**Interview 21**

**(person with MND)**

**I:** Should get a message, I think. Ah there it is. OK, it's just started recording. So, I guess to begin with, I wanted to know how you got on with the website.

**P:** Uhm yes, I read it through completely once just to go through it all and then broke it down into sections. So, I allocated a day to do one particular section and go through it and then a few days later to go through another section because just to read it all in one go, you can't take it all in. And then I decided to put it actually into practice, each section where it was relevant. And then from that, obviously I'll tell you what the results were, yes.

**I:** That was a very sound like a very like systematic way.

**P:** It had to be a plan rather than just reading it all and then you forget some things and you don't understand others. So, for me to go over again in sections, you know when I'm at when I feel like well enough and I'm comfortable enough and then just to sit down and think about it.

**I:** Yes, yes.

**P:** I did that.

**I:** That's brilliant, I'm…can I go through the different sections then and you can tell me after trying it whether something worked or didn't work as well. So, I guess the first section is about positivity and that had pleasant activities, finding positives and values and goals. Did you try all of them or one of these?

**P:** Well, you are quite lucky there because I am a very positive person right from the word go learning that I had MND. And at the beginning I was very sad, had a little cry but became positive. I’m gonna tackle it head on and look at those sorts of things that you had in that section and look at it head on. That thinking, about there’s lots of good things in my life, rather than focusing on those... And then I started picking out the good things in my life to think about them. Yes, so and I have goals. So, I did set myself goal, goals that are totally different from before I had MND, obviously. But yes, because I'm very positive and sort of already planned that sort of thing in my mind that was going to go forward, so that section for me, sort of confirmed to me, I must be doing the right thing in my mind.

**I:** Yes.

**P:** Yeah.

**I:** So, did you do both of the finding the positive things and goals already before, and it helped the way you coped?

**P:** Yes, I did but reading the parts of trial made me actually sit down and list them and write them down rather than them coming into my head and then forgetting about them. I actually wrote them down and go back to them to see if I have achieved it, or I must still be on the right path to that goal. So, because with reading your trial then it made me sit down and make the list if you want rather than it just coming in my mind, I'll do this later. I set that goal and made the list, and that list I… even today this morning I refer to it just to see how I'm going along with it. But again, I've got that from the trial that prompted me to do it.

**I:** Yes, oh good, good can you give me an example about the kinds of things that are on the goal list, if it's not too personal?

**P:** Yes, yes not at all. I think to begin with, when I was first diagnosed with MND I… 'cause I have always been active outdoor person, I go scuba diving, I go skiing, gym three times a week. I'm out all the time with my friends. I think I started to become more secure just staying in the house and feeling which I suppose is understandable apart from COVID and lockdown and everything, staying in the house and then I started to think if I'm not careful I'll become a bit sort of… a bit of a hermit. So, one of my goals is to make sure I get out more, and one of them, even if it's just sat in the garden because I wasn't even doing that at one stage, I felt more secure in the house. So one of the goals was initially go sitting out in the garden and then now we're allowed to meet friends even with COVID. Meeting more friends outside and them coming to see me. So, now it must be the same with a lot of people with COVID because we've had a year of it, a lot of lockdowns, it's getting back to socializing, so now I'm socializing again. One of the goals was to actually go out for a meal, which, oh, I've always done that, always loved it. But when you're in a wheelchair and you can't move very well and you can't go to the toilet on your own or anything like that, was a big thing. So, one of the goals was to go out for a meal, but I made sure it was with my family, so I felt all safe when we all went out. And another of the goals the first time ever going in a wheelchair taxi, I had never been in a wheelchair vehicle before, so I had to ring around about 5 companies to make sure they knew what they were doing and I've picked up the friendliest chap and I've been using him. So that's one of the goals I’ve set and I got over and now I go out in a taxi with a friendly driver that's nice and safe. Scary to begin with, wheelchair and bouncing about in the car, so that's another thing. And another thing… goal is I'm not gonna stop this disease letting me go on holiday. Uhm and I found that with a lot of research my sister, sister and my daughter then the same researching other facilities for people like myself. Uh, unfortunately there's a lot of places that… there's a lot of very poorly people at these holiday places, and it sounds awful, but I want to mix with lively people and happy people. So yes, we found a few places where they cater that for the disabled very well. But people that are not disabled go as well for a holiday.

