**Interview 9**

**(person with MND)**

**P:** To be quite honest because of my condition at the moment, although I’m slowly losing the ability in my leg, I’m sort of pretty positive about it all. So I think it's fine. I can see the point of you starting this online. But an awful lot of it, didn’t really refer to how I feel if you know what I mean? I’m sort of still relatively happy and positive. I can imagine once things get worse, I might find it of more interest really. You understand what I mean?

**I:** Yeah, yeah, I completely get it. I think I remember you telling me something similar even when I came round to interview you. Yeah, I know that that completely makes sense. And I tried to in the website itself, just add things that were a little more practical I guess so you know, there are some people who it may not be affecting you emotionally yet. But there's still bits like, I don't know if you had a look at the doing pleasant activities or stuff like that to just keep your mood you know, happy and positive?

**P:** Yeah. Yeah, right I understand that. That’s absolutely what I do, because you know, I like doing me gardening and do other things. So as long as I can do that then I'm OK, but I realize a time will come when I can’t, so I’ll have to cross that bridge when I get there.

**I:** Yeah, yeah. Can I just ask, when did you typically have a look at the website? Was it like regularly on a weekend or whenever you thought about it really?

**P:** I can’t remember. It was quite a long time ago I looked at it. I can’t remember really. I only looked at it properly once to be honest, I went through it all and I could see, I felt I could see the point of it. And I did feel better, but at the moment I didn’t feel it applied if you see what I mean?

**I:** Yeah, yeah. Can I just ask which, if you can remember which sections or which topics you looked at, I can name them if that's easier.

**P:** Yeah go on, name them.

**I:** There was a there was a section on building positivity so it had pleasant activities and finding positives and values and goals, those three activities? Did you look at any of those?

**P:** Yeah, I did look at them. When I went through it, I looked at you know, what you were supposed to follow. I guess is the only way I can put it if you see what I mean? I went through the whole thing as well.

**I:** OK, OK

**P:** Although it didn’t take me all that long because as I said a lot of it was… I mean I can see the point of it, but I was quite pleased it didn’t really apply to me (laughs), if you see what I mean?

**I:** Yeah, yeah. Uhm.. Just to kind of unpick that a little bit, it's because it's not affected you, MND hasn't affected you too much at the moment. Is that why?

**P:** Yeah, yeah, yeah. Obviously it’s affected me, but at the moment I can cope because as I say, I'm losing my ability to walk but I can still hobble about as I put it. You know, I feel as though I can cope with it and get on with life. I don’t see the point in getting all upset and burying myself before I need to, is the only way I can put it.

**I:** Yeah, and do you recently as well like have you got upset or anything has been frustrating, those sorts of emotions as well?

**P:** I suppose so, I guess sometimes I feel…how to put it. You know, some days or moments in the day, if you can’t do something you want to do and you therefore feel sort of breathing? On to you. But generally speaking I can get on with what I want to do without getting down-hearted about it.

**I:** Yeah, yeah. Just because I'm curious as well, in those moments when you do get a bit down and.. how do you, what are the things you do to kind of get yourself back on track?

**P:** Thant’s an interesting question. How do I get myself back on track…I guess well, because I just try and think positive. And also think that, well, you know, there are many kinds of people that are in a far worse state than I am. As long as I can, you know, do what it is I'm trying to do in the long term, which is, you know, live my life and do the things that I want to do. Albeit I can't do them as well as I used to, but still I can do it, you see what I mean? There are people for instance who can’t walk or losing their arms or speech or whatever. You know, there's plenty of people far worse than I am.

**I:** Yeah, yeah. So at the moment you can kind of adapt what you're doing.

**P:** Yeah, and you know, sometimes it still hurts, I think in terms of time. But I just manage to cope. I mean an awful lot compared to say 3 or 4 years ago, my life has changed totally I would say. Because you know, I used to be very fit and active, do a lot of running, the gym and that sort of stuff. But I’ve just been able to come to terms with what is slowly happening to me.

**I:** Yeah, yeah, OK. So things like staying positive or doing things that you would normally do but slightly differently. Those are the kinds of things…

**P:** Yeah yeah. To quote the film you’ve got to look on the bright side of life.

**I:** Yeah, yes, OK, that's good. So some of the things that were mentioned in the website were along the similar lines I think about finding positives, and doing activities and things like that. But I guess did you find that relevant or for you or was it, you were already…

**P:** Yeah I did. And also there were pictures weren’t there? I liked that, I could see the point of it all, certainly yeah

**I:** Yeah, OK, so it was useful but at the moment you're not struggling with anything…

**P:** No, no, I'm not really not now. I'm struggling (laughs), but I'm not overwhelmed by anything is a fair way of putting it I think. I’m obviously struggling, I struggle to get around and all that, but I’m keeping on top of it.

