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**(family member)**

**I:** It should come up.

**F:** Oh yeah, yeah. The notifications come up.

**I:** So I guess I don't know besides the questionnaires, I don't really know a lot about, um, your background and things like that. So is it your mum that has an MND, and it's fairly recent, isn't it?

**F:** Yeah, she was diagnosed end of January she got a diagnosis um, so. She's got the type that starts with the facial and sort of throat muscles. Um, so she's still got her mobility, but she can't speak anymore unfortunately, and she's now got a feeding tube 'cause she was, she lost quite a lot of weight and so I think the feeding tube was fitted end of March, which has made so much difference. Um, 'cause she… really after the diagnosis she really went downhill. I think it's a psychological sort of you've been diagnosed with it and yeah, very quickly went downhill. Um, but yes, since having the feeding tube fitted, things have improved I'd say. And I think my dad said, you know, the feeding tube has literally saved her life 'cause she was just losing so much weight and then she got her chest infection but didn't have the energy to sort of fight it off. So yeah the… since the end of March, it has sort of the deterioration in places has plateaued a bit which has been quite a relief. So it doesn't seem, it's obviously not a great situation to be in, but compared to where we were at the beginning or middle of March, it's, it seems a bit more managed, I suppose.

**I:** Okay, she's able to do some things now I guess.

**F:** Yes, yeah we had a family holiday in May. And I think she was very anxious about going anywhere, 'cause she really struggles to eat now. Um but it was a really nice week and I know she even looked at sort of the day before we went, she was unsure whether she would be going. Um, so I’m glad she did. And yeah, they are looking at booking somewhere, mum and dad, just to go, the two of them somewhere. So I'm quite relieved about that, 'cause otherwise they’re just sat at home sort of and it's that whole thing of doing things while you can, because obviously the mobility is gonna go, um. I think there's a big psychological battle. I think of coping day-to-day with what you can and can't do, but also making the most of being able to do things while you still can.

**I:** Yeah and do you find it affects the rest of the family as well? I mean it sounds like it does.

**F:** Yeah, I mean I have days where you just sort of get on with it and it's there in the background and then I have days where it's sort of, it affects me a lot more. But um, I think that the whole not being able to eat and she's not confident to eat in public. And a lot of what you do socially revolves around going for a drink or a meal or having a bit, you know, pop round to friends for a bit of cake or whatever. And she won’t, she just doesn't have the confidence to do that. Um, so yeah, for me and the children we can still do that sort of maybe without them, or we invite them over and mum’s very conscious but comfortable around us. But they won't go to other friends particularly. So I worry how it is impacting my dad I suppose 'cause he's sort of missing out on that social side of things.

**I:** Okay, okay. It's almost affecting it differently for different family members I guess.

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

**I:** And I just wondered when you looked at, uh, the study and the information about it online. Did you have any sort of expectations about what kind of support the website might give you?

**F:** Um I think it's the, it was maybe a reference to go to for sort of not, I don’t know if coping strategies is the right word. But you know that just you know, if you’re feeling a bit, if you're feeling a certain way on a certain day, it's… I thought it could be somewhere you could go and sort of think ‘oh what, what could I, what information 'cause I get from the website that might help me cope with it?’ A couple of weeks ago I had a bit of a down day and I know that I've seen on the website there's there was a section says ‘how are you feeling today?’ And so I went and found that and clicked on that, which I like that bit. I thought that was a really good area. So I think it was if you're feeling sad or angry or… But and then there was some sort of… that obviously then lead into other sections about how you might deal with those feelings.

**I:** So okay, okay. And that leads very nicely on to how did you get on with using the website?

**F:** Um, um I liked it. I like the images you know, you said about the images of nature are sort of calming. And I really, I really did think that, that was true. You know, just sometimes you sort of look at an image and think ‘well, what, how does that relate to the information on the page?’ But it doesn't need to it's just a sort of, um, it's just there to give it a feeling. I don't know what the word is.

**I:** Yeah yeah, almost just like a background atmosphere.

**F:** Yeah um.

**I:** And um, yeah. We… so when you used the website I guess you mentioned specifically, um, so you had a down day and then you looked at a section that related to that. But um was that typically how you used it? Or initially did you just in your spare time, maybe, have a look at the website?

**F:** Yeah initially it was just, I just browsed through and sort of looked at the different sections and I think because I'd done that then I knew that there was an area when I had that down day that I could go back to. Yeah, the first couple of times it was just a case of having a look in and seeing what was on there. I sometimes found it a little bit difficult to navigate through or to find. I wasn't quite sure what it would lead to um, you know, just when you click next you sort of think ‘oh what's coming next?’

