, as I am the sole family carer, the stress is quite high and there, there is no, you know, you can't get away from it. If you're, if you're a carer coming in to look after somebody or you're popping in and out, you always get the break, whereas if it's a family member it's the 24/7 situation. But it's very difficult to step away and do something for yourself without feeling guilty about it, in that I shouldn't be doing this I should be there providing the care all the time.

**I:** Yeah, yeah I know that a lot of people have said something similar and I wondered… 'cause I know that the technique or activity suggested was mindfulness. Did that help in any way?

**F:** No, (shakes head) in all honesty, my way of getting stress relief is getting up an hour earlier in the morning than I get [name of person with MND] up and just sit and have a cup of tea or a coffee and watch the news or whatever and that's kind of my me time in the day. And that obviously doesn't suit everybody 'cause not everybody wants to get up early to do it but… And then for the rest of the day, obviously I'm involved at, you know, involved with her care and I have to be here, but that's kind of, that suits me. Now it maybe, I'm aware of somebody else who's in this similar situation to me, she's a full time carer of her husband. He goes to bed earlier on at night and she has an hour later in the day. So you know, trying to find yourself a space within that situation to do something that you want to do and allows you to unwind.

**I:** Yeah, yeah, no that’s absolutely fair. I know some people want to try things like this, but some people also would rather do something a bit more practical. Yeah, I tried to put some practical tips in there that's more just to sort of get an idea and then, you know, adjust it to you on the situation, I wondered if that was relevant in any way?

**F:** I think practical tips are relevant depending on the person. It's, it's very much an individual thing. It needs to be something that you're happy doing because it, whatever your escapism or relaxation of de-stress is, if you, if it's not something that you particularly enjoy, you're not gonna do it. So it's got to be something that's very much related to the individual.

**I:** OK, OK, and just out of curiosity, how, how do you deal with the stress? I know you mentioned one…

**F:** How do I deal with this stress? Ooh, I get grumpy (laughs), so I'm told. No, I try to avoid it an as best I can. As I said, I have my break time in the morning, occasionally this time of year I'll possibly go out and do a bit of gardening. I've got my phone, [name of person with MND] has got her phone, so she could always get hold of me. Or sometimes it's just a matter of just going and sitting in a chair in a different room for five minutes and just taking a deep breath and then come back, just a quick chill.

**I:** Yeah, I see what you mean, it's like taking that time to look after yourself also, not just the person you're caring for.

**F:** And that's the difficult thing is that you tend, you probably tend to sacrifice yourself to look after the person you're looking after, where in reality, it's probably at least equally important to look after yourself so you can look after the person that you're going to look after.

**I:** Yeah, yeah, I completely agree, I'm just being a devil's advocate here. Some people say that you know if there's a lot of caring tasks to do, etc and they're so busy, it's all well and good, you know, someone giving you advice and saying, take care of yourself. How do you…

**F:** I think inevitably you put the other person first, because you are, you're caring for them, you're looking after them. And certainly from my point of view, and I think a lot of other individuals, you would sacrifice your own time and probably your own well-being, to try and ensure you doing the best for the person you were looking after. You know, we're probably all guilty of that.

**I:** Yeah, yeah, I know that that's really good, sort of way to frame it is what I was trying to get out because yeah, a lot of people ask me this question as well. Did you, I wondered if you tried any, it sounds quite similar to this, sort of self kindness stuff, I don't know if you had a look at it? But it was again more mindfulness I think to encourage self kindness…

**F:** I think I'm a bit old school for the mindfulness thing. You know it's probably not something I would look at.

**I:** OK, yeah. OK, uhm, speaking of worries and anxiety as well, there was another technique called thought distancing. I wondered, did you remember it?

**F:** No, I don’t remember that one.

**I:** It was, I think, to basically take a step back from difficult thoughts. So learning how to firstly notice when negative thoughts are upsetting you and then almost compartmentalizing put them away so they're not bothering you while you are doing something. Uhm? Did you try that?

**F:** I don't think no. I mean, I probably find when something is praying on my mind it’s pretty difficult to get rid of it. Although in the main, you tend to be so involved in what you doing, it’s probably difficult to compartmentalize things and put them to you back in the mind. You're almost going at 100 miles an hour all day, to ensure that you provide the care and you get, you're also getting all the other things in your life doing that has to be done. That, if you've got a particularly negative thing, you probably just throw it to the back of your mind and forget about it subconsciously, and then at some time it will reappear again and the secret is probably not to allow too many things to pray on your mind at one go.

