**Interview 22**

**(person with MND)**

**I:** It should come up with a message saying it has started recording then I know for sure. Yeah, I can see it now. OK. So yes, you were telling me you first opened the website as part of the study, and then yeah, what were your first thoughts about it?

**P:** Well, I have looked at it again today so I’d know what I was talking about and I don't really think it is for me. Because, what shall I say, I aim to keep myself positive. I don't expect to require help from somebody else. I looked at all the things you put on the website and how to keep cheerful and how not to be sad and how to be positive and well, I do all that myself.

**I:** OK, that's fair enough.

**P:** I don't reckon to be... I am frustrated 'cause it's a very annoying disease, but so, you know, it could be worse. I could be in worse condition. I can just about afford to have full time care for the things I can't do. And I've got a lot of good friends on the fantastic family.

**I:** OK.

**P:** What more do I need?

**I:** That sounds perfect, so it was more that you didn't see the need for that kind of support and you were managing fine?

**P:** You won’t like this. I think mindfulness is a load of old rubbish. Sorry.

**I:** No, that's OK. That's sort of why I sort of put different kinds of things on the website 'cause I know some people would either take to it or not, so that's OK.

**P:** I think it is better for people to look after themselves. And I…perhaps I'm lucky because I've always been a glass half full, but I've always been positive, so then I'm lucky. But I do think people are too inclined to give up too easily. I’m really not your ideal subject, sorry. (smiles)

**I:** No, there isn't really an ideal subject for this. So, I guess, I understand where you're coming from for the mindfulness and there were a lot of mindfulness style exercises for anger and frustration, and all of those bits. I wondered what you thought of the building positivity, section and focusing on the positives and I think that was one bit on values and goals and trying to do things in line with what's important to you...

**P:** I think, well, probably if one is always been positive and looked at the good side rather than the bad side then. But if you're the other sort of person, then it will be a really helpful website. You know, the people who say ‘oh, poor me. Why did this happen to me?’ Well, why not? Why shouldn't it? You know, who makes… sorry. I just think that there are a lot of people for whom your website will be excellent.

**I:** OK, so it's more for say people who were struggling with staying positive and that kind of thing, something like this would be helpful?

**P:** But I would suggest that they perhaps weren't very positive in the first place.

**I:** Yeah, if they had difficulty with it, that's why. OK, I see..

**P:** And particularly people who suffer from depression. I have a very good friend who is, gets very depressed and I do appreciate the way she comes up things. But I can't help her because I'm too positive.

**I:** OK, OK, I see what you mean. Yeah, I wondered if you felt that maybe there was any other kind of thing you were struggling with emotionally that was either not covered on the website or something you would have liked to see?

**P:** I'm really sorry, no. I'm sorry, I’m not very helpful, I told you I wouldn’t be. (laughs)

**I:** (laughs) That's alright.

**P:** I just think people should generally, I think people should take charge of their own emotions and view of life and... There are some people, of course lots of people who would like help with that. For me, I feel it's down to me, to sort myself out.

**I:** OK. Uhm.. Linked to that as well, have you kind of accessed any other support psychologically or have you felt you didn't really need it?

**P:** No, absolutely not.

**I:** That’s okay, it's just for me to understand the context, really. There's one more question I wanted to ask you, you said it might be, potentially might be helpful further down the line or things like that. Did you mean once symptoms get worse or things like that, you’d see something like this is helpful?

**P:** I can't think that I'm going to change that much. So when the symptoms get worse, I'll deal with it or not, you know. I don't think I would be going onto your website for help. That's a really bad thing for you, I’m sorry.

**I:** No, no, that's alright. So how long have you had MND for?

**P:** I was diagnosed the week before we went into the first lockdown, so just over a year. And I'm lucky in that it affects my hands and arms so I can't lift my hands. I can't actually lift them up, so I can't… well, I can if I do that (gestures). So I can't easily feed myself, I can't do the cooking, can't pull my trousers up after I've been to the loo. That’s all at the moment.

**I:** OK, and typically, how do you normally cope with all of this? Is it with carer help?

**P:** I have living in care. Because I believe eventually, I shall need ventilation. And because I can't get my hands to my face if I had a mask on, I wouldn't be able to take it off. I was told that I would eventually need to have somebody here because they put the mask on overnight I believe, and so I'd need someone here at night in case I panicked. So I thought well, I'll get the care in place whilst I'm still able to talk to people and so forth and (indistinguishable), I’m a bossy woman you see. I like to be in charge.

**I:** So I guess in a sense also sorting out care and things like that is also a way of just coping with the disease and making sure everything…

**P:** Absolutely, I felt it was better to get organized now, while I still could. So that when I'm unable to cope then whoever is caring for me will know how I like things to be.

**I:** OK.That all sounds very sensible.

**P:** Yeah, I'm lucky that I'm not.. touch wood, too bad just yet.

**I:** OK. And do you have a lot of support as well and terms of Motor Neuron Disease Associations and other people like that?

**P:** Well, I'm afraid that again comes under the same category as your website. At the moment, I mean people are very good about ringing up and saying ‘am I alright’ and ‘do I want to go to a zoom meeting’ and so forth. And the answer is not at the moment, thank you.

**I:** OK, OK that's fair enough.

**P:** I may well need all of this support in the future.

**I:** Yeah, but it's also a matter of preference, really. There's no, there's no right or wrong way of coping with things is there..

**P:** I don't… I haven't done a lot with the association. Way back my late husband had Parkinson's and when he was first diagnosed, he went to a meeting and it was so… people were in such parlous you know, they were really much, much worse than him. It was actually depressing. So, remembering that, I'm thinking perhaps I won't go to MND meetings just yet.

**I:** Yeah, that's really interesting. I wondered even this morning I guess, when you looked at the website did you, did you feel that any parts of it reminded you of say, depressing things like that, that you read and might have felt that this was upsetting or something like that?

**P:** When I looked at the website, I thought I really don't want this at the moment. I can manage on my own at the moment if you like, for all the things that you've covered in your website. It may well be in 12 months time, you interview me again and I say ‘oh, your website is fantastic. It's been such a help.’ But just at the moment I feel, I think probably it will be fair to say I'm in denial, head in the sand or whatever. Because I can't believe I'm going to get to a stage where I would need your website or a lot more support. I mean physically I may well, but who knows what the future is.

**I:** No, that’s perfectly fine. I just wanted to check more in terms of, you know, as you said, when you see someone at another stage it might upset you. So I was just checking whether examples on my website didn't really upset you in that sense…

**P:** I didn't read all the true life comments because I thought, ‘well, OK, let's deal with it’, because it's so… people are affected so differently. I didn't think I wanted to read other people’s experiences 'cause I might not like them. I mean keeping positive is one thing, but keeping positive when you hear terrible stories is more difficult.

**I:** Yeah, yeah, that is completely fair. I'm glad I understand your perspective, I feel like I can see that that's your style of coping and how…

**P:** I’m not very helpful to you.

**I:** No, it’s just not a very good match and that's fine.

**P:** Well, you know people… there are worse things, aren’t there. There are people in more difficulty than I am.

**I:** Yeah, and that's a perfectly fine way to see things and if it keeps you positive then that's a good thing.

**P:** You see when I finish talking to you, I can call my carer. She'll make me a cup of coffee, I'll go to the loo, she can pull my trousers up for me. It's a lovely sunny day. I can sit outside. All good. But I'm really sorry it's not much help to you. I'll be happy to talk to you again if you wish.

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