**I:** OK.

**P:** On that. So, a lot of the goals are to do with getting out, more meeting and trying to get back to having an outdoor life again. I've still got more goals to go because I need some good weather sometimes you have to get out in a big wheelchair but say that yeah, those are some of my goals.

**I:** Yeah, you know that, that's really useful because when I was designing it as well, I was looking for examples that say you could do if you had some sort of disability, so these are really helpful suggestions.

**P:** Yes, 'cause I can go out with my family. I mean, I can still use my hands and I can still use my arms a little bit. Can't walk at all and can't really sit up straight yet. But also, as you can tell, I can talk and I love talking. So, talking with people, different people 'cause along this journey of having MND, I've met so many very kind, wonderful people, whether it be in the NHS, whether it be Marie Curie, whether it's like yourself at research centers, 'cause I've volunteered for a few research trials, but they’re very friendly people and I find it all very interesting, all what you are doing, so that's interesting.

**I:** I'm glad yeah, that's really helpful. I can kind of put it into context in terms of your life as well, yes. So, I guess being a very positive person, etc. How did you find the other sections 'cause they were more about like anger, sadness and frustration? Was that much of a problem?

**P:** I had that at the beginning of the MND. But again, with reading through, you know all what you sent to me, I've sort of learned to stop and put that worry, that frustration in that other box sorta thing as it said the [shopping] cart. Start thinking of something different and that has worked on several occasions, and I don't seem to get frustrated as much now. I don't know if that's 'cause it's working or I've just got used to you know, what's happening to me. I don't ever seem depressed. Frustrated is totally different to depressed. I don't think I'm depressed, I'm lucky there. I don't seem to have a certain anxiety. But at times I've got to say yes sadness comes into it. I do get sad, which is obviously a natural, natural feeling. And again, I've tried, and I've been unsuccessful and I've had just to stop and think of something nice. And I have. I have all these, I’ve collected lots of nice thoughts, again, reading what we've been… taking it all on board, putting some nice thoughts on one side. So, when I get sad then I'll think of these nice thoughts. It does help at times, but I've got to say there’s times when I've been very sad and I thought let me think about something nice and I thought to myself, no, I want to be sad. I want to have a good cry and get it out my system and that's worked as well. So, times I don't want to stop being sad just for half an hour or so, let's have a good old cry and then I feel right again. So, it's yeah, let your feelings out rather than trying to push them to one side or think of something else. So, both works, but on different occasions you need different solutions to them.

**I:** Yeah, that's completely understandable, especially if you're feeling that emotion quite strongly. You may not want to do any technique right then, but, after that point.

**P:** yes, after that, yes.

**I:** Yes. OK, I guess in terms of techniques that was… is this the one the thought distancing one that you were talking about, which is putting your thoughts aside?

**P:** Yes yeah, very nice thoughts, memories all that I have at the back of my head, ready for when I feel like that. Then I could stop and think of these lovely things, and yes it does work. It got to say it does work, OK then then I might go back to being a little bit sad but for…it just stops me being overwhelmed. Yeah, I think of the nice things and yes, take control. I've got to say it takes control but it's a positive thing to think about, that just calms you down.

**I:** Yes, did you do this before as well or is this?

**P:** No, no it's because I've been reading so much of it. What you put made sense to me, so it was quite easy for me. It was, it's like you were giving me a solution on some of the things that yes, that's a good idea when I'm down or whatever, think about these lovely things and so it's through reading your trial that I thought good, sensible idea. So, I put it into practice and it… for me it worked, might not work for everybody, but they certainly work for me.

**I:** Did it take a bit of practice to sort of learn and put the technique into practice? Or were they quite intuitive?

**P:** Because, to be truthful I forget about it, I forget to think about these aspects, so yes, it did take practice. Yeah, it doesn't come automatically. You've got to force yourself in a way I don't force myself now because now I do it automatically. But to begin with, I had to force myself to stop being sad, to think about something else, but now, because I must be doing it quite automatically because I don't see myself as much nowadays. No.

