**Interview 14**

**(family member and person with MND)**

**I:** Like a notification thing that's happening. Yes, it's recording, yeah. OK. Uhm yeah. So just a general question to start off with about how you both got on with using the website.

**F:** I found it reasonably easy. But I just did it as a looking at it as a whole and just working methodically through it, and I found working through it methodically quite an easy thing to do.

**I:** OK.

**F:** Whether when I'm actually coming to use it and I think ‘Oh I'm gonna need some of the information from that website, where do I go?’ But I think with what I've learned from doing it now I think I should know what's on the website and I should be able to get reasonably quickly to the section that I think I might need when I need it.

**I:** OK, so it needs a bit of time to first almost just look at the whole thing and then work out where each bit is, OK.

**P:** Yeah, I found that when I first looked at it, I thought it was a little confusing 'cause you can come at the same thing through different ways. And I thought I just looked at that and I'm now going on to another section and being thrown back there again. But once you get used to it you sort of understand it. But I think I'm just more old fashioned, I'm used to more of a top down indexing, ‘Oh, that's what I want, there it is,’ you know.

**I:** Yeah, I'm just making a note of that it’s useful point. Uhm, and typically how did you use it? Did you both go through it together or separately?

**P:** We’ve done both actually

**F:** Yes, we’ve done both.

**P:** Yes, we've been through it together, but we looked at it subsequently without each other.

**F:** Yeah.

**I:** OK, and even in terms of choosing which bits to look at, it was more a methodical thing as opposed to ‘I'm feeling stressed let me look at this section.’

**F:** Yeah, it was really to find out what was there. And to get a good overview of what was there.

**I:** OK. I was going to go through each section just to get specific feedback about that, if that's OK?

**F:** yeah.

**I:** So, to start off with there was the building positivity section, and that had three activities there - pleasant activities, finding positives and values and goals. Yeah, just what you thought about these and whether you felt it was relevant for you?

**F:** I think talking from now when we seem to be in a reasonable mental emotional state, reading through, I thought they all seem to make a lot of common sense, and I'd like to think we're doing quite a lot of that stuff now. There was nothing that I thought although I don't agree with that, it all seemed surely good there. And I've been looking through it thinking, ‘well, yeah, I know that that's what I would do now.’ But at the back of my mind, there’s the fact that we don't need it at the moment, but at least I know that if anything does go wrong, if I do get into any sort of state, I'll know that it's there, and I could sort of go and look at it. And… I mean things like just sort of the take 3 minutes breathing space. And I can imagine myself later on getting really, really sort of frustrated about something and then just thinking, ‘just remember that’ and if I can't actually remember what it said, I can go back to it and look at it. And just follow those instructions and doing that I would like to think, might calm me down little bit.

**I:** OK.

**F:** So, it's very helpful knowing that this stuff is all there, for when you get in such a state that you can't think for yourself really.

**I:** OK.

**P:** In fact that was a, if you like it, a general observation. One of the things that the MND Association tell you right at the start is that it’s a bit like COVID, you need to be at it again. You can't wait for things to go wrong and then try and find out what to do. That’s our doorbell it’s a bit loud because we picked the loudest chime on the on the way. You know if you, at some stage further down the line, I might need a wheelchair which there’s no point waiting till you do and then start doing the research because at the time you need it, it's gonna be too late. And waiting for… we've always taken that advice on board, and I feel that lots of this is stuff that I probably don't need it at the moment but I can quite see a time in the future period where it might be very, very useful to have this on tap, so you can... So, I think I remember something about that in CALM I'm gonna look that up. So take that as a general observation.

**I:** Yeah. That’s a really interesting point, I have been speaking to a couple of other people as well and I just want your perspective on this as well. When you do think about, you know the future or things that could go wrong and maybe any of the suggestions does that… did anything in the website kind of make you think of the future and get upset or something like that?