**I:** Ah okay, yeah

**F:** Um I guess that would. And then it says it's about positive or negative feedback that I suppose that might be, yeah. I don’t want to be negative, but you know.

**I:** That's fair. I think um, yeah a couple of other people have said something similar about um, just knowing what to expect before starting something.

**F:** Yeah, and that section I said was really helpful about saying ‘how do you feel today?’ Um, I know when I went to find it, it took me a little while to remember where it was um.

**I:** Okay, yeah.

**F:** 'Cause I thought ‘oh is it in that set?’ I think it was a couple of clicks into a section so it... And because I couldn't remember which section it was in, I was sort of clicking between them saying, it's just maybe navigating around. Maybe it could maybe flow a little bit better, I don't know, but like I knew it was there somewhere so I… it was just finding it like I said.

**I:** Yeah yeah, just a little bit more intuitive I guess.

**F:** Yeah, maybe yeah.

**I:** Um and yes, since we're talking about that section as well, um, I remember there were three different bits, so anger, sadness and frustration. Did you look at all of the sections? Or did one um relate more at that specific time?

**F:** At that specific time it was the sadness, sadness one that I went into. And then it had this sort of strategies. I think it was the ‘stop’ strategy one.

**I:** Yeah.

**F:** I've done a bit of recently through work, I think with COVID and everything work have been… I've done quite a lot of mental health awareness, sort of training and mental health first aid, I think it was. So it's sort of it, it married up with that a little bit. Whereas I guess for some people it would be completely um, new concepts to them. But equally when you're in that place in that sort of sadness or anger you don't, well, I don't necessarily think ‘oh what? What do I need? What do I need to do? What was on that thing?’ I need to actually go and look at it and go through the steps, so that was why it was a really nice reference to be able to go back to 'cause.

**I:** So almost guidance at that point, helped.

**F:** Yeah, definitely yeah.

**I:** Okay. Um okay, so you tried from that section you tried the stop technique for yourself..

**F:** Yeah.

**I:** Um did it help in any way?

**F:** It did. I think a lot of the strategies in the advice when you read it, it makes perfect sense and you sort of think, well, yeah. I’m not saying it's obvious, but when you're in that moment it, you just can't think of it yourself. So now it, it did. The whole of them, just, you know, following the steps and sort of compartmentalizing things. And yeah, no, it did help. I mean I'm working from home as well so, being on my own quite a lot, so it… no, it did help. There wasn't somebody there to sort of talk through things so it was like the next best thing.

**I:** Yeah yeah. Uhm, OK, Uhm Did you also at other points, look at either the anger or the frustration section?

**F:** I did when I was doing like the initial look through. I can't necessarily tell you now what was in them (laughs). But I did look at them…

**I:** yeah, yeah. I'm happy to prompt whenever. Just to make it easier to remember, I think, UM, both of them had like mindfulness style activities, so one of them was like a three minute breathing space, um, and the other was a compassion break. But yeah, I mindfulness is… something some people like or don't like. So I thought I'd just ask you how you got on with them?

**F:** I’m sure I looked at it but I can't remember that…

**I:** That's OK, uh. Was it more the tips and things?

**F:** yeah, I think and I remember watching a video that somebody was speaking through something. Uhm, I actually found reading it myself uhm, easier to. I think that's just the way my mind, where it's at. If I read something it goes in a bit better. It always has, you know, revising for exams and things I've always written and read things. Just hearing it doesn't necessarily sink in to me, but I do remember doing that.

**I:** Yeah, yeah, that's fine. We had different options because of this very reason, so uhm… Yeah, I guess, there was, in the similar section there was anger, frustration, sadness, but there was also worry and stress and I just wondered whether these sections, did you find them relevant to you and what you're going through as well?

**F:** Yes, yeah no I did. I mean it's, you know, there are worrying times and it can get, it really can get sort of, well, they're quite linked, aren't they, worry and stress? But, yeah, I did look at them. I did look at those sections as well.

**I:** OK OK uhm, I'm trying to think the for the worry I did recommend quite a similar technique like STOP. [F: yes] Uhm yeah you mentioned about trying that. Did you find it was helpful for worry as well?

