**Interview 7**

**(family member)**

**F:** I wonder if anyone does take shorthand nowadays? I very much doubt it.

**I:** I do make notes while I'm listening to someone, but it's also good to have the recording.

**F:** Yeah yeah, but notes isn't shorthand, I mean shorthand is verbatim.

**I:** Yeah, no, I wouldn't be able to do that.

**F:** Yeah, very much doubt that anyone can nowadays. Yes, it… as I said to you previously, I think one thing that could help is possibly an index to it. It does work quite well, and you can work your way around and this morning, the things which I think are very useful are the anxiety bits. And I went there this morning and I saw anxiety and stress and I saw meditation. Meditation doesn't work for me and I've tried it before, but I went onto it. And it's interesting because one of the things that we do have, and I'm not sure, I think it's open to all people with MND or it might just be some of us who are working or volunteers, but I think it's available to everyone, is that there's a mindfulness site. Is it headstart? No, something like that…

**I:** Oh, headspace

**F:** Headspace, which we have got free access to. And possibly, it might be worth thinking about getting a link to something like that. If I check that I'm right that it is available to everyone, and if it is, put a link to it in there.

**I:** yeah. I've heard of it and I think it is available to everyone, but it's a sort of paid subscription so…

**F:** I know. Well, I get it, we got it free through MNDA. I mean, yeah. Now, as I say, I'm not… I think it's available to everyone. If you can't find anything on it, check up with me and or it will come back to me and I'll do a double check for you.

**I:** Yeah, I'm just making a note of… I didn't realize there was access. OK, yeah, so it's almost like if you feel you want more exercises, Headspace has loads of them, so link to that…

**F:** Yes. But I have to say that I've listened to them and I've sat in this very chair, listening to them and my mind drifts, and I just can't meditate and I can't get my head around empty spaces. And I go off into all sorts of places and I'm always thinking about something and… I've got all my workbooks here as well and so I tend to drift into them so that, which is a shame. When I say I just drift into them, I used to design and build bridges and big buildings, and so I sometimes start thinking about things like that, it's, it's not where I should be, however. Yeah, possibly, I think that and I don't know how, but it would be an idea to be able to expand the website, and I think when I say that I mean possibly with experience and more things to make it much larger, so that people have got more areas they could go to. Another thought is going back to the… links, it might be an idea to think about links. I mean I can't remember, I don't know if there's anything there to MND Connect.

**I:** Yeah, there's a more general link to the help line, I think that is called a MND Connect, isn’t it?

**F:** Yes, yeah, and that one is quite useful for people to go to and try and find out things. But then a lot of it, what I find is a lot of people do go to things like that, but we also talked to our own little groups of people.

**I:** Yeah, it was a tricky thing to do. There are some very general websites or links that you could put links to, but also support is so different in different areas that as you were saying, your local team might actually know much more than what we would suggest.

**F:** Yes, I think the whole thing is that it's almost like the famous post code lottery, in so far that... I had an email from my colleague in (name of place) today and she was saying they’re only, they're down to 1 1/2 Association volunteers (AVs). Now, I don't know if you know what the Association volunteers do, but we've got something like five or six in (name of other place). And we're lucky actually, in this sort of area around (name of region) that we've got an awful lot of AVs and out of something like 200 people with MND 140 have got AVs, now most of the country isn't as well covered as that. And then you've got things like CHC and PIP, which really are problems with postcode lottery as to whether or not you get it. We, as I say, we've got 24/7 cover. A friend who's just got it, the chap I talk to about RIGs and PEGs and various other things, they've got CHC cover but they've got it for something like 4 hours a day. And another one in (name of place) is just being turned down, so it, it is hard and it's difficult. And it's going back to what you were talking about was the different levels of support in different areas, and I think it's true of everything there's this problem.

**I:** And I guess I'll ask you in terms of psychological support as well, have you tried to access anything in your area that you found helpful?