**I:** OK, OK.

**P:** So, with practice it gets easier.

**I:** OK, yes, yeah. OK, I wondered if you tried any of the audio the mindfulness ones?

**P:** Oh, I love that. Yes, Oh yes. I've got to say I just sit back with my eyes closed. I've used that a few times because I like it, calming voice yes. I've got a good imagination as well, so you know, I could imagine all of the beautiful things and I've got my eyes close and yes, I do like that, and I even use it now. Uhm, you know you sent me the trial like a few months ago, but I go back to it, just not even when I need to be calm down, just when I've got a nice half hour when I haven't got visitors, have not got to go to appointments, I can just relax in a big chair, put my air pods in and it comes in my ears and just sort of listen to it and drift. So, I do like that, yes.

**I:** There were a couple of different ones. I thought I’d just ask you about them specifically.

**P:** Yeah.

**I:**  I think there were some shorter ones, about 3-minute breathing space.

**P:** Yes.

**I:** And I think compassion break and those sorts of short ones, did they seem relevant to you?

**P:** The compression break, not particularly, no. I don't... I don't really think I need that because I don’t sort of beat yourself up about anything or blame myself for anything I don't know, I don't. I don't look back to think if I had done this different or now… Yeah, it's awful to say but I quite like myself in a way so I don't, I don't think I need the compassion breaks so that I don't think that particularly works for me.

**I:** Yeah, and I guess the other one was the breathing space, which is just literally focus on the present and yeah,

**P:** Yes, but I do a lot of breathing exercises anyway because of MND got to keep your lungs as strong as possible so that I've been doing the breathing. Nice thing that makes sense. Yeah, just nicely slows you down, calms you down and everything, so that's something I do regularly anyway.

**I:** OK. The one I wanted to ask you about was the body scan. I don't… have you tried that one? you think about the different parts of the body?

**P:** Yes, because I used to do yoga and again, we did all that type of thing in yoga there to scan all your body, how it was feeling. So obviously I've not done yoga for… oh well over a year since I've [been] diagnosed. So, that was quite welcome to me. So, I forgot to do it even though I was doing it in yoga. So, reading that reminded me. Yes, I can do the body scan, so I do that again. Again, I have to pick my times when I'm doing it, when I've got quiet time when there's nobody about, nobody's going to visit because when you're into that, I don't like to be disturbed. I just like to stay and just go through it. So, that prompted me, to remind me that I used to do it when I was doing yoga.

**I:** OK, OK.

**P:** So, it has sort of… I adjusted it slightly for MND.

**I:** I just wondered as well because it asks you to think about your body and I guess you know with certain parts not functioning was that a problem or was it OK to sort of do?

**P:** Yeah, it doesn't. Yeah 'cause my legs don't work at all. I can't make them move. So, when I say it, it does bother me, but it doesn't bother me to think about them because I'm quite practical as well because my legs won't move at all if you lay in bed, the legs straight out and you can't move. But I've devised myself, had some straps made that I could put round the top of, above my knees with handles on and I can pick my legs up, roll them over to one side, turn on the bed. So, even though my legs don't move, I'm still friends with my legs because I can adapt something to make them move so it doesn't upset me when I'm thinking about them and I’m scanning them with my mind because even though they won't move on their own, I can make them move now by using things that I've devised and things I’ve got. So, now I'm just having to use things in a different way.

**I:** Yeah, yeah, yeah, I was just wondering more in terms of, I didn't want to necessarily upset people, but if I asked you to think about it so I tried to say you know, think about the warmth and the comfort in them rather than trying to move them...

**P:** Yeah, because I can still feel those feelings of warmth and comfort, like you say. So, yes. And yeah, they’re still my legs, so yes, that feeling of the comfort is, yes, it's still there. Yes, I can… it doesn't... it's not a negative to me, thinking about them that way.

**I:** And similarly, was the safe place meditation OK, where you imagine a place?

**P:** Oh yes!It was a really good idea. Found a beautiful, safe place. It was a memory from years ago, forgotten about so yes, I can even picture it in my mind as I'm talking to you now. So I do like that idea. Yes, yes and I can very clearly remember and imagine and conjure up my safe place when I need it.

**I:** And were any of these mindfulness ones helpful, more say in your spare time or did you kinda use them when you were upset?

**P:** I’d say I've used them more in my spare time when I've got the time to sit and think about them rather than sitting with nothing to do and pondering about what could have been happening in the future, so it's stopping me thinking about bad thoughts for the future. But as I say, when I've been sad or when I'm falling and I'm upset, it does take a bit of practice to put them in, turn it into action when you’re crying away on your own.