**F:** Uhm, I think it is because it just it makes you rationalize things a bit, maybe put things in perspective or help you to sort of place those…so is it worth worrying about or? Uhm, just trying to think it how to explain (laughs)

**I:** No that makes sense, um to like, just think about what you're worrying about and…

**F:** yeah, but equally not overthink it 'cause you can build things up to be, maybe far bigger than they need to be, or they're having a bigger impact. They're impacting sort of more or less all aspects of your what you're doing in your day to day life. Whereas it's actually… it's not, it's really not very healthy. So yeah, it's just so it's sort of reigning it in a little bit I suppose and putting it into perspective. So that’s how it helps.

**I:** Uhm yeah. And I wondered whether the, did the examples I added, a few situations and things like that, whether it made sense in the context of MND?

**F:** Do you mean the personal experience there's a sufferer and a carer?

**I:** yeah. And even when explaining the stop technique and things like that trying to give an example. I wanted to try and be MND specific rather than just any kind of worry I guess, so I was just wondering whether that related to people or whether you found it...

**F:** I tended to look at the people that are living… um 'cause there's some examples of people that have been who've been diagnosed and then there's examples from it was carer or family member. So it did tend to go for the family member option. But yeah it did. It did, sort of, it made it a bit more real or you could sort of, identify more with it. Although I think for me because I'm not a ‘carer’, and… I mean I see my mom and dad a lot, but they live sort of 10 minutes away, and I say see them several times a week. Um… but I didn't, I don't know if I was 'cause I'm not a carer, I'm not living with somebody in the same building, it's not.. it sort of felt a bit like maybe... Uhm I can't, I don't know how... like I wasn't quite in that situation, if you see what I mean? I'm sorry… maybe another step removed. But I mean having those personal stories and explanations really does sort of bring it home and make it so much more personal. I guess like you say, it is personal to MND and not just a blanket sort of example of any, any sort of situation.

**I:** Yeah, yeah it was like you're explaining in the beginning as well, it's different kinds of worries for you and your dad and that sort of thing...

**F:** Yeah, exactly, and I guess anybody that's ever had the diagnosis, everyone’s at a different stage or going through different, having different experiences so none of us are the same are we? you know, whatever we're going through...

**I:** OK, uhm. Well sorry, I'm just asking questions as they come. So were there any other activities that you tried or found useful?

**F:** I'm trying to think… I should have gone back to the website a lot more in the last couple of days

**I:** Should I kind of list them?

**F:** yeah that would be easier...

**I:** Uhm, so there was a pleasant activity, there was a section on building positivity and it had pleasant activities, finding positives, and values and goals.

**F:** Yeah I remember the finding positives in things. I know my mom can be quiet, even if you know for the last few years I've always thought that she can be quite negative about things. And you know, if they've been out for a meal she'll cling onto the negative aspects. So going through that I thought I can relate to it and I think she really hopefully would as well. But you know, you try and pick out the positives 'cause otherwise you’re sort of dragging yourself down, but yeah, finding the positives in in a bad situation. Yeah, I do remember looking at that and thinking it, it's a really important sort of skill to try and do.

**I:** Yeah, yeah, uhm as you said it's not always easy in a difficult situation, but it's about just trying to do both I guess…

**F:** Yes, and I think some people naturally can be very positive and others will just always, uh, focus on the negative even… As you say some, you know some of these situations they are really sad, negative situations, but if you can, if you can learn to focus on a glimmer of positivity, it's going to make a difference day today I think.

**I:** Did you find that exercise easy or difficult to do?

**F:** 'cause it was, there were lots of stages or examples I think, and some of them I thought ‘I can, I can see how I could do that,’ uhm.. I can't think of the specific now… There were other ones that I thought that would that would be harder to try to bring out a positive from. It's not a very, very (laughs) not a very clear answer I know, 'cause I can't think of the specifics, but I think there was a mix of ‘yes I could do that’ and other others that, yeah that would be harder.

**I:** And yeah, I think there were a different kinds of statements like uhm.. ‘From this situation I could learn this…’ or uh ‘this is the one thing I'm grateful for…’ or something like that. Yeah, yeah, but I see what you mean that it, uhm… it doesn't necessarily mean that you have to find something for all of the sentences, but maybe I need to explain that a bit more clearly. Yeah. Uhm, did you try the other ones about values and goals and trying to do more pleasant activities?

**F:** Uhm, I remember reading through it, uhm, I don't know if I actually, uh, did the activity, I guess.

**I:** I guess, you kind of spoke about it early on when it was like going for holidays and things like that, which is a similar sort of thing I guess. Yeah, about doing what you can while you can.