**F:** Funnily enough, I haven't. But the chap I’ve been talking to about PEGs and RIGs who sent me an email this morning talking about going to (name of hospice) which is about 10 miles down the road from me. And the help that they have given, and I know that (name of another hospice) have given help over there. Now we, [name of family member with MND] is under the (name of hospital) for her treatment and as part of that for respiratory, she's under (name of another hospital). It's the same site, but they're two different National Health Trusts, you wouldn't believe it, but thereby hangs one or two tales which we won't go into. But they did ask [name of person with MND] last year if she wanted any psychiatric assistance and we got it there and they were very helpful as well. It was straight away, the chap was training, but he was so good and so helpful. Because I sat in all the sessions and I think without, I couldn't tell you exactly what we talked about or what happened, but I think psychologically there was probably a help to me and there was definitely help to [name of person with MND]. And she was seeing him about anxiety because she was extremely anxious and I think a lot of people with MND do have anxiety for fairly obvious reasons.

**I:** Yeah, yeah. Was this sort of around diagnosis stage or after that?

**F:** No, no. She was diagnosed five years ago and this was… it was about two years ago she went on NIV so it was about then

**I:** OK.

**F:** I have to work out and trying to think she was in hospital January last year, but that was in [name of place] and then so after work out when she was in the hospital and it's about two years ago in [name of place].

**I:** I'm glad you got some support, at least like some face to face support as well from there. Yeah, and that's what the other support section of the website is also about to try and 'cause you are limited in a website in how much you can actually help people. It's more almost a self help kind of situation. So pointing to other places and your MND Care team would likely know I guess, psychological professionals working.

**F:** Yeah, it's interesting though, you know, because. I don't know how it is in other areas of the country. But [name of region] is not a terribly big county, but we've got people who are under (name of one hospital), under (name of name of another hospital), and under the (name of another hospital). And I think those are the only three I don't think we've got anyone under anywhere else. And the service we get is different in all three hospitals. It sounds to me as though (name of hospital) is probably the worst, but (name of another hospital) has got benefits that sometimes I think we don't get from (name of another hospital) and this is supposed to be the best or one of the best. And it's the only purely neurological NHS Trust in the country.

**I:** I've heard this as well from other places some people get really good support and I think that was a tricky thing, we're trying to suggest avenues for support 'cause you don't want someone to go looking for it and then it not being there as well

**F:** No, yeah. Well, you know it's a big problem that it is so frustrating. We have an MND nurse specialist, actually I think she's an integrated neurological nursing specialist, I think that's her title and in the five years [name of person with MND] has had it I think we've been on four or five different ones, and I think we're back to the original one now who's had two maternity leaves in that time. So you know this is the sort of problem that does happen just trying to get continuity, and of course the consultant is now changed because (name of consultant) has dropped out and we've got a new one whose name I can't even pronounce. Looking at the name, I would think he's from (name of country). And to be honest, I don't honestly, I don't see the point in going to see your consultant after a bit because they don't do a lot. They can't do anything it's really, I think it's for their satisfaction and for any research they're doing rather than for the good of the patient. Uhm…

**I:** Has it been easier with Covid and maybe a video call at least rather than…

**F:** Oh, there… we haven't had a single video call that I can remember. We've had a lot of telephone calls and we've had telephone calls with the respiratory consultant with the PEG RIG lady, who we thought hard, this was at (name of hospital) and we saw it before Covid. We've spoken to her, I think twice post covid, and always we decided it wasn't needed. So [name of person with MND] goes in the hospital, they give her the opportunity of having one while she's in there and she said yes. And I think she was right as well, because I've always felt that she should have had it fitted anyway, because… There's the danger that you don't have it fitted because you don't see the need, and then when you do get the need, you might not be fit enough to have it fitted. And these are the sort of things which it's difficult to tell someone with MND, even when it's your partner. But luckily when, we were lucky because she could get it put in while she was in hospital and they decided she was fit enough to do it. And the other thing that was strange was they did, they did it under local anaesthetic and she watched, she said ‘I saw all my internal organs’ and I thought ‘that's not like her.’ She normally wouldn't watch things like that and since then she said to me, ‘I wish I hadn't done it.’