**I:** Yeah, there isn't a right or wrong way. I was just trying to work out how people use it more.

**P:** I use it more when I've got the spare time so my brain doesn't go off thinking awful thoughts about the future, so I stop myself and then gonna start think about the nice things because when you're on your own or just lay in bed for hours, everybody's mind just wanders through you know, and lots of the time you think about things you're going to do in the future. And if I sort of realized I'm not going to have a very long future, I don't want to stop brooding on it. So, that's when I start thinking about the positive things.

**I:** Ok, I guess there was another section on other support that's available, whether it's speaking to other people with MND or professional support. You say already know all of that or something you want to say.

**P:** I've got plenty of professional people that I can speak to, and I ask them questions nonstop to know all about this disease, not just how and why I've got it, but what's happening in my body and what's going to happen in my body. And I told them, you know, and [name of organization], doing trials in [name of place with name of person]. I've asked them all to explain fully, even the bad bit. What's going to happen to me, why it happens, and how would they expect me to react. I want to know as much as possible, so I ask lots of questions about…for professional people, as in I've got lots and lots of friends, good friends and family where I talk ideally, nothing about MMD. Nothing about, anything wrong with it. I want to talk about anything and everything else that's going on. But I avoid really talking about that because I don't think other people want to talk about somebody's illness. They come to see me and sit and have a nice time with a cup of tea. But they don't want to be listening to all my aches and pains and problems. So, I have lots of people that I can talk to and have friendly conversations, nothing to do with the disease at all, and that's good. That's why I cut the disease out when I'm talking with my friends. So, it's just like I used to be before.

**I:** OK, so it seems like you have support kind of in place.

**P:** Yes, absolutely yes. Again, I have to make sure I have. I've got to say a lot of people initially, because I've got MND, and they didn't really know nothing about it. They don't know how to approach me, or… I've had friends that didn't… couldn't contact me because they were too upset and didn't want to upset, upset me talking about it. So, I've got to tell them ‘don't be silly, if you want to ask anything, ask it,’ but I'm not upset. It's what it is, and we get on with it, so I have to keep trying to give them confidence to talk to me.

**I:** Yeah.

**P:** And them not wanting to upset me and didn't know what to say. So, we've got over all that now with all my friends and they're all fine and all happy again.

**I:** Yeah, uhm. Yeah, I guess I wondered if there was anything that say we hadn't covered in the website that you may have liked?

**P:**  I don't know I did like that specific part about where you said ‘all the things that I used to do that I can't do anymore. Think about other things that you will be able to do in the future.’ You can do things you used to like doing years ago, and because I've always been active at skiing, walking, running, diving everything. Then I'd sit down, and I thought, and I made a list of the things that I can do now. I would have liked to have done years ago, but I didn't have the time. But I absolutely love, I love looking at the sky and the clouds. I've always wondered all about the clouds, so I've bought myself lots of books now and I'm reading about the clouds and learning the names. That's something I always wanted to do, but never had the time, but it's something I can do now. And also, I love nature and I’ve got out walking, loving nature again. I've never known really the name of the wildflowers that arise, so I'm learning those as well. I can sit down and I can learn through, so I'm doing different things now that interest me. That have always interested me, but I've never had the time to do it, so I've just got new interests now.

**I:** OK, OK.

**P:** But I did like that section.

**I:** I guess, I guess you kind of answered my next question, but I'll ask it anyway in case. Just in summary, since you've had a look at the website, has anything changed for you in terms of how you cope emotionally?

**P:** Yes, I think it has. It's definitely the safe space that I really do like that and having all the nice thoughts for when I am down, a bit upset, which anybody could use that you don't have to have a disease or you know, it's just nice to stop. And I've got to say I appreciate everything now, which is nice. Why didn't I appreciate everything before I wonder? But now I appreciate somebody just giving me a call just to say hi, how are you? I even appreciate somebody coming in with a piece of cake and a cup of tea whereas you know… it's now, it's just wonder. I appreciate just looking out of the window and watching the children play outside. Well, they've always played outside, but I've never actually stopped and watched and appreciated watching them. So yes, on the whole, the trial’s made me stop and think about things I used to take for granted, and now I realize that they've always been there, these things. But I've got to appreciate them more now, and I certainly do, I certainly did.

