**Interview 16**

**(person with MND)**

**P:** I made notes, because that’s my style but anyway you carry on…

**I:** OK, so firstly I saw you went through quite a lot of the different sections and all of that, so don't worry we'll go through each section one by one.

**P:** I was very impressed I must say

**I:** How did you generally get on with it, just how did you find using it?

**P:** Oh quite easy. (laughs) if I found it easy then it was. I found it good.

**I:** That's good, yeah. Were there any bits that weren't working properly or that you had trouble with?

**P:** No, no. I didn't have any trouble. I’m just looking at what I’ve written. No, it was very interesting. Of course, it was a long time, 2005, when I was diagnosed. Quite a while, a long time ago, when all that happened, when this would have been most relevant to me, I suppose. But it was interesting.

**I:** So you’re saying you think if it was available earlier on, it might have been more helpful? Is that right?

**P:** Well, personally, I am the sort of person when something happens, because like most people in life, have come up with obstacles before which were more serious then because I was younger. When I was diagnosed with MND, I was already 90, I’m sorry 76. I’d had a fair innings anyway, but… So I had already learnt strategies which were possibly… well they worked at that time, which is when anything happens I just looked for a way out, have something to focus on and get on with it. I never dwell in the moment on anything bad. I just think, well, what can I do to escape it all.

**I:** That's really… do you still use strategies like that even now?

**P:** Yeah. I mean when I was diagnosed with motor neurone, I immediately thought ‘well I can't stay where I am.’ I was in a form of depression, but I didn't realize it at the time, I realized it afterwards. I had to move house 'cause I couldn't stay where I was living 'cause it was a Victorian terraced [house], with three floors and stairs to get into the house and stairs to get out of the house. So I had to solve all that. I spent the first year hunting for somewhere to move to, so that occupied my mind.

**I:** Yeah, said there was a lot going on at the time as well with…

**P:** An awful lot of support from the local hospital team there, so I was very lucky. You know, wheelchair and all these things appeared very soon.

**I:** That's good. Uhm…And I guess when you were using the website as well, did you feel that it was kind of telling you things that you already know or already do, or was it kind of showing you some new things as well?

**P:** I don't think it showed me anything new. I have a daughter who's very keen on mindfulness, although I must say that… what did I say about them? I have to look at my notes (ruffles through paper) But personally, the idea of lying down thinking but my body does not appeal to me. I have so many minor problems like I don't want to focus on. That wouldn't work for me personally, but I'm sure it would for other people.

**I:** Yeah, yeah, can I ask you a little bit more about that, because I think there were quite a lot of mindfulness activities in the website. There was one about the body scan as well about…

**P:** I didn’t like that one

**I:** You didn’t like that one?

**P:** No, but I’m sure for some people it would be good.

**I:** OK, can I just ask you just a little bit to explain which bits about it you didn't like? Or is it just the general activity of doing that?

**P:** With the body scan, I can’t find my notes, but if I remember correctly, we were talking about thinking about all the different parts of your body in turn. I don't want to do that 'cause they’ve all got problems, so I don’t want to do that.

**I:** OK, there was some other ones which kind of asked you to kind of take a few deep breaths so that kind of thing, how do you feel about those sorts of…

**P:** That’s good, but I can’t take deep breaths at the moment. But if I could that would be good. My breathing is relatively shallow, but that would be good. What I do when I get in bed at night, 'cause I keep myself busy all day, very organised and I have a planned day, so I don’t get time to think. But when I get into bed at night and lie down, that's when I probably… well, if I've got things on my mind that's when I think about them. And then of course, the deep breaths would be good. But like you said, I don't know if it was in the mindfulness, but I think of something good, something different.

**I:** Yeah, I think there was one which said sort of think about a place that you like and imagine yourself..

**P:** I’ve always done that

**I:** OK, so that one was better?

**P:** Yes, that's something I do and probably have always done. I had a bad part of time in my life between 10 and 12 years old, but apart from that yes, I always have done that.

**I:** That's good. Yeah, so those were the sorts of mindfulness ones that you didn't really like the breathing or the body ones, but..