**I:** OK OK uhm so do you think something like this would be useful at maybe a later stage or something like that, or for people who have probably got worse symptoms?

**P:** Oh yeah, you mean the stuff on the tele, I mean on the website? Yeah, I could see the point of it when I was going through it.

**I:** OK, were there any things or sections you felt that might be more useful to people than others?

**P:** I think the ones we were talking about really, the one you know, being positive, those sort of stuff

**I:** Ok, just to ask you, I wonder, did you try any of the kind of activities that were there, like there was some meditation recordings and another one called thought distancing?

**P:** What distancing?

**I:** Thought distancing to deal with negative thoughts. Did you try any of those?

**P:** Ah right. I didn’t actually do any of them. When I went through it, I could see the point of it. And I felt that, you know, in a sense, unfortunately, sometime in the future I was gonna find it useful, that’s the only way I can put it.

**I:** OK, no, that's that makes sense. I'm just going through the different sections just in case we miss anything out, but I think I get the general point that it's you went through it but didn't really feel the need to try out any of the techniques…

**P:** No, I didn’t see the point. Because still, at this moment in time, it didn’t apply to me you see. I could see the point of it all, I could see that I might be coming back to it, unfortunately, in the future, is the only way I can put it.

**I:** OK, OK. Uhm, I wonder, did you have a look at it by yourself?

**P:** Yeah.

**I:** Uhm, just out of curiosity, do you think it would be also relevant to say your wife or other family members?

**P:** Yeah or the wife anyway. You know, when things get worse, I can see the point of that. [name of wife] would want to be involved in any way because she’s that sort of person.

**I:** OK, OK. Yeah, I was just trying to work out if you know people preferred looking at it by themselves or with other people?

**P:** Uhm… I think. Yeah, I think when it becomes relevant? I think I would wanna look at it with my wife. And she would want to be involved as well.

**I:** OK. OK. Uhm, yeah, I guess one more thing. Was there anything you were expecting to find on such a website that say we didn't cover or, we didn't really talk about?

**P:** No. I didn’t really know what to expect or not. You see what I’m trying to say?

**I:** Yeah, that's OK.

**P:** I mean to me, there wasn’t anything missing, but on the other hand I'm no expert…

**I:** No, that's OK. It's more like if say, you had a particular problem and you went on the website and saw it didn't really talk about this at all or…

**P:** Ah I see. No, no, I didn't think that about any of it, but then it's because party because, you know, I haven’t got a particular sort of problem, you see what I mean? So can’t help you there I’m afraid

**I:** That's OK. That's good if we've covered everything. Just another quick question, in terms of support and things like that, I wondered if you had a look, there was a section called ‘other support.’ Which basically pointed people to other places they could get support just in case the information was not there on the website. So things like going to see a psychologist or going to an MND support group or something like that. I wondered if you had tried any of these kinds of things for support?

**P:** No, I haven't no. Because at the moment, I don’t think I need it frankly. I do you know the MND association so I go to those meetings every week, every month, or on zoom or whatever it now. But uh, I am aware anyway of the psychiatrist and all the rest in the background there. And I certainly wouldn’t be, not want to go see him if you see what I mean? I feel as if I have enough damn sense to you, ring up the MND association and see the psychologist that they’ve got.

**I:** Ok, so you know where to go if you needed support…

**P:** Yeah I think so. You know, I got a lady, but I haven’t seen her for a while now because of this damn Covid business, she’s a physio. And then there's another one, that funnily enough I was in contact now, who’s a speech therapist because I decided to do this voice banking, you know.

**I:** Oh OK.

**P:** You know voice banking? Not that my voice is going, but when I first diagnosed in 2018, voice banking was rather onerous in that you know it took hours and hours to use physically. So talking into a microphone to get it up and running. But now it comes down a lot quicker, they got better technology I suppose. I’m just in the process of, I’ve got to record I think about 300 phrases they give you. And then they somehow produce a voice on a machine which sounds like you. (laughs)

**I:** That sounds like fun.

**P:** Yeah, yeah. And to get it going and all that, alright so I got to see, talk to a speech therapist who said how it worked and gave me a key? To go on a computer to the company’s website. So yeah, I think I'm aware of what there is around to support me. And in touch with the local authorities as well about the various things that they can do when needed.