**P:** No, not really, because I think we've done it in a way. I use the wheelchair as an example, I mean when we thought about that and [family member] was particularly astute in that she said, ‘well, we need to check this out’ because we live in a flat. And if we can't get a wheelchair in, we have to move. Again, there’s no point in waiting until that time, so we've had some people in and demonstrated it. I've been driving wheelchairs around the flat about two years ago. We know that we can do it so we can sort of park that one for now. And I think an awful lot of things that might go wrong in the future, probably will, we have thought about. But it doesn't mean I don't like to have a sort of list of things like this, things that you can do to help you through these things, I mean.

**I:** So it almost gives you kind of comfort to know that there are those things.

**P:** Absolutely yeah.

**F:** Absolutely, it really does.

**P:** That’s exactly the word. Again when all this first started, we joined ‘dignity in dying’ because we uhm, how do I know how it's gonna pan out the end? What I might need to do. And I'm well aware that most of the people who joined that don't actually go and never get to Switzerland, but it does feel good to know that if you do get into dire straits, you've got that behind, you can do that.

**I:** OK. OK.

**P:** It is good to know that things are there even if you're not using them now.

**I:** Yeah, yeah that's interesting, yeah, Uhm, OK so, in terms of the activities as well, finding positives or doing things in relation to you know your values and that kind of thing. Do you feel you currently do stuff like that?

**F:** Yeah. I think we do. I think we are… I mean, we get out as much as we can do. I notice the bit where you took, you put these lovely pictures of nature up and saying that that's very calming. And we were saying to each other that at the moment we are actually able to get out and go to nice peaceful places or the noisy musical places, that's what we want to do.

**P:** Well, we’ve just done it haven’t we?

**F:** But you know, there's the knowledge that when we can't, you know, then we can go look at pictures just to remind us of what it was like. And it's just actually made me think which is great, is that I always, always been sceptical about virtual reality stuff. You know what you can put on this virtual reality kit, and you go walking in the mountains, you can go kayaking down the rapids or whatever. And it just occurred to me that it might actually be quite useful later on to be able to do something like that.

**I:** Yeah. Yeah.

**F:** I never thought about it, but you know, I can almost think well when things get really bad. We can get these little headsets and we can do all the things that we would never, that we were too frightened to do when we were able, when we could have done them. Put that on the list of things to look forward to climbing Mount Everest.

**I:** Yeah, and that's the sort of intermediate step photographs and things that can also help. Do you feel the similar way with activities and trying to do that [name of person with MND]?

**P:** Sorry do I feel...

**I:** Do you feel similarly with like how doing activities you're still able to do it now, but the website kind of triggered maybe things you could do in the future?

**P:** Yeah, it's… it's a bit tricky though, I think with photos. Uhm, I mean the things I like to do now… Well, I suppose one of our main activities has always been going out and walking, walking in the hills and all sorts. So I'm sure that looking at old photos and things like that, would deal with it, that would help. There are other things like my basic hobbies, I play drums. There’s no point looking at pictures of drums, in fact, I'm gonna get bloody frustrated.

**F:** But you can listen to really good drummers.

**P:** Yeah, and watch videos and things.

**I:** Yeah.

**P:** But it has given me the idea that even when it… even as these things are taken away, you can replace them with things that, OK not it's not quite good as the real thing, but it’s better than nothing, much better.

**I:** Yeah, I was hoping that would encourage people to adapt things that you liked doing, but just in a slightly different way, I guess…

**F:** Well, I think right at the beginning, when [name of person with MND] was given his diagnosis about six years ago, and I can't remember what you said. But the consultant said, he said ‘you will adapt. You'll find that you know, you might not think that way later, as you adapt.’ And I think we have had this process of six years where we’re just adapting all the time. We don’t actually notice, well I suppose occasionally, we do notice sometimes when we're having to adapt. But I think it's just a very general process of adapting all the time, so there's not sort of any sort of cliff edges or anything, it's just that…

**P:** Well, that's true. That’s what [name of person] said ‘one of the things that human beings are good at is adapting’. And even though it's a very nasty illness, it.. not for everybody, but for most people it doesn't come on just overnight. It is just a slow process and as the process goes on, you find ways around things. So, I can't do shoelaces up, but I found these things called lock laces. They are sort of elastic things with a catch on there, I put those in, and you just find ways to, you know to get around them so it's slow process.