**I:** But is that what a lot of the anxiety is about thinking about the future? And what may happen?

**F:** She's never actually expressed that. I think you're probably right, I think one of the problems… [name of person with MND] is a very positive person, and she still says when she gets cured she will do this, then the other. But when we actually were for when she was first diagnosed and we went to (name of hospital) for the first time, she was told that they'd seen lots of people who came in and took a negative attitude and it didn't last very long. And some people with a positive attitude have lasted a lot longer. And I’m Facebook friends with a number of people who, some I’ve met once or twice, others I've not met at all. I can think of two girls, one in (name of place) who's had it for 20 years, she's in a wheelchair, she can't speak, she can't do anything for herself, but she is very positive. She's been on the radio a few times I don't know if you can see this, can you see that painting?

**I:** Yes, yes.

**F:** She's done this on her own computer.

**I:** I think I know who you're talking about.

**F:** (name of person) is her name, she is incredibly positive type of person and there's another one called (name of another person)… Anyway, she writes books and she's had it for over 20 years now. I think as well, and she can still walk as far as I can see, and talk. I've never met her, I’ve met (name of other person). And they're both incredibly positive people, and there's a person who I know who's in, he does the same job as I do for the Association in think it's (name of region), (name of person) is in a wheelchair, and he's another incredibly positive person. He's got more mobility than [name of family member with MND] has. He can still talk when I last saw him, which was probably 18 months ago. He wasn't on NIV, I don't think he's on NIV now from anything I've seen. And he's another of the people I've been on the emails with this morning, but I think the thing is that if you got a positive attitude, it helps tremendously with this disease and. Do you know, I think that things like these little photographs in your website, which are gentle, soft, soothing, help give positivity.

**I:** OK, that's what I was aiming for.

**F:** Well they work, they work for me and the one I was talking about the mindfulness this morning, where you've got the see going on the coast to be honest, instead of closing my eyes and thinking of a nice, safe place to be, I'd have been better off just watching that.

**I:** Yeah, you can do that. That's alright. It's interesting as well about some positivity from other role models or other people's habits as well. I can try and do more of you know, stories about other people and learning from other people's experiences to boost up positivity. Does that help you as well?

**F:** Yeah I think it does. And maybe speaking (name of person previously mentioned) I think talking to people like (names of 3 people previously mentioned), you know, and getting their sort of positive approach and stories in might help. And the reason I know (name of two people previously mentioned) is they both do the same job as I do in their branches, campaigns coordinator or campaigns contact. And the vast majority of people who are volunteers, volunteer because of partners or family members or very good friends who've had the disease, and then you've got people like (names of two people) who are suffering and there very, very powerful advocates as well, because they can put it over much better than you can or I can.

**I:** Yeah, that's true. Are there any other things just out of curiosity, 'cause there might be, that you do to help stay positive?

**F:** In the present circumstances, (laughs) no because there’s bugger all any of us can do! We're both in our own houses by the look of things at the moment, and I bet you wish you were back in the university. What I used to do and I still, one thing I do still do is I go out for walks when I can and I would… There's one house between me and the country that way, and there's about five houses that way, and it's about half a mile the other way. So you know I can get into the country very easily from where I am and have a walk out in the country and forget things and go away. And I used to go and watch football matches lots, interestingly (name of person) and I have quite a quite lot of talks about that because he does the same sort of thing. And we’re both interested in amateur football, not the big boys. And unfortunately, things like football or going swimming, which I know some people find very good, haven't been open. The swimming pools now have been reopened and I know that one of my Facebook friends who is a full time MND person, she's just gone back swimming and she's been full of it, ‘Oh back in the pool, thank goodness!’ But I think we all need to get back into things that we can do. We’re coming into the cricket season, maybe I'll start going down the local cricket ground which I used to coach at years ago and haven't done for 15 years or something. Maybe I'll just go down there for something to do. You know, things like that, but I think if you you've got to have something. And the odd thing is that, I am a reviewer and examiner for the Institute of Civil Engineers and I think that that has helped me get through the last year. I had to read probably, I've probably gone through 30 or 40 people who've gone through our professional examinations or reviews, and I've probably gotten… So I've had to read all of their papers, work it all out, think about how good they are, work out what we're going to do on the interview, and I think things like that have helped me enormously. So that I've been able for at least those times to forget all about [name of family member with MND] and what's going on and all of that. I spent far too long every day doing the silly little games in the paper, all the sudokus and types.