**I:** yeah OK. I think that’s all…so the practical tips I covered uhm… Yeah, did you have a look at the other support section as well? Which kind of points you to other resources

**F:** That talks about the MNDA and the GP and things like that. Yeah yeah, I mean that's kind of pointing you in the right direction. I think there was a mention of social media groups as well, wasn't there? Which certainly we use quite a lot of. Although you tend to have to be quite selective as to what is on there, some are more realistic than others, shall we say…

**I:** The groups?

**F:** Yes, the social media groups. I think some are very good, very honest and obviously not everything works for everybody, but there are quite a lot of hints and helps in some of the groups. I would say there are some, shall we say worldwide based groups which are a bit less than factual, I think you might, my honest view on some of them.

**I:** As in they are not much help?

**F:** As in the advice they are giving, I would describe as a bit airy fairy if that makes sense.

**I:** OK.

**F:** And they're probably similar to the ones who have all found cures for MND as well, so you know you have to choose where you look. As I say, we tend to use ones that initially probably other people have used and said if you got a problem, have a look at this the answers are quite good. Or someone would say don't bother looking at that social media group because it's full of… in fact, the one or two of them do tend to be a little bit depressive as well. You know, it's, some are quite full of useful hints and how to cope with things and what to do in this situation. And unfortunately others tend to be full of death and doom. So you gotta be a little bit careful what you look up, but then that applies to social media in general.

**I:** Yeah, yeah, I know, I was trying to be a bit careful when I… 'cause I can't endorse any particular group... yeah, but it's a tricky thing. When you sort of feel ready I guess it's OK to look at a particular group, but some people find it useful, some people don't…

**F:** So I think you know we do, we found quite a lot of support from various groups. And I think it's probably a sign of the more modern times, you know, 20-30 years ago it wouldn't have been there. Nowadays it's probably another extra layer of support to a lot of people especially if you're in lockdown.

**I:** Yeah definitely. Uhm, I guess I just wanted to speak a bit more broadly about the website not particularly about activities or techniques or things like that. So I guess when you signed up was there anything you were expecting from the website? Any particular concerns that you were struggling with or something like that?

**F:** No, I think I think my initial thing was that that it worked and it did what I wanted it to do, which was fine, and I think there's plenty of information there and it came with it. Back to my original comment, it was very simplistic, which is not necessarily a bad thing, you know, so it was easy to use. Not, not everybody is really tech savvy, therefore it needs to be easy to use and if you're somebody who hasn't got a lot of dexterity in their hands, it's easy to use because you just, you know, you're pressing on a large box. You're not using the, you know fiddly mouse things like that. And potentially it would work with eye gaze technology for people who can no longer speak. So in that situation, that kind of situation, I think you know, it's very good. I would just like to have seen it, as I said, maybe a little bit more attractive.

**I:** OK, OK, so it was more the presentation angle…

**F:** Yeah, so you need a software guru or someone, calming music in the background (laughs).

**I:** (laughs) People have suggested that. But in terms of content I guess was it what you were expecting?

**F:** I think I may have thought that they might have been a little bit deeper content. But, having looked into the couple of times, and the other, second time I looked, I thought, well, no, it's not a deep content answer to everything. It's more a signposting exercise to kind of give you hints and point you in directions to look for what's possibly a deeper answer.

**I:** OK, OK. I'm just trying to unpick this but deeper in the sense of, not like a quick fix more of talking you through your problem step by step…

**F:** yeah, bit more bit more, a bit longer, look at. Certainly, so the psychological bit coping with stress and anger, but maybe a bit more in there because with the best will in the world, I think there is a lot of stress and possibly some people get angry and frustrated. And I mean our classic one at the moment is now [name of person with MND’s] voice is almost gone completely so trying to work out what she's actually saying sometimes and that becomes very frustrating for both of us and so coping with that type of issue. Maybe a little bit more advice on there in that type of thing.

**I:** OK, OK so also maybe a bit more I guess like link to the problems rather than being generic…

**F:** Yeah, yeah, you know, if you look at it, let's say stress and frustration and anger in an MND situation, it tends to come from mobility, communication issues and feeding issues. So maybe if there's a lot of stress relating to communication might be possibility to link it to, point them to if you have a problem, you know a speech and language therapist. As opposed to a GP, because obviously if it's a communication issue, it's pointless going to your GP, so therefore… You know, or with these issues you would refer back to your multidisciplinary team at the hospital, in a way you've got the speech and language in, the dietitian, and all these people who were the kind of the experts on MND, possibly rather than GP.