**I:** OK. Is there any anything you either disliked about this section or any other comments about this section before we move on?

**F:** The only one comment I would make was in the questionnaire that we filled in today. It was talking about the use of, about wanting appearance, so you sort of as interested in your appearance. I think in lockdown that's not really a good time to ask questions 'cause everybody just… (laughs)

**I:** (laughs)No one really cares now.

**F:** It’s the same place every day.

**I:** Yeah. I didn't even think about that.

**F:** Yeah, and sometimes on some of the questions I'd like to have been able to put something in brackets. This would have been… like do find that you’re laughing at things as much or whatever, and we both independently said I think sometimes we laugh more at things because we bloody well have to.

**P:** When I said that you were watching me fill it in, you said, ‘oh, I felt exactly the same way.’

**F:** Yeah.

**I:** Yeah, no I think some of those are questionnaires which are more general questions. It may not necessarily be for MND or those sorts of things. So yeah, definitely.

**F:** Can, I just ask a question?

**I:** Sure.

**F:** We've got a friend whose husband has got another ghastly disease. Would you mind if I let her have a look at this website 'cause I think it might help her.

**I:** Yeah, I could send you a slightly different version, it has the same stuff, it's just this particular website kind of because you're part of the research study, measures certain things like you know how you're using it and things like that. So, I could give you like sort of a demo version that you could share.

**F:** Yeah, that would be great, yeah.

**P:** That would be helpful yeah

**I:** Yeah, I'm happy if people find it helpful.

**F:** Yeah, I think she would do.

**I:** Uhm, OK. If we move into the other section which is adjusting to changes, I think we've kind of already spoken a little bit about adapting and things like that. But it specifically had anger, sadness and frustration and techniques to deal with the emotions. Uhm, did you find any of this relevant or?

**F:** Yes. Yes, I did. I found it sort of, all as you say, very relevant. And it's the sort of thing that you’d like to think that you do when normally, if you sort of get angry or sad or frustrated occasionally then you should just say ‘OK, I'm angry’ basically just step back a bit so you can sort of look at it. Uhm, but I can see a time where we might be so sort of low, so tired from dealing with day-to-day problems whatever, that you just lose track, you lose sight of that. And to have that to go back to say ‘OK..’, just reading it, I think to say ‘I'm feeling angry, let's look at that’ and it might calm you down. The same way with this sadness bit, it's what can I do to try and overcome it. So, I found all of it helpful very sort of, all helpful I mean, very sort of suggestions. All the helpful, very suggestions (laughs because mixes up words).

**P:** Yeah I found it very… well, in particular because I don't tend to get angry or sad or anything, but I do get frustrated occasionally. It usually is very simple things like I'm trying to put a sock on and I'm in a bit of a hurry. Well, it's actually quite difficult getting a sock on with one hand 'cause one arm doesn't work too well, and I'll get very frustrated and I you know, start to throw in a wobbly.

**F:** Your frustrations seems to me like anger. (laughs)

**P:** Yes exactly. (laughs)

**I:** To be fair, a lot of these emotions also kind of mix.

**F:** Yeah they do that, don’t they.

**P:** But it is usually something small like that, that really triggers it. Some of the major, I mean some of the bigger problems, I just seem to… I don't know, I recognize it's a bigger problem and gotta deal with it, so I just get on that. But these niggling things you…it really annoys me sometimes, but there we are, we get used to it.