**I:** Yeah, I think things like that are also still important and there is a section in the website also trying to encourage people to do more of this. Although I agree like Covid has probably limited the amount of suggestions that I could sort of put on there. I think as a constant reminder as well it's also good, a good thing.

**F:** Yeah, I think, I think covid has been so difficult for so many people because I'm lucky as I say we’re up on the edge of the country. We’ve got a reasonably well, it's a medium sized back garden, but it's also private so we can go in the garden and we can enjoy that. And I feel sorry for these people who live in tower blocks of flats and they're stuck there, they've got nowhere to go. It must be soul destroying at times like this. Mind you, I have occasionally lived in blocks of flats and quite enjoyed it, but not for any length of time and not when I've been locked up. And of course the problem with that is, I used to work in (name of city) and I was on the 25th floor in one block of flats and the 13th floor in another block of flats when their power went out, so that's a heck of a walk up the stairs if it's 25 blocks. But no, it, it, I do feel sorry for the people, but it's another thing going back to what you said earlier on about different areas. It's all very well me living in the country and doing this, but if you're living in a city you probably got parks you can go to. But there again, there's also the danger of at the moment is social distancing etc. And this is a real problem, of course to people with MND because they’re shielding they need to shield because they are very, very vulnerable. Uhm…and conversely, if they go into hospital…When [name of family member with MND] was in there they gave her covid tests regularly and there was no danger, but because she's on NIV because she's on a cough assist, these are both seen as aerosol producing machines. So any staff who came in had to wear all sorts of protective equipment to protect themselves, just in case. So it's, it's a strange place there. Incidentally, I was always allowed in the hospital 8-9 hours a day. And in fact, the first three days my son and I were there 24/7, and we dropped that down. But we were lucky insofar that they did allow me in, because otherwise [name of person with MND] would have been very lonely in there and that must have happened to a lot of people during Covid

**I:** Yeah, and tricky to communicate as well, I guess with all this machinery as well..

**F:** Yeah yeah, you're right, because apart from anything else when she was in there she'd obviously she got a ventilator working and that you're in a smaller room than she is here. The feed pump would have been working at times and because of covid they've put vent axias, extractor fans in all the rooms and although she was in the side ward because she had to be… yeah terribly noisy and wearing a mask made it so much more difficult for anyone to hear us, yeah. And not everyone was a native English speaker, and let's face it, even native English speakers because of the difference in parts of the country it can be difficult. I sometimes go up to (name of region) which is where I come from and I speak to some of my cousins and that there's at least one of them, I have real problems understanding now. But it… it can be a problem you know, for people with MND because of the… if they've got a mask on getting it across and so many of them have got bulbar problems and can't talk, at least we're lucky that (name of person with MND) doesn't have that problem.

**I:** Yeah OK, that makes sense. I was just wondering whether you looked at the website on your own or did you also kind of..

**F:** I’ve always looked at it by myself. I think… I might show it to her. I was gonna say I thought that it might not be her sort of thing, but there again it might well be her sort of thing, come to think of it..

**I:** it's completely up to you, I was just wondering how you used it. And linked to that as well, were there any particular times that you would do it or go on to the website? I appreciate it might be different because you're taking part in a research study, but did you feel the need to look at it?

**F:** I'm one of these people who tends to be fairly self-reliant. And I take things on face value and I don't, I don't tend to look things up. Now I say I don't tend to look things up, with over the last year I've seen so many films etc. and I'll spend half my time with my phone out looking to see who the cast is and who the people are and what's going on. But on things like that I tend to be self-reliant or speak to people I know, but I can see that for an awful lot of people that the website would be very useful. And I think people who aren’t as self-reliant as I am would find it much more useful because there is… it is… once you get into it, whether or not it's got an index or not, it's fairly easy to get around because there are only three or four areas. Each area is split into two or three different bits, so it's it is fairly easy to work your way around. And I have got it, I haven't got it open at the moment, but it is still open. Yeah, I've got actually got the opening page on it at the moment for some reason. Oh, I've lost you now, where in earth, I lost you too, there we go I've got you again. So yeah, I've got it open at the moment, but pure and simple because I wanted to have a quick look at it before I spoke to you, but as I say I did have a quick look at it and had a look at the mindfulness bit and the well being bit.