**I:** Oh, I'm glad, I think.

**P:** You see in the sky and the sun every morning and now you believe it, believe it, I believe it now. Every morning when the blinds and the curtains are opened for me, even if it's raining and foggy and horrible, I look and I say what a beautiful day it is, and I appreciate every day now. But yeah, I just took it all for granted.

**I:** Yeah, you're right, we just end up doing lots of things and don't stop and think, but sometimes we are forced to.

**P:** Then yeah, yeah, these trials have made me sit and think and realize that you need time in your own head to think about these good things and stop the negative thoughts. So yeah, I've really, I've really appreciated it. Yes.

**I:** Yeah, was there anything at all that you didn't like about the website, or you thought maybe could be improved?

**P:** Uhm you gave samples of where somebody with MND would talk and give their side of the story. Then they would give the carer’s side of the story. I don't know why… I didn't… when I was reading the carer’s side of the story. That sort of upset me a bit, because OK, I might think I've got problems. But carers have as well, and everybody just takes them for granted. So that side, I'm glad I read it, but that side made me realize it isn't just about me, it's about people that are having to live with me and look after me so that just made me a bit upset sort of thing, that I hadn't realized that before.

**I:** OK, OK. You know that's… thank you for pointing that out 'cause I didn't, I didn't see it that way. Yeah, I thought mainly about it being relevant for the carer or for the person, and not if you read the opposite, then other way round.

**P:** Yes, yeah, just so that I will be sad when I read those. Yeah.

**I:** OK, I'll make a note of that, yeah. Let's see how we can change it.

**P:** Different people might think of other ways you see, it's...

**I:** Yeah, we can sort of change things to say you click a button and it opens up something that's meant for you, and someone else can do something different or something like that.

**P:** It’s the same as well because also… when you were reading it all, now you're asking me questions about things, when I was reading it, I might have had a different thought at the time. And I just wonder is there anything well… as I'm reading it, there could be just a tick box if I liked that or I didn't like that, you know. So, while I'm reading it, rather than just talking like a few weeks later about it, so what does it make me feel like as I'm… when I was reading it, you know. It was a surprise... was I glad about it… what was I think reading that, just to tick off my reactions as I was reading it, I thought might be helpful for you.

**I:** OK, yeah. And you can sort of save ones you liked and ones you didn't like or something like that, yeah. Yeah, that makes sense… sorry that's to do with my very basic technology.

**P:** Just a thought that they might just help. Yeah.

**I:** Yeah, yeah, I know that can definitely be improved, yes. Yeah, I think I finished asking you most of my questions. I wondered if you had any anything else you wanted to…

**P:** I think we have covered most of it. Yes, there's some good points, but as I said there's just one or two things but if you… at the time of reading it, if you knew what I felt when I was reading it, I think that’s more helpful than asking me quite a few weeks down the line, you know, to me.

**I:** OK, yeah.

**P:** A little tick box if that's possible to do anything like that, would be more helpful. Other thoughts, all in all, it was… I must have read it completely through about 6 times. But kept going back to certain parts probably a dozen times. You know, little sections that I prefer to use that I put in my air pods, airpods.

**I:** Yes, I guess there’s one quick question that came to me is… with the information or sometimes with some of the activities as well, when I made suggestions or practical tips and things like that uhm did you feel that it was kind of framed sensitively, say if you couldn't use your legs were there still relevant options?

**P:** Yes, a couple of… I just remembered, remember at the time, thinking, ‘well, that's OK if you can go out for a walk,’ yes. So yes, it's only it's only a few places, wasn't much, but there was only a few parts where I thought, ‘well, that's not relevant to me,’ but it can't cover everybody, can it?

**I:** OK, OK yeah, I'll have a look at where I think I know where but double check where I've said that.

**P:** Yeah, that's the thing. If there was anything where I could respond to myself, where I could just mark them out as and when I'm reading them…

**I:** Yeah, yeah yeah OK. That's alright, yeah. If any feedback strikes you even later, that would be fine, yes. If there isn't anything else, I'll stop the recording, but I can still be on the call.

**P:** Yeah that’s uhm...