**F:** I think that just happens, whether you got any problems or not really. Possibly not just the frustrating things.

**I:** Can I just ask you [name of person with MND] as well, how do you even without the website, how do you typically deal with those kinds of frustrations? 'cause if there are ways that both of you find helpful to cope with things, I'd love to learn from that too.

**P:** I shout and scream a bit. (laughs) Swear a lot, and then I think ‘don’t be daft. It is only a pair of socks, calm down again’ And I’m sure just taking deep breaths would probably help, perhaps I should try that.

**I:** OK, just like stepping back and taking a few deep breaths.

**F:** But we had quite an occurrence over our holiday. I think it was the last day and we had to get out of the path that we were on to a road, so we could cross the road and I think there were three ways we could get out of the woods onto the road. One meant going through this bog or swamp, which we thought we’re not going to do that one. Another one there was a dip down into a ditch and then you’re coming up from the ditch. Uhm, I said ‘I’d do that if I have to, but I'd really much rather not do that one.’ And then [name of person with MND] spotted a gate and he said ‘Well we can climb over the gate.’ Normally I'm the one that doesn't like climbing over gates. But I thought I'd have a go at climbing over the gate. It was the bottom few rungs are quite close together, so it was actually easy enough to step up onto the gate, onto the uhm… to get high enough so I could put my leg over and climb over. I was pretty proud I’d done that, and [name of person with MND] said ‘well that's great I can do it, that's easy.’

**P:** I don’t have a problem climbing up gates and things like that, I never have, but this was a metal gate and so it was a circular part. It's quite high. Anyway, I got up onto it and I'm wearing, I have to wear gloves because I get got Reno’s syndrome in my hand, they just stop working when they get cold. And I suddenly found that I was sat on top of this bleeding gate, and I've got nothing to hang onto it with, because you really need a couple of hands to hang on to, get your leg over and get over. And I was just stuck for a bit, because this arm doesn't work. And so we ended up roaring with laughter, (both laugh) because it looked as if I’d saddled a horse, I was sat on this bloody thing thinking how do I get off it.

**I:** How did you, how did you get down in the end?

**P:** Just did it in the end.

**F:** We just we worked out how to do it in the end. But, it's just one of those adjusting things that normally [name of person with MND] would be able to just get over that and it was very different because I got over easily. And it's normally [name of person with MND] saying that ‘you be calm. You can do it, you can do it, just move that leg gently and do that’ and instead that it was me saying that, ‘be calm, do that and I’ll lift your leg over.’

**P:** Like I remember really Marvel Comics and? it looked like that and I was three.

**F:** Sorry, that was just a bit about that, frustration and adjusting to everything.

**I:** You just sort of take turns and learn from each other, I guess. Uhm, yeah I guess as a family member as well, did you feel any of these emotions were relevant to you [name of family member], anger, sadness, frustration?

**F:** Uhm…Do I get angry about [name of person with MND] with MND? No, I mean you can't get angry about something like that.

**P:** It’s a disease.

**F:** I can get angry when something on a website changes or something on an application I get changes and I used to be able to do something easily, and they change it and I can't do it anymore and I can get quite cross about that. But you know, I've learned how to put up with it. So that's nothing to do with MND. Sadness will obviously you know, if you sort of stop think about is…if something sort of crosses through your mind and you feel sad about it, but you can't let it dwell. So, you just have to find something to take your mind off of it. There’s lots of different things you can do to do it. Just basically looking for something positive, looking something else going on. And just doing as much planning for the future so we can do. Frustration, little things at the moment. Everybody, if people don't get frustrated, there's something wrong with them. So, it’s the small things. We’re just we still in a position where we can do most of the things we want to do. And that will change so I can see that there might be times when I get frustrated and I can't just do what I normally do. I've gotta find another way of dealing with it, and again I think this would be very, very useful, helpful. Even if it just says don't do anything for two minutes, make yourself a cup of tea. Do something.