**I:** OK so it was more to just see what was in there rather than if you were worried then you looked at it or something like that?

**F:** Yeah, but I think that, as I say different people would… I can see that it would be useful to different people. But for me it's a case of, ‘oh, let’s have a look at that and find out what's going on’ and seeing what's going on, and I have been right the way through it. If we're going to be honest, it was smaller than I expected it to be originally. But there again, I think that if you made it too big, it would become unwieldy.

**I:** Yeah yeah, but I can see what you mean, having more options for uhm.. either more activities or more in depth information in case people want to go further into a particular topic.

**F:** Yeah, yeah, yeah.

**I:** You did mention that the anxiety and stress from the particularly relevant sections for you…

**F:** Well, I think the anxiety obviously is something which [name of family member with MND] has had and if I'm going to be per brutally honest, if I think about it and think about the end, there is anxiety about that. Because you know that what tends to kill people with MND is that they lose all the muscle control and eventually the muscle control of their throats, so they can't swallow and they can't breathe. And it's a particularly nasty form of death, and you know, it is something which is an anxiety. But at the same time, I tend to deal with things like that by not thinking about what's going to happen in the future. Uhm, no, I'm sorry you mentioned anxiety and you mentioned something else which I'd said… stress, yeah. Stress is something which I think all of us who are carers have got in abundance. We've got the stress of worrying what's gonna happen to our partners. We've got the stress of looking after them. Before we got CHC I was doing it 24/7, and before [name of family member with MND] went onto a NIV. One of the strange things is that because she was wasn't on a NIV, she wasn't getting enough oxygen when she was sleeping. That was giving her headaches, and it was also making her want to go to the loo a lot. So four, five times a night, she wanted to go to the loo. Now when she was still active, that wasn't too bad because she could walk to the loo and I might have to lift her legs back into bed. But when she became unable to do that it meant I had to get up, get bedpans, do everything else. And within three months, I mean she lost the use of a leg when she came home, and within three months I was in hospital with an internal bleed which they never found the source of and we could only put it down to stress. It was bad enough instantly to have 11 units of blood put back into me, so it wasn't a small bleed. And as I say they never found anything down to it, but it's stress and stress is something… Again talking to other carers and we have social meetings in our branch and we also have carers meetings, and when we're able to get out and about we actually have carers dinners, and we do not invite the people with MND to these because we can talk much more frankly with each other when they're not around. And that's one of the reasons why (name of carer) and I, the chap who’s wife had a PEG fitted, he and I can talk to each other so easily because we've met at these things and know what's going on. And you do talk about it and it's… It's the stress and the anxiety are the things which the carers have got.

**I:** Yeah, that section also was mainly I think for carers and other family members as well 'cause yeah, it sort of builds up, doesn't it? So yeah…

**F:** (interrupts) I’ll tell you one thing. I'm sorry..

**I:** Yeah, no, go ahead…

**F:** Something I have thought about and because pure and simple it doesn't occur to us, something which I don't know if you've got in there is a section for children who’ve got parents who got MND or grandparents who've got MND. Now the MND Association has books on it and very helpful, and a section in there for children.

**I:** Yeah, that's the reason I actually didn't put it in because I thought that the MNDA had excellent resources related to this so... Yeah, they do definitely have to be included, but maybe I could link it too the MNDA resources as well.

**F:** Yeah, I think it would be worth doing because of course, children are much more computer literate than majority of the people my age, probably more than people of your age are as well. So they are more likely to look up things like that, and I think that yeah, it might be worth thinking about.

**I:** You did mention that for anxiety you tend to try and not think about some of these things, and one of the techniques as well that I suggested was a kind of a thought distancing. I wonder if you had a look at that and maybe had a chance to…

**F:** I haven't seen anything about thought distancing, it was probably on the same page more or less as I was on before.