**F:** Yes, yeah. I think it is a sort of a… I think it's a really important thing to do, but it's hard to. I find it hard to have that type of conversation with my mum 'cause it… We are close, but we've never really spoken much about, really our inner feelings I suppose. She can't speak now, she has to write everything down, so you're trying to get her to do what she can while she can it's quite… It's almost highlighting that you know, we know things are gonna get worse and it's hard to sort of navigate around that conversation without actually causing upset rather than creating something positive [in its place?].

**I:** OK, I see. So you, you might find it easy to look at that and get it, but probably to have that conversation with her would be tricky.

**F:** Yeah I mean, I think it depends on what kind of day she's having, you know things like that, which is true for all of us. I think we all have days where we don't want to face up to things and days where we’re in a better place to handle it.

**I:** Yeah yeah no uhm, that is incredibly difficult about thinking about the future and things like that without getting too upset, I guess. Yeah, uhm… those were those three activities in the building, positivity section and then there were other ones, like the thought distancing then there were a bunch of mindfulness ones like the three minute breathing space and… So those were the audio clips basically that had the person talking and you said you preferred the writing bit…

**F:** I'm not sure if it was the um… I found it, I found the voice was so slow, but rather than creating a sort of nice calm mindfulness, I was probably getting… not annoyed, that's the wrong word, but I just felt it… Maybe the voice wasn't, it just didn't sit with me, so I thought it would be better to read it. It's having the… not having the right effect on me.

**I:** That's fine. Did, I wonder, did after you read it did it sort of make sense or change anything in terms of perspective?

**F:** No, it did make sense. I think I've already started with a lot of these things it… you learn about these things or you read about them and it, it makes perfect sense. And it seems almost obvious but you almost need somebody to put it in front of you and, and not spell it out, but just to sort of remind you that this you know, that it's quite simple things that are very easy to do, but it can make so much difference to how you feel

**I:** Yeah, no that makes sense. Uhm, yeah, and there were other ones about self kindness. I don't know if you had the chance to look at them, because they were kind of tucked away in the ‘all activities’ section. It was, uhm, compassion break, self kindness letter things like that. But yeah, uh, they were quite similar to the mindfulness style activities.

**F:** I'm sure I remember reading about the compassion break and just sort of giving yourself time to yeah, yes...

**I:** Yeah, so that that was a similar thing as you said it makes sense at the time, but you need a reminder…

**F:** Yeah, yeah, I mean, that's just how my mind works, I think. I’ve done a few mental health awareness things through work and when somebody there says, if you find yourself in this sort of situation, this is a really good way of coping and dealing with that, and you think, ‘well, yeah, it makes absolute sense,’ but when I'm in that actual situation, I can't break myself away to think, ‘Oh, what should I do? What could I do to help with this?’ So yeah, that's where having a references for me is really helpful.

**I:** OK, uhm just because I'm curious as well, have you used similar kinds of activities? You mentioned at work some of these programs as well. But I guess were they similar and the kinds of techniques? And have you done this kind of thing before basically?

**F:** Uh, no, no. I haven't, uhm. The thing at work recently we did it was mental health first aid, I think it is. It's sort of a government initiative, maybe didn't, and so they had some… they introduced some concepts and strategies of noticing when you're maybe starting to feel a bit down or whatever, and they sort of provided some techniques. And it's only because that was sort of in the last month I think that I did that, so it's sort of at the front of my mind. But apart from that I've never sort of looked into it in great depth till now.

**I:** OK, just for me to kind of judge whether some of the information or techniques were new or, um, whether you tried them before, 'cause different people have.

**F:** No, I haven't really. (laughs)

**I:** Uhm, and I guess linked to that there was a section in the website called ‘other support’ which if say you needed help with anything else and you know, it wasn't there on the website you could go to all these other different places, did you have a look at that?

**F:** I looked I clicked through to it but I don't think I actually followed any of the other links, but knowing it was there I thought was really good to have a section where you know, it's collated a list of other places that you might want to look at if you need anything extra, I think that was good.

**I:** No, that that's fine. It was only if you sort of needed it. You didn't have to kind follow through. Yeah, I think we've sort of covered all the different sections. Uhm… yeah, I wondered if maybe from a family member’s perspective, do you think there was any topic that we haven't covered that say you would have liked or say something you were looking for and couldn't find?