**I:** OK. Yep, just reminder that.

**F:** Forget about it for a bit.

**I:** I guess I'm just.. while you were talking it reminded me there was one technique inside the sadness section about thought distancing. I don't know if you went through it or tried it out, but I was just wondering what you thought about that?

**F:** I didn't actually look at that one in too much detail, I have to say.

**I:** OK. That's fine, it just sounded like something quite similar to what you were describing when you spoke about the sadness bit about just kind of keeping those negative thoughts at bay.

**F:** Yeah.

**I:** Yeah, so it's probably something you already do, which is why you didn't look at that. That's fine. Did you also have a look at the stress or anxiety bit or is that not really relevant?

**F:** Yeah, I did look at it and again, I thought it all sort of quiet useful. And I do like the way you sort of stress quite often, is talk to people, talk to people, ask for help. And I think, this is what we say to friends and family, just talk, talk to somebody about it, you know talk to doctor, talk to whoever. And again, it's something that I would do now, but I may need reminding of that later on.

**I:** yeah.

**F:** And people do want to help, so give them the opportunity to help by talking to them. Something else we’ve said anything a lot of this might seem sort of quite common sense at the moment, but later on it might be a lifesaver.

**I**: Yeah, and a lot of this actually I can't take complete credit for it. It was a lot of other people from interviews I've done previously, who other people who had MND who gave this similar advice. So, it's coming from people in a similar situation.

**P:** Yes, and on the subject of talking, I think it does help if you talk about your condition. I know some people are not very good with illness and they don't really wanna talk about it. And I don't think that helps, you know people trying, put their illness keep it under the carpet. We've never done that, and I think it helps. It helps friends if you're not reticent about it, just saying what the problem is. And I find what normally happens is you meet people you talk to my same way, ‘how's it going’ might speak for a little while about it and then you move on. You know, you got that out the way, everybody knows what the position is. They know your legs are not feeling too good today, so we won't walk too far or whatever, and then you can forget about it and get on with life.

**I:** Yeah, that is helpful. Uhm…

**P:** I'm thinking in particular of your dad, [family member’s] dad had dementia and he would never accept it, even in the early stages, when it was obviously something wrong. He would never talk about it. He would not do anything about it and eventually it was a long, long time before we got any drugs, and had he got onto the drugs early, it might have made his life a lot better. But he just refused to have anything to do with it, 'cause he didn't like it.

**F:** And it made life difficult for everybody else because we were always skirting around the fact that he had Alzheimer’s and we couldn't talk about it. And it just it made it really difficult for my mum who was living with him at the time.

**I:** So you almost need a bit of acceptance I guess in order to ask for help. I mean, yeah, even from a psychological point of view from website or any dealing with emotions and things, you almost need to accept at first, I guess.

**F:** Well, when [name of person with MND] was diagnosed, we went round where we told everybody we knew, we have local friends and we just went down to see them and just told them. And I think it was one of the people she just said, after this sort of thing that people say that, ‘I am so pleased you told me. You won’t believe it,’ she told me ‘I had a friend, who got MS and he wouldn't tell anybody. He didn't tell anybody.’ She said, ‘I am so angry with him,’ and.. so that really helps a lot, doesn’t it?

**P:** And it is, this all stems from the idea of talking, that’s how we got on to this. Because I know we wandered a bit from the initial thing, but it’s all relevant.

**F:** Yeah, yeah.

**I:** Yeah. Sorry, I didn't catch the last bit.

**P:** It’s communication I suppose.

**I:** Yeah. So, this flows quite nicely to my next question was about other support. There was a section as well about if you need professional help or peer support or any other resources and things like that. Maybe not now, but in the future as well, trying to kind of point people to different sources other than this website as well. And I know you probably don't feel the need right now, but also, I just wondered if you had used any of any support for things like psychologically? Did you like contact, maybe any psychologist counsellor, things like that?

**F:** Well, I think when [name of person with MND] was first diagnosed, Uhm we were both offered counselling from our GP, and we both went along for counselling session separately. I found it incredibly useful.