**I:** It was on link in the anxiety section, but it's also in the all activities if you want to just jump straight to it..

**F:** OK, I'll have a look at that one later on. It's… I don't understand thought distancing, but from the sound of it, it's what I do half the time anyway.

**I:** Yeah, it explains what it is. So yeah, if you have a look at it and maybe tell me what you think about it, that would be…. 'cause it's I completely understand that some strategies like meditation or mindfulness may not be appropriate for everyone. So I was trying to give a couple of other options as well, so I think something like this might be handy

**F:** Alright. Can I ask you a personal question? I'm just listening to your accent and you sound pretty English to me, but there's just that little pinch of the (name of country) accent coming across as well.

**I:** Yes, I am from (name of country).

**F:** You are? You've got a very English accent.

**I:** I've been here for a while now, but I've grown up in (name of country).

**F:** Yeah, yeah, it's surprising. I honestly thought you were English from the way talking to you, but there's just that occasional little bit. Anyway that's got nothing to do with it, how is MND in (name of country? I mean how it was it's funny because when [name of person with MND] was first, when she first had the problem, it was in her left arm only and it was put down or something else. I can't remember what it was called mono something or other which the Americans refer to as hariyama's disease, or hariyama, after an American baseball player. And it was it's an interesting thing because the specialist said I can't understand why you've got it because it normally is of men who were about 20 and either of (name of country) or (name of another country) extraction. And [name of person with MND] is English, she's British, she was in her 60s at the time, of course female, so she didn't fit any other normal stereotypes, but he was absolutely convinced that it wasn't MND.

**I:** OK, I do not know, I haven't heard of that one. Even MND cases are actually quite rare, but that again could be there's a low prevalence or also just testing and diagnosis may be better in say cities as opposed to other areas of the country…

**F:** Yeah, yeah. It's an awful disease that I mean it's, what is it, one in 300 of us will get it in this country. And I've spoken to one or two MPs and said think two of you sitting in the House of Commons are going to get this disease.

**I:** That’s a good way to put it...

**F:** Yeah, but we don't know who's gonna get it, that's the unfortunate thing.

**I:** Yeah, I guess linked to that as well when you do get it and you look for information online, it's useful to have resources that are a bit more positive and don't always talk about all the things that could potentially go wrong…

**F:** Yeah, I think you’re dead right there because of course when [name of person with MND] was first to first diagnosed with this disease, she was sent for a second opinion. And the second opinion, and this was done privately, this was not an NHS doctor, he said, ‘well, I suppose you know I've been asked to give a second opinion on whether or not you've got motor neurone disease, and I think you have. Have a good holiday.’ 'cause we were just about to go off on holiday the following week and you know, I can tell you the car ride home 'cause this was about 30-40 miles away, the car ride home was not very comfortable. There was very silent, that doesn't, [name of person with MND] said ‘I haven't got that disease.’ Anyway we spent some time looking it up and then you see the things like, there's no cure, there's no remission, there's no hope, really. There's one. There's only really (name of drug) the one drug which works, and they say that extends life by six months and it improves the quality of life. And yet I've seen so many people have died very quickly. I've seen people who've gone along fairly evenly and then if at a sort of cliff edge and gone over it. It's one of the problems about these social meetings, you get to know people and then they die off. However, cheerful sod aren’t I?

**I:** I guess linked to that as a family member would this kind of positive psychological support, do you think it might have been useful earlier on? At say the diagnosis or a bit after that, or maybe it's too much information at that point?