**P:** I didn’t mind reading them but I didn’t do it. I did try to relax and think about nice place. If I really can't escape, which is very rare, I play bridge, which I can do on my phone. If I can't go to sleep, which is rare but it happens, I play bridge for an hour and then I go to sleep. Like you said, it takes my mind and concentrates my mind on something else so you are not trapped in there.

**I:** Yeah. Something to just distract yourself. OK, uhm. I'll just kind of go through each section, don't worry about your notes, I can explain the section to you…

**P:** I don’t know why I took notes I can’t read now…

**I:** That's alright I'll explain what was in there so it's easier to kind of remember. There was one section on positivity and trying to build more of it, so it kind of said to do more activities that you find enjoyable and try to work it out based on what's important to you and yeah… How did you find that section?

**P:** That’s right, it was very good. That’s what I do, 'cause what's important to me of course is my family, my great grandchildren, my grandchildren. My great grandchildren first, then my grandchildren and children because my great grandchildren have all my life ahead of him. And so I can see them, developing and whatever.

**I:** OK, so you use it in that way, but that's what you normally do as well..

**P:** Yes, yeah. That’s my main enjoyment and I'm very fortunate, I can show you if you like. I sit in my chair facing my patio door and facing my garden which is very small, but I have a bird feeder. And they’re a great joy to me. I’ll just show you so you can see… (turns camera) And you say oh,

**I:** Oh nice, lovely big doors!

**P:** So that's my view. And I’m very fortunate to have that. So during lockdown, people could come and sit on the patio and talk to me, through the patio door. I wasn't shut off in a room, so I’m very lucky.

**I:** Oh, that's good. I'm also aware that you know, when I shared the website with you and things like that it was during lockdown time or we had some restrictions. So I just wondered if any of the activities or things were difficult to do because of lockdown?

**P:** Well, as I said I had a member of the family that was able to visit every week. I think my daughter came every week throughout lockdown and sat and talked to me at the back. And then my son is nearby I saw him, I don't see… although he lives nearer, I don't see him as much, but he would if I wanted him to. And my grandchildren came as well, and my great grandchildren came into my garden so I could wave and see them. I wasn't tempted, all of us with motor neurone who are in my position are practiced in lockdown anyway. No, I do a lot of ancestry research which I could go on with. And I even met, new members, relations through my research during lockdown. So that all keeps me going. And I'm researching ancestry for my one of my granddaughters-in-law and my daughter-in-law, you know, it's very time consuming.

**I:** And you can do it from anywhere, so it doesn't really…

**P:** From my chair, yes. And I got out of my scooter last year and toured round on my own. Some places I didn't know, I've lived in [name of place] for 20, 21 years and locally for another 22. But I found ways to get around [name of place] that I didn't know existed. (shrugs) So I did that once a week in that last summer weather last year. So I found things to do.

**I:** That's good.

**P:** I’m a bit like that, I like my own company.

**I:** Yeah, in that positivity section there was another kind of activity which sounds like something you already do, but it was about focusing on the positives and trying to find positive things. Is that, was that relevant to you and your situation?

**P:** Yes, it was relevant, but as I said, that was something I've always done, well, since I grew up. And that's important and I try to pass it on to my children and grandchildren. I always say, ‘this is today, yesterday is gone, and we don't know tomorrow. So enjoy today and start here, you can't do anything about what happened (indistinguishable).’ So that is my attitude anyway.

**I:** That's good. Yeah, so I guess that was the positivity section. There was another bit on kind of adjusting to changes and dealing with things like anger, sadness, frustration. Did you have a look at that or what did you think about with that information?

**P:** I don’t think I get angry. I do get angry but not about things I can't do anything. I don't get angry, I never got angry 'cause I’ve got motor neurone. I just thought, I'm so lucky I'm in my 70s. It would be different if I was younger. I don't think… even going back things that happened in my life, I didn't think I got angry. I did when I was in my early teens (laughs) we all do don’t we. And I got angry once my 30s when my marriage split up, bitter about it as people do, and that took me a long time. So I'm lying when I say I don’t get angry. But anger is connected to fear I think, is it? It was when I was in my 30s, I think it was connected to fear…

**I:** It's not something since you had motor neurone disease…

**P:** No, no I didn’t. I thought I was lucky and of course I've been very lucky 'cause it been very slow. And I've had time to plan in advance for what might happen. I've been a bit proactive really, and I’ve been fortunate... I know people don't have time, but I have. And I've been very lucky to have the Motor Neurone Association to help me and be there to support and you know, for what might happen. Anyway.