**P:** I didn't really, it was far too early. I mean, I understood why it was being done and the fact that it is being offered was certainly, you know, I was pleased about that. But I didn't really feel that I got anything out of it, and I didn't wanna waste her time. And well, that was six years ago. But I mean if I had to go to counselling sessions for six years, it would’ve driven me up the wall, I think. But I can understand it, again like so many of these things in the future, I might be very grateful or very pleased to talk to someone other than friends and family.

**I:** Yeah, when you said it was far too early, did you mean because you weren't having any symptoms or problems at that time?

**P:** Yes. Because when I was first diagnosed, I was just getting some cramps in this hand that was about it, there was nothing else. So it didn't really affect my life at all, not for several years. It is beginning to now, I think, things are getting difficult. But that was very early on, and I didn’t really need that. But then it's just the way the disease goes with some people and other people have been diagnosed and they’re dead within three months, so a bit of counselling might help you. But in my particular case, because it was going fairly slowly so… but I see it may be helpful, it could be..

**F:** But again, it was one of those things I just felt that I really did appreciate having that initial talk with the counsellor. And then I knew that if I did feel the need to talk to somebody who's not a friend, to get somebody completely outside, then there would be a counsellor available that I could talk to. Yeah, and that's what helps a lot, because then you could talk to a counsellor every now and then. I have these thoughts and I sort of almost have an imaginary conversation with somebody else, I think back to what she said, ‘OK, you solved that one for now.’ But it could be, it will be there, sometime when we need it.

**I:** Yeah. OK, I got it is useful to know I didn't realize it was also offered by your GP, so that's a good thing.

**F:** Another thing that we do for support is we go to the Motor Neurone Disease Association branch meetings. And they're excellent, they really are great.

**P:** In fact, we go along, we’re supposed to belong to the [name of place] branch. But when this first started, we couldn't get in touch with them, and they had some kind of problems the way they were managing things. And so, we went to the [name of another region] branch. And not realizing that you weren't supposed to do that, it depends on where you lived and which medical department you came under, where you should go. We’re going to them for about a year before we realize that we really should get in touch with the [name of first region]. But of course, you got to know these people in [name of other region] so we go to both now.

**I:** Nice. Oh, that's good.

**P:** Technically we shouldn't do that, but nobody cares.

**I:** I'm sure they don't mind.

**F:** But that really is great. They are very, very helpful. And you just you see them, the help and support they give everybody, to other people. And the reassurance that if we get to that stage, when we get that stage, you will get the same sort of same level of support again it's all this sort of comfort for the future. That we sort of…

**I:** Yeah. Yeah, I, I think I did put a lot of links to the MNDA there because they are helpful.

**F:** Yeah.

**I:** I guess one quick question about mindfulness in thosekinds of audio exercises.I wondered if you I just wantedto know your opinion about it.Is this something you’d likely do,or is it not really your cup of tea that sort of thing?

**F:** It is not reallymy cup of tea at the moment.It may be at some stage, and Iwill look into a little bit more,but if I want to relax,I'm more likely to go into the shed, we have in the garden and play my saxophone.And if I do that, I just forget about…I mean I'm useless,but I can do thatand you know, an hour and a half can just go. And I think, yeah I found something for me,so that's my way of relaxing and forgetting about things.

**I:** Ok.

**P:** I feel pretty similarly I'm..It's not something that grabs me at all.I could understand it might help alot of people are not knocking it, or having a go at it, but it doesn't really suit me very well.

**F:** At the moment.

**P:** At the moment. And I’ve got any number of interests that I can do or take up. I need to do...I've got things, I mean one ofthe questions on the [questionnaire] do you get bored.Well, I haven’t got time to get bored.I’ve got a stack of 10 books I'm trying to get through it.Mucking about playing chess,mucking about with that. Every now and again,I'll play drums and do those sorts of things.There isn't time to get bored. But who knows when I'm more physically handicapped and can’t do these things.