**F:** I think when you’re first diagnosed you get all sorts of information thrown at you. You get all sorts of we got called into the [name of hospital] and we got seen by all sorts of people, we got seen by our own consultant, we got seen by the specialist nurse, got seen by the physio by someone else, someone who talked about financial side of it. It's all too much! It goes straight over your head! And so I think getting that sort of thing at the same time, possibly wouldn't help because it would be too early and too much other stuff coming in, but… and here's the big but. I think it would be useful because it would be something positive. It would be something which people could bob in and out of, you don't have to take it all at one go, you can look at it in bits and pieces. And so yeah, I think it would be useful instantly. I mean, one of the things they give you when you first get it is this book. I don't know if you've ever come across this one ‘Living with motor neurone disease,’ 114 pages. It's not, I mean it covers all sorts of things, accessing services, living with them, and the eating and drinking etc, speech and communication. I've read bits of it, I might do, I mean I do keep it close at hand so I can always get hold of it when I want to. But this, you don't want to read all that stuff. It is actually fairly easy to read and it is easily spaced out. I mean it's, it's well illustrated and it is spread out in such a way that you can look at it easily, much better than some of the other reports. I’ve got another one here, can you see the name of that one? (shows the report titled ‘six months to live’) That report of the all party parliamentary group for terminal illness that is not quite so easy to read. But uh, it's one of those things that occasionally we get involved with. ‘Six months to live’ is another of our campaigns, this business of yes, it's very difficult and you can't say that someone's gonna die within six months, you've got no idea. I would, I asked our specialist who’d been looking at [name of person with MND] for 10 years. 10 bloody years he'd been seeing her! And said, ‘what's the prognosis?’ And he says ‘normally I say two to three years, but she's already had it so long, I've got no idea in this case.’ And that's the problem with it. You've got no idea, you're living under a death sentence and you don’t know when. I am amazed, absolutely amazed how positive so many of the people with MND are not just [name of family member with MND], other friends with it… There's very few of them who seem to sit back and say ‘oh it’s…’, but maybe that's because the people who I see at social meetings are the people who go out, are more gregarious types of people and have a more positive attitude towards life.

**I:** Yeah, there are a lot of people as well who... I guess don't want to necessarily see how the disease might pan out, and in that sense not meet other people. So it's kind of balancing you want to be positive, but you also don't want to scare someone into you know, looking into the future…

**F:** Well, yeah, and from a personal point of view, when [name of family member with MND] first had it, she used to like the social meetings that we have. And we learned quite a lot, and she saw other people who were with it. And then she started noticing that people weren't there anymore. And then she got worse and now she doesn't want people to see her like she is. And it's, it's difficult, I guess it's much easier to be a carer than it is to be a person with it.

**I:** Yeah, yeah, I was just gonna say like because it is so different, any resource would have to be something that people pick and choose when they feel comfortable to look at it, or when they are ready have that information.

**F:** But I don't think there would be any harm whatsoever for this information, this website to be made available to people at their first appointment and say… Even to have in the book which you get ‘living with motor neuron disease’ have a link to it in there. Because that way they can go to it when they want to. And I was almost wondering whether or not to instead of having it as a website you go onto to have it on a CD stuck into the book and then thought no, that's not a good idea because it doesn't keep updated.

**I:** That's true,

**F:** So I don't think that's a good idea.

**I:** Yeah, you could have some things that, I guess the mindfulness meditations or something that may not change. Yeah, that’s a good point. Was there anything from a carer’s point of view that you felt either it didn't cover or you would have liked to see in there?

**F:** Not that I can recall. What I will do is I've gotta look at this thought distancing anyway. What I will do is I will have another look through it over the next couple of days and come back to you. I'll come back to you before the end of the month.

**I:** Yup, that sounds fine. Uhm, did you have any other comments about the website? I can stop the recording, if not?

**F:** I don't think I do offhand. I mean, I think everything we've spoken about either today or before, but I will have another look at it, looking at it from the carer’s perspective and see if there's anything I think is missing. So I think we've covered most things. Whether or not you've got any meaningful notes out of this, because we seem to have covered all sorts of areas and you don't get all my flashing hands in the notes.

**I:** (laughs) I’ll stop the recording but I will still be on the call.

Follow up email:

I have been on it 2 or 3 times now and I quite like it – especially the calming photos which live up to the description!  What does surprise me is that there is no search option to quickly find your way around. My wife suffers from anxiety or panic attacks at times and I now know where to find stuff on these but to have a search option would, I think, be beneficial.

I looked at the thought distancing (which took me some time to find!) and on an early sheet there was a portrait photo of a beach.  I thought this was particularly relaxing – but might have been even more so if it was a video so you could watch the water lapping and even with the benefit of sound.  However, I know that my wife always felt this way about water and others might not.