**I:** No, that is important and other people have said as well, planning and preparing for the future is quite helpful.

**P:** It is very helpful, but some people don't have time, do they?

**I:** Yeah. And in the sadness part as well, there was there was something about distancing yourself from any negative thoughts, I don't know if you remember? There was some like metaphors and things to think of, like a beach ball and…

**P:** Oh yeah, yeah. Yes, well, I think of nicer times and nicer things, that's what I tend to think of. I think the beach ball wouldn't apply to me, but I think of nicer things and nicer times, and how my garden will be when my June berry tree comes out here, it has berries and all the black birds will be jumping up and down and I think of things like that.

**I:** OK, OK so you think of positive things to keep the negative thoughts away..

**P:** I do. I've had my moments, but not since motor neurone I think. I think the bad time with motor neurone was before the diagnosis, when I was going through what it might be. All the tests and wondering what it might be. Then I didn't have a laptop in those days. I was fortunate that I got my first laptop the year I was diagnosed, I think. But when I, pre-diagnosis, I relied on the library books.

**I:** Well, that's why I'm really impressed that you logged on to the website and navigating through it and all.

**P:** (laughs) Believe you me, I do daft things. Like I did today, that was a memory lapse. 'cause I knew first thing this morning, how I would… where the link was. I think I did yesterday, yesterday I looked it all up, got the notes out and all that. But with all this cataract business yesterday, I sort of forgot today where the link was, sorry about that.

**I:** That's OK and even I guess, say if someone was new to using a laptop or I don't know, if say their hands had trouble on that day or things like that, was it still OK or easy enough to log in and navigate?

**P:** It was very easy, at least I thought so. But if they’re new, I think it was as easy as it can be for somebody new. It's hard to remember when you first use the laptop, but you have difficulty doing the simplest things.

**I:** And when would you typically like look at the website? Was it just sort of whenever you remembered, or was it maybe you felt a bit upset or low and that's why you looked at it? Or did you just look at it in your spare time?

**P:** I looked at it really in my spare time to familiarize myself, ready for when I talk to you. And then I know I went on it yesterday to go through it all. The only thing I did find, there is an awful lot there, and so I was going to one section, and that’s partly me and my age, but as I was making notes I forgot. I lost where I was, no reason why I should, but you asked.

**I:** No this is this is useful…

**P:** When I got back to the front page which had all the headings and all I would forget which ones I've done and which ones I wanted to go into. So I had to take a look at my notes and think, you know, and that was partly my illegibility, my poor notes...

**I:** No, no there are ways to make it easier, so I'll just make a note of it...

**P:** There's a lot to it, and unless you… I would never… If I hadn’t written down the heading of what I was going to do and underlined it so I knew where I was, then I would not have gotten… lost my way, but that's all I can say.

**I:** OK. Because of that, did you have to kind of go back and check if you’d seen it…

**P:** I’d go back somewhere and then think, ‘Oh no, I've been here before.’ I’ve read that whoever it was, I've been here before and then I thought I must have done this section, and go back

**I:** Did you ever feel like it was too much information? Do you think maybe it could have been simpler?

**P:** I don't know how you could simplify the sections, 'cause it's all relevant, isn't it? So having a certain area… so I don't know how you could have done that. There is an awful lot. But whether when you’ve done a section somehow you could mark that.

**I:** Yeah, we can do that. Yeah. OK, that's a good tip.

**P:** It sounds daft I know, but if there was a way of knowing where you left off, if you only went into two sections and came back the next day, to make sure where you were.

**I:** Yeah I think that's important 'cause lots of different people will be using it so you would need to know kind of what you looked at already.