**I:** Yeah yeah, I see what you mean. Sometimes the other professionals can also help, it's all linked, isn't it?

**F:** Yeah, it is. Yeah, your average GP probably sees one MND person in his lifetime, whereas your multidisciplinary team are dealing with all sorts of people with MND, at all sorts of stages and they've seen most of the problems previously. Whereas to the individual carer or patient, with them and everything's new, each day’s a new step. And it is worrying because, you know, inevitably you know that the stage you're at today, tomorrow you're gonna be worse. And that kind of, you know, it is quite a stress building situation then.

**I:** Is that a similar concern even for family members as well?

**F:** Yes

**I:** OK. I guess on that note whether any issues that you would have liked to see in there that were not covered?

**F:** I don't think so. Whether you would put something in about dealing with a diagnosis. OK, there's a lot of people who, it can take a long time to get a confirmed diagnosis of MND. And certainly our experience was that although the diagnosis was pretty horrific after a period of 12 plus months to get a diagnosis at least you knew what you were battling with. You have this great big monster in the back of your mind that you haven't explained what it was. Yeah, so maybe something in that sort of area might be a useful bit to add in and, that's kind of stage one really. But that's where there's a lot of stress and pressure appears on people and a lot of frustration that their not sure what's wrong, their struggling to get an answer, and then all of a sudden they get a diagnosis of MND. And yes, it is horrific, but you know what's wrong, you know and I'm OK. There's still nothing you can do about it, but you can then set yourself to try and cope with that as the situation develops, if that makes sense.

**I:** No, it definitely does I was just making notes as you were speaking. I guess because you've had experience of dealing with it for so long as well, do you think something like this might have been more useful at an earlier stage?

**F:** Yes, I think so. Yeah, yeah. At the earlier stage you have no preconceived ideas, you have no idea what's going on both… Initially there's all sorts of things that are thrown at you at the point of diagnosis, and probably more so now than it was seven years ago. But this is possibly something that will be worth having to you know, all sorts of problems are gonna occur, this is something you could look at that might allow you, might guide you in the right direction, or, or things like that. And yeah, I think earlier certainly earlier in the cycle than later in the cycle, so to say.

**I:** OK, OK. Yeah, I guess just overall in terms if this kind of information source as well, do you think it's something I know in your case, you looked at it yourself. Would it be typically something that you do like that or with [name of person with MND] or…?

**F:** We both looked at it, can't remember when, we both looked at it the first time. But no, I think I would probably troll through it myself and then maybe say that I had a look at this, why don't you have a look and see what you think. That's maybe a man thing.

**I:** Ok (laughs) Yeah, I'm just trying to see if it should be kind of pitched at...

**F:** Yeah, I think it would probably go to both. Because if we go back to sort of stage one where we're talking about the diagnosis situation, it may well be that the person that's getting the diagnosis is the only person that's involved at that point, you know, not necessarily, not everybody is going to be a married couple as we are or have a partner or things like that. You know, they may have to cope with it on their own or want to cope with it on their own initially, I don't know. This could be something that's useful for them as a sort of coping strategy. We were very open, we had the diagnosis and the same day we just went and told all our staff and our family and everybody, just put it out the way. Now other people may take a while to tell people the diagnosis and.

**I:** OK. Yep, I think I’ve covered…let me just check. (turns pages) You're one of the first interviews I'm doing, so I'm just making sure I’ve asked you all my questions. Ok, I think I know the answer to this, but I'll ask you anyway. Do you think there's anything from there that you might either use in the future or that has made you think about something differently?

**F:** I think, I think the coping with stress is the one that I would probably look at. [noise in background] Historically I've always tended to keep things very much to myself and that’s not necessarily the best way of dealing with it, you know so maybe this stress management.

**I:** OK

**F:** Or at least find myself something to do to allow me to destress.

**I:** Yeah, you would I think in your case it's either doing something practical or taking some time to yourself or support groups and information and stuff like that. Is there any other thing just so I can learn from other people's experiences as well?

**F:** Yeah, I mean we had a good network of support group and which obviously stopped once the Covid restrictions came in. And that was very good because that was, it was peer to peer support. Everybody else understood what everybody was going through, so that was quite useful. And we have a good network of friends which provide a lot of support as well, and I think again, everybody needs a shoulder to lean on you know, whether it's your best mate, or the guy used to go to football with, or someone that lives over the road. We all need somebody somewhere just to have that 5 minutes chat to, sometimes just air off all the bits and get it out of the way.

**I:** OK. I've finished asking all of my questions, I don't know if there's anything else you wanted to add…

**F:** No, I'm quite open about it, I think. I've tried to be honest, I hope it will do some good.

**I:** Yeah, that's exactly what I wanted. I will stop the recording. I'll still be on the call…