**F:** I was casting around thinking of things that [name of person with MND] could do when he can't get out, play drums, and just get out so much. And I think at the time and still is interested in anthropology. And I would say why don’t you do a review course on something like anthropology and you’re not all that interested in doing a formal course. And I was just talking to friends about, you're looking for something in anthropology, and she said, ‘have you come across an organization called the great courses?’ And I said ‘no,’ and she told me all about. It's an American organization, but they do online courses, DVD courses, and they're up to college level. There’s some pretty high-level things on almost anything that you can think of. And… you've done about three of those now.

**P:** Yeah, that's interesting. I did one, it was about maths and music and how they relate because they do you know, there's all sorts of connections. And every now and then, they will send you a pantry, and it's a sale, so you can get it 'cause they're not cheap. Some of these things are about £80-£90 per course. Anyway, there was another one about Opera which I was interested in. So, I've got that and there’s another one all about Western civilization and I thought ‘that’ll be interesting.’

**F:** Geology.

**P:** Geology, was another one. So in the end you see we’ve got about eight or nine of these things stacked up. I am doing one about Western civilisation. But uhm… I don’t know how we got on to this, it’s about doing things, it keeps your mind busy.

**I:** Yeah, yeah.

**F:** I think talking about mindfulness and trying to do something positive

**I:** Yeah. Do something to make you feel better.

**F:** A different way of making yourself better, but that doesn'tmean that's always going to work,and there might be times when we need to, it would help to look into introspective things.

**P:** I'd like to be doing something of interest, you know, something where I'm learningsomething rather than just being out infront of the box and watching junk. I’d rather do that for the last couple of hours of the day with a glass of wine, but I don't wanna do that all day, you know.

**I:** Yeah no, I only ask because different people have different preferences. Some people find things like, you know, just taking a step back and doing mindfulness very calming and some people like to do things, and both are equally good strategies. It's just, I'm just trying to hope that there was something for everyone, if you use a website like this. Yeah.

**P:** The thing I haven't looked into yet, I don't know if it impinges on that, is Tai Chi. That's always interested me, but I have not got round to that. That’s a lot more of a mental discipline.

**I:** That's kind of almost a mind-body combination of things, yeah. That's also useful. Uhm.. I guess, I know at the moment your strategy, sort of this because you can, and you are able to do things to do as much as you can do. I just wondered whether like at this stage where you're at having a look at the website, did it did it change anything for you or is that more of a future thing?

**P:** We keep going back to this, but it’s just that thing that ‘oh, yeah we probably do that anyway. I'm probably not relate too much to this section now,’ but I can see they could be very useful. It's uhm, like the MNDA, it's very reassuring to know that people like yourself are looking into these things and providing support should I ever need it. I suppose in a sense I can say I hope I never need it, but if I do, then I know it's there that makes you feel better and reassured.

**I:** Yeah, I see what you mean. Is that the same for you [name of family member]?

**F:** Yes, yes, yes it is.

**I:** I just wondered whether before you took part in this study, did you have any or have a look at the website, did you have any expectations of what you might find in something like this?

**F:** Deliberately didn't think too much.

**I:** That's good.

**P:** Open mind.

**F:** Yeah.

**I:** I'm just asking more in terms of whether, 'cause some people are either struggling with something and would like a website to cover certain issues, but that was not the case for you both? [both shake head] No? OK.

**F:** No, we weren't actually specifically looking for something. But we're looking for yeah, but so we weren’t specifically looking for something but were quite interested to look at something that could be of use. Which I think it will be.

**I:** OK. I’ve asked most of my questions. I wondered if you had anything else you wanted to comment on. Any other feedback?

**F:** I don’t think so really. I mean to say thank you very much for doing this.

**I:** That's alright. I can stop the recording, I'll still be on the call, but I will just stop the recording.