**P:** Yes, yes, that's right.

**I:** But just generally with all the different things you looked at, did you find that you related to what was there?

**P:** Yes, yes yes. I could think of….Yes, it was all relevant I think. I could think that ‘yes, that applies to you know, when I, initially or whenever.’ Yes, I think so.

**I:** Did, were some sections more helpful than others do you think? Any ones you liked more?

**P:** Building positivity, finding positives, you know, values and goals and all that sort of thing. I think that was very important. Yes, I actually put down under anger… No cause I haven’t felt anger. The breathing and space, breathing space is a good idea. (indistinguishable) Sadness, wonderful support from, I’ve had wonderful support from the healthcare team. So that was that.

**I:** I think frustration may have been the next.

**P:** Yes, unhelpful thoughts I remember now. I did have unhelpful thoughts ‘what if…’ Because I've always given my grandchildren, sent them a card on their 18th birthdays, other milestones, their partners, they’re all in their 30s now. But my youngest was going to be 18 at this time, way back, and so I wrote his card out and put a cheque in it for him, so that if I was dead he’d still get it. I put money in it not a cheque because I thought… I always thought, until I was 90 and very very recently, I thought I’d probably be dead next year. So I did things in advance and that was something I, when I had thought about it, I would think ‘well what do I want to do that I won't be able to do if I die’ before then, I would do it. That was… I remember writing that card for [name of grandchild/greatgrandchild] and putting in my important papers, and that solves the problem. I didn't have to worry anymore. And I still do to an extent, like my great grandchildren, I was giving them X amount on their birthdays and I go into my bank and I program that money to go to them well in advance in case I'm in the hospital, or can't do it, or dead (laughs) whenever.

**I:** So if you have some kind of unhelpful thoughts and prepare for it and that helps.

**P:** I think ‘why do I have these bad thoughts’ ‘cause I don’t want to be, or not do this or whatever. And then that solves the problem, for me..

**I:** That's a very useful tip actually. Did you find any of the bits about worry or stress also relevant to you or not at this stage?

**P:** Um…what doe it say about worry and stress…

**I:** There was some practical tips and...

**P:** That again was focusing on something positive, wasn’t it?

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

**P:** Yeah… I don’t… you can't worry about what you can't do anything about. And then, I'm going to have these cataracts now, and she’s concerned she said I won’t be able to… I said ‘well I don't know. I have that brain that's able to switch off.’ I don't think about it, I assume it will be alright. I remember, before I was diagnosed, I had a something… somebody wanted to trace my blood vessel 'cause why couldn’t I use my legs properly or they wanted to trace my blood vessels going into leg and doing quite an extensive thing up to my heart or something. I think that was it. [name of doctor] didn't want me to have it done. But the other doctor I saw, [name of other doctor] I think you suggested it and [name of the first doctor] was a bit worried about it. Because apparently it was quite new then, this particular thing. Anyway, I agreed to see this, I was [name of private healthcare] at that time, which is why I could afford to have all these things done. As soon as I was diagnosed, I cancelled [private healthcare]. It was far too expensive and it was incurable. During my diagnosis time, it was worth it as far as I was concerned. So I went to see this consultant and he did his usual thing about warning me about all the dangers, and I said, ‘well, how many people have died that you have done it to?’ And he said, ‘well none actually.’ And I said ‘well how many have you done in the last year?’ And it was only two or three, but is it more than 100 is what I said. He hadn't done 100 but he had done more than anyone else in the country published. So I.. so on that basis, I said, ‘well, you know…’ and I didn't worry about it. It was just something that had to be done. I’m not a worrier, I switch my mind off. I don't mind the dentist. I don’t fear the dentist at all. (laughs) Even today I don’t mind going to the dentist for a root filling or whatever.

**I:** So none of those kinds of worries…

**P:** I never had an inoculation for filling in the tooth. Not until I was very old. I remember getting very annoyed, I went to a dentist in [name of place], when I was, I would've been in my late 50s about 50. And he was a new dentist I hadn’t been to him before and before I said anything about it, he’d injected into it. He didn't say he was going to do it. And I had an important meeting I had to go to. He said go in the waiting room, well, I went off to the meeting. By the time I got back, because I couldn't use my face. Anyway, what I'm saying is I said to him, ‘I don't have any injections’. So then if you don't have them, he had to be careful not to drill too far. (laughs) Anyway I’m sorry to bore you…

**I:** That’s OK, I understood that you’re not someone who really gets stressed about these things. I guess I just wondered before you signed up for this study and you heard that this website was about the psychological side of things. Did you have any expectations about what kind of help you might find?