**F:** Uhm, I don't think so. I think it's… as I said, as a sort of family member rather than a carer or someone who's been diagnosed, I did... the website did feel more directed towards either someone that has been diagnosed or someone that's physically living with a person with the diagnosis. Uhm… Just because of some, I guess with the examples, like personal examples, I don't think there were any of these that were from somebody sort of a family member, but not living with somebody, if that makes sense. And obviously the information is all still relevant. I just wondered whether… or maybe I don’t I fall into the remit of who the websites for? But equally, the information for me was helpful, so I don't know.

**I:** No that that makes sense. Yeah, you found it useful, but it could give examples of how it could relate to you specifically, which might make you think ‘OK, this is for me as well.’ Yeah that makes perfect sense, I can add more examples. I have interviewed a couple of people who were not specifically carers so yeah, that's definitely something we can add.

**F:** It just might sort of make it open, open it up a bit to sort of feel more relevant. I don't know if that's the right term, but as I say, the information that is there is really helpful. Just maybe, I didn't feel like as a family member that it was directed to me, but then it's supposed to be for everyone I suppose…

**I:** yeah, but did you feel that, say anger, sadness, all of that was also like relevant to you or was there something else, maybe, 'cause you did mention, say, talking to your mom about stuff maybe?

**F:** Maybe a section on how to, how to not worry about talking to people or not wanting to upset people and discussing things, but… I was going to say something else, then I forgot…

**I:** Yeah about being comfortable to talk about decisions and the future and that kind of thing...

**F:** Yeah, I mean all the feelings and things that are on the website are definitely you know, it's definitely relevant to a family member. 'cause mum goes to appointments and I know Dad goes with her and I know that the MND association offer support and stuff but as a family member you don't, no one reaches out to you so you have to go and if you want any extra support or information, you have to go and find it sort of thing. And then Mum's got a contact like a nurse that if there's any questions or anything she can contact her. But then as a family member you don't have that connection necessarily. I'm sure if I contacted this nurse she’d be more than happy to help, but I sort of think well, I've got lots of questions, but it's sort of who could you go to?

**I:** Yeah, yeah, so yeah in that sense the website kind of had an area or space where you could go to and look up stuff.

**F:** Yeah, definitely.

**I:** I see what you mean. Uhm, one more quick, quick question uhm I don't know whether… right now did you feel the timing was also right in terms of when a website like this is offered to people because I know you said it was quite stressful initially during diagnosis and things like that. So would that probably be too early or not the right time?

**F:** Uhm. I don't, I think with the diagnosis that it was… there was an element of shock and it took a long, it took quite a while for that to sink in. But those first few weeks, especially with me, we were in lockdown at the time and so there was an awful lot of other life stresses and home schooling and things. I guess then it would have been helpful to have some of those exercises in and strategies to sort of deal with feelings. I mean there was definite, high levels of anxiety and worry at that point. But then I guess a lot of that was about what's gonna happen and what's the prognosis and things like that. But yeah, I mean I don't see why that would be too early to have the website introduced to you and so you know that it's somewhere you could go to help with those initial feelings. And… 'cause I think feeling sort of come and go, don't they? And it's a sort of rollercoaster of anger and worry and anxiety and things. So yeah, I didn't think it would be too soon to be on, you know, be showing the website. And it could help prevent things escalating further down the line, I don't know.

**I:** Yeah, I know it's.. as you were saying because it comes and goes it's a tricky thing really, to predict when you'd need it, but I just thought I'd ask because everyone’s situation is so different.

**F:** Yeah, I guess when you've just had a diagnosis your mental health maybe isn't at the forefront. You are too busy worrying about the testing, what's happening right now, the physical side of it. But you should be thinking about your well being as well. So yeah, it's difficult.

**I:** Yeah, I think that's most of my questions. (looks at notes) Yeah, I’ve asked you everything…

**F:** I hope I've managed to actually answer them and be helpful. (laughs)

**I:** Was there anything else you wanted to either talk about any other issues or anything we haven’t covered?

**F:** No, I think. Is the hope that the website will be introduced to people like what's, how, how will people be told about out about it?

**I:** Yeah, so part of that I am trying to work through with talking to people because um, I know maybe how to improve it. But then at what point it will be introduced to people and yeah, when and how. I think everyone receives support quite differently in different parts of the country. So we’re trying to work some of those things out, but it's useful to at least gauge when the need is there.

**F:** Yeah, yeah.

**I:** I can stop the recording and still be on the call, just so I don’t have to transcribe all this