**I:** Yeah, yeah, OK, that's good. So you know where to go. OK. I just ask that because there was some information about that on the website, but as long as it's clear to people, that's fine.

**P:** Yeah, yeah.

**I:** I guess one more thing, did you, if you can sort of think back to when you were first diagnosed, I wonder if you had any… struggled with coming to terms with it or anything like that at that point, and a website like this might have been helpful, or was it not the right time really?

**P:** Yeah, well, let me think… When I was diagnosed, the lady told me that I had MND and there would be the prognosis 6 months to 3 years. And to be frank, I don’t remember a lot else about the conversation we had. (laughs) And for the next couple of nights, I didn't sleep at all, or not very much so. I actually got some tablets from the doctor to make me go to sleep. By about night 3, I was okay, never took any of the tablets. But I would have certainly had a look at it, yeah. Whether it would have been any help or not, I don’t know.

**I:** Yeah yeah I understand. It’s sort of hypothetical…

**P:** Yeah, if I knew it existed I would certainly have had a look at it.

**I:** OK. Would it have been too much information at that point? Would a website like this be too much information at that point?

**P:** (Sighs) I don't know really. Because there’s an awful lot sort of going through my mind. I certainly wanted to find out what MND was all about, obviously the first thing you do when you go home. Told my wife and look up on the Internet and find out what it is. There’s all sorts of stuff on there as you can imagine. But I think it might be useful because it'll be something which might counteract all the nasty, horrible things that you’re learning about on the internet. That's the problem with the Internet, you know, if you want to know what MND is, if somebody’s just told you you’ve got it, in many ways, it's the wrong way to go out about, I think looking back. I should have not gone on the Internet. Perhaps your website would have been the perfect thing to calm me down a bit.

**I:** Yeah, I didn't think of it that way…uhm, more like a positive place to get information.

**P:** Well, I might have been yeah. Of course, one of the big problems certainly at the beginning about MND, although you look up all this information the bottom line is that very little known about it. People just tell you, you know it’s a muscle wasting disease, and in the course of time your muscle’s wasting. There’s no cure as far as everybody knows. So you can't even say ‘Oh your leg’s a bit dodgy at the moment, will my arms really…what muscles will I lose next. It’s a bit of a countdown? really, 'cause they don't know. That’s one of the great problems because you can’t come to terms with it when you don't, you just don't know what's gonna happen.

**I:** OK, I see what you mean, so there's only so much you can really do at that point, because you're not sure what will happen.

**P:** Yeah and nobody can tell you what the progression of the disease is gonna be. They can’t tell you what muscles will be affected. So it’s difficult to get your head around that, first of all.

**I:** OK, that’s really interesting actually. Thinking about how something like this is relevant in the beginning, it might have to be worded slightly differently to help people come to terms with not knowing.

**P:** Yeah, the problem is not knowing, I think. That’s what was going through my mind in the hospital. Firstly, should I tell my wife or not tell her. And as I was approaching home, I thought I’d tell her, I know I’d have to tell her, but you know that’s how it is. Then I thought, perhaps what I should do is go into the funeral director and get my burial sorted out, you see what I mean? In your mind it sort of, bottom line is they don’t really know what’s going to happen, it seems that nobody can tell me. Perhaps I’ve only got 6 months to go, and as I’m driving my car I’m thinking.. then I thought ‘C’mon [own name] get your brain in gear. You can’t be going to a funeral director’ (laughs). Anyway, that’s just in passing as I was driving home what I was thinking about.

**I:** Yeah but other people have said something similar as well, you think of the worst at that point, and maybe you need something that's going to put it in a bit more perspective I guess…

**P:** Yeah, yeah. That’s right.

**I:** OK. That's really useful to understand how it might be relevant earlier versus later…

**P:** Yeah. I went to the doctor, I can’t remember, it was a few days after, I talked to the doctor, this is the GP I’m talking about now. And I said ‘Look doc..’ in the conversation I said, ‘the bottom line doctor is I’m dying.’ And he said ‘But we’re all dying’ (laughs). And I thought ‘he’s actually right’ I don’t know what I’m getting so uptight about dying because you know, everybody's dying and you could walk out the door in front of me and get hit by a bus.

**I:** Yeah. OK, so he helped with putting a bit of perspective.

**P:** He did really, whether it was a right way to put it or not (laughs).

**I:** I've asked my questions about the website just before I stopped the recording, I was just wondering if you wanted to say anything about the website specifically?

**P:** No, I don't think so, I think we covered it.

**I:** OK, I'll just stop the recording, but I will still be on the call.