**P:** Well, no, I just waited. I didn't know, I didn't think about it too much, I suppose. I just thought if I could be helpful you would write to me, that's all. No, I didn't think deeply on that. I was intrigued.

**I:** That's OK, I was just wondering more from the point of view if you wanted some help and we hadn't covered it or something like that…

**P:** Yes, well, I suppose I would, at this point I would’ve have asked but no.

**I:** Uhm, just trying to look through my questions... Yeah, I think I've covered most of it…

**P:** I hope you do, because I know my grandchildren say I gabble and gabble and gabble…

**I:** No, no, that's useful in an interview. I was wondering if you wanted to just tell me any like anything about the website that say we haven't spoken about or something you didn't like? Or something you felt was really useful for you?

**P:** Well, as I said, personally I wouldn't, I'm not so keen on the mindfulness part, and part of that. And I certainly think the positivity that is very important. It’s very easy to say, but people I know with motor neurone, I have a friend and she's not like me. Thank God everybody isn’t. So she feels really... at one stage she said she would rather die, she said she didn't want... So I think to say to her she had to be positive was last thing you would say to her. And she was, we only emailed. I have met her through MND Association functions. She was diagnosed after me and unfortunately progressed to ALS, which she has now. So she got very upset when people said you know be positive and all that and she wouldn't, she just didn't want to meet people because of that. When I emailed her once, 'cause I used to send her copies of MND PMA-PLS newsletter, have you read it? That’s good, its edited by [name of person] who's a doctor with MND, she's been a highlight in the MND Association. Anyway, it's called the PMA-PLS and I sent her copies. And through that we kept emailing and she emailed me once, and said I think you think I’m horrible, but I would rather die. And I emailed back saying ‘well, I quite understand that that I don't think you're horrible at all, I understand.’ That seemed to help her, more than if I had said try and be positive.

**I:** No, I understand what you mean, even from the way we presented the information we were trying to say, ‘you know it's not that bad things are not there, they are there…

**P:** That's right. I think reading it from your leaflet is different from somebody standing there telling it with a smile on their face, telling you ‘look on the bright side’ you know. It's hard to know what to do.

**I:** OK, so I see what you mean. That section was easier for you, but it might be harder for someone else also, who's…

**P:** Yes, if you're in a bad place, you're not going to be interested in people telling you to be…at that time you’re just not going to be.

**I:** And… Sorry?

**P:** I'm not a psychologist or counsellor so I don’t know what you should do in that case.

**I:** But you just helped her by saying ‘I understand how you feel’

**P:** That's right. I said ‘I quite understand I don't think you’re awful at all.’ And actually, I have been able to do something good out of that because I told her, emailed her one day, ‘I have these two wonderful women who do my garden.’ Obviously I can’t do it, they come every fortnight and I told her about it and then. I think I said something about flowers being wonderful, I have these two lovely ladies and she said, ‘well, my garden’s in a terrible state. I've lost…I can’t… nobody to do it.’ So I said ‘well if you like I could ask’ and they've been and they’ve transformed her garden, it’s wonderful. And I know, she doesn't have to tell me, that to look out on the beautiful garden, when you've always done it yourself, I’m quite pleased about that.

**I:** That is, that's really helpful, yeah that's a really good example. I might use it for any of the future...

**P:** Well, that's right. There are people who will put things like…like her garden, who will do it. And she’s got the money to, and it's wonderful when it's done. Mind you, everyone who comes knows it’s my new garden, all my family who come they aspire to keep it like mine is. (laughs) But I don’t do it, I have very knowledgeable ladies who do it. So if you want a garden…(laughs)

**I:** Gardening is important (laughs). I'm just gonna stop the recording, but I'll still be on the call…