**Interview 4**

**(person with MND)**

**I:** Soon. Oh, there it is OK? Uhm, yes, I guess just to start off, how did you get on with using the website?

**P:** Well, I thought it was, you know, well presented. It's very easy to navigate around. Sorry. Can I just stop whatever on my screen? There’s a line which is right across your face and it's quite distracting. Let me see if I can get rid of it

**I:** is it a light?

**P:** It’s a line showing me that it's being recorded…

**I:** Oh there might be a button saying dismiss.

**P:** That's not helping, so there's more action, let me just see if I can… That’s better is it's moved down now, so at least it was right over your face. Sorry, it was distracting.

So, I thought the website was well laid out, the website it's very easy to navigate around, so that's another really positive thing and it's also split into sections so. And it's easy to go back into the one before and navigate around. So that was all very good. I think a lot of it I probably knew already, but there's no harm being reminded. You know, there's a lot of techniques, in there that I've heard of before, but then some I hadn’t, not saying I knew everything. But, you know, I think it's very good to be reminded all of these things because we all forget. We all get wound up in our concerns, and we forget to step back and to focus on the here and now, you know breathing and all of that. It's easy to forget. I think the very first time I went into the website it made me cry and I think that's because it was a real acknowledgement of what I was going through. Maybe that's the first time, I've really, kind of sat down and gone gosh, this is huge. That was quite powerful, but you know I’ve gotten over that as I started using it but it did have quite a powerful effect the first time I used it, it’s that acknowledgement of what a huge thing, I’m going through. Maybe I'm guilty of just keeping busy and trying to forget about it, which is useful as well, but you do have to sort of (indistinguishable – accept it?)

**I:** No, is that more of like reading other people's stories or a particular section….

**P:** Actually no, I mean, reading other people's stories was interesting, but I think it is just more about stopping and focusing on what I'm going through. And acknowledging really, how, what a big situation, what a big problem it is. I think, it’s a good thing it's good to sometimes have to deal with stuff, that's the whole point, you know, positive light, you know dealing with it in a positive way. But also pushing it to one side doesn't necessarily help in the long term. Yeah, really my comment was just that it had quite a powerful effect. But, you know, I think that's a good thing.

**I:** You know, I find that really interesting as well, because some say other people might also have a similar reaction when they have a look at it. So I was just wondering, how did you, how did you bring yourself to have a look at it again cause, I guess, that initial experience could be slightly negative or upsetting.

**P:** Um, I don't think that was a problem. I mean I didn't, I didn't think the experience was negative, I thought it was upsetting, but that doesn't always mean it's negative. That's just, it brought up powerful emotions, but that can be positive thing. Does that make some sense? It's recognizing that it’s good for me, and so focus on some of the issues. But that doesn't mean it's not painful, but I also just thought it was a good thing to do. Does that make sense?

**I:** Yeah, yeah,

**P:** being upset isn't always negative. It can be. It can be helpful to move through things and accept.

**I:** Yeah, yeah, no, that that's really important. Uhm? And sort of, when did you decide to log on to the website or have a look. Was it at like regular intervals or when you were feeling upset?

**P:** I think it was for me, I mean, I've been extremely busy the last few months, so it's just been really when I have time. My partner’s just moved into this house and I’ve been doing an awful lot of work in my house to make room for him and his furniture. So, there's been a lot going on and so yeah, I’ve been incredibly busy, so it's been more when I just have time and time to sit down quietly, sitting on my own and deal with it. You know, it's like having an hour or two to just sit and use it properly. So there hasn't been a specific time, it’s just as and when pretty much.

**I:** OK, and at those moments, how did you choose which section to look at?

**P:** I think I tended to just sort of work through it. As I say, I made some notes, 'cause I found that I can look at it even when I don't have access to the website, I can look back at those. Think I just tended to work through it in a more methodological fashion to make sure I haven't missed anything. And yeah, it's more about that for me than focusing on particular sections.

**I:** More like a systematic looking at the whole thing. OK, and did you also say after you looked at most of the things go back and choose particular sections that you might find useful?

**P:** Yeah, I mean I through went some of the exercises, I didn't do the first time 'cause you know, I didn't have time to sit and listen to them. So, I went back and went through the exercises at later date, when I had sort of time and space to listen to them. Then I sort went back through areas that are more relevant to me or I found particularly useful. Yeah, it's just, it was a mixture of things really, but it's nice that you can just dip in and dip out and look at things.

**I:** Yeah, let's go sort of into each section, I guess in more depth. So, let's start with the building positivity. So that had the three activities, pleasant activities, values and goals, and finding positives. Yeah, just in general what did you think about those?

**P:** That was very good. I mean, I think I've started to do some of that myself. I think lockdown makes you think about. What we're going to do you know? So, I'd already made a list of sort of nice things to do but I've kind of expanded that because, sorry I was going to go onto something else, but I'll focus on your question. Yes, it's finding something positive that's very important as well, and the values and goals. Actually, I will say what I was going to say, this is something I think perhaps is slightly missing, it is covered but very slightly missing. Something I'm having to do is to change my life completely. I'm very active person, or I used to be. My life revolved around walking with various groups and friends, going out dancing in sort of partner dances like salsa. I used to do ice skating, I used to go cycling. I used to go to the gym all the time. My life has to change completely, and I have to acknowledge the grief saying goodbye to all the things I can’t do. So, there isn't very much on the website, correct me if I’m wrong, about dealing with the grief of letting go of your previous life and your hopes for the future, because my hopes were to go travelling. So, that’s changed, it's just saying goodbye to your previous life. And yes, finding new goals and new values, new dreams, which you do cover. You know, you’re saying values and goals, which I’ve been doing, finding… all of that is really important. But you actually have to say goodbye to what we had hoped to do. I'm not sure that's really covered, correct me If I'm wrong about this…the grieving

**I:** Yeah, you know, I we did think of. Yeah, we did think of covering that, but we weren't entirely sure how to do it, mainly because. I guess like you said, sometimes just talking about it potentially upsets people. And if they can't see past the things they've lost, then we didn’t sort of, want to leave people in like a distressed state. I guess that was the thing, but I understand a lot of people have mentioned something similar as well, because when you think of something new, it's also acknowledging in some way, what you can't do anymore, so it is there. Yeah, I guess just how much you discuss it.

**P:** Yeah, I see your point about not wanting to upset people. I think it's a difficult one is that I think I just thought I'd mention it, but it is part of the process, isn't it? It's, it's acceptance then it's grief. And then you've got to move on and find new ways of doing things. But you know all the things about finding positives, values and goals, doing things you enjoy, that’s all really positive. And you know, I've done them and tried to focus on them.

**I:** But as you were saying as well, you needed some time to deal with the loss angle of it. And some guidance I guess about that or what…

**P:** It’s that acceptance. You have to come to terms with it, you have to accept it. And I haven't yet, I'm getting upset 'cause I haven't.

**I:** Yeah, yeah, OK. Uhm? Yeah, I'll make a note of that because yeah, it's different when people actually try it out in their lives, and if this is an important part, then probably it should be included. Uhm, OK, so that was sort of values and goals and pleasant activities I guess is linked to that similar. What about the finding positives or was that something relatively easy?

**P:** Well it, you know, I wrote a list, and I think it's important to think about that because there are bound to be some positive we’ve all had to think of positives in lockdown, it was awful but we’ve all managed to find some things that we can say, ‘actually this has been good.’ So, I think it is important to also look for the positives, in everything that we do, I’m actually a great believer in that. Actually, that another thing that's not covered in the website. This is a weird thing but COVID-19 I think actually helped me to deal with my diagnosis in a strange way because there were lots of people dying and I think it's always important to look at the fact that there's always people worse off than yourself, and at least OK, you get a diagnosis of MND but at least I wasn't in hospital, isolated from my loved ones because of Covid 19, and I think that's the other thing about finding positives is that recognizing that there’s always people worse off than yourself. And at least I’ve got a few years to be with my loved ones and friends, which a lot of people don’t get, you know, if you’re struck by a buss or in hospital with something terminal. I have got some time. So that’s finding positives but it’s also accepting there’s always people worse off, people are suffering and it helps you stop feeling sorry for yourself. Because that is something you could fall into, even though it’s all bad, it could be so much worse. It’s just about finding positives, this could be so much worse I could be dead. You know, at least I'm still sitting there. (laughs)

**I:** (laughs) Interesting, I hadn't thought about it that way…

**P:** Yeah, I was diagnosed just as we went into lockdown, so I had this little double whammy of covid-19 and how scary that was. That was frightening you know, worrying about who was dying. And my own diagnosis and actually it put things in perspective. However awful it was you know, at least I wasn’t, it could be worse really. No, it's difficult one on how to phrase that perhaps. It's like the fact of we are still here at least we do have some time, make the most of it. Instead of feeling sorry for yourself, at least you think I have some time and things to do.

**I:** Yeah, and just recognizing that. Also like it's still there, but just taking that time out to, just yeah, pay attention to the fact that it could be worse…

**P:** yeah, it’s all part of finding positives like how you asked. There are lots of people dying every day for various reasons. Sometimes you can be given the gift of time to do stuff, and see friends. Yeah, it is the gift of time.

**I:** I'm glad I thought Covid would make it more difficult to do some of the things I suggested, but I'm glad it sort of worked in the other way…

**P:** Yeah, well, it's obviously it has made a lot of things more difficult. But I think in the early days, I don’t know about you, but I was really upset and worried by the number of people that were dying it was really, really scary at first. It still is, but it was, I think initially it was very worrying about what might happen. It just kind of put things in perspective a little bit, you know, literally with thousands of people at the dying and the problems of people. And at least I was still here.

**I:** That's really interesting. I mean, yeah. It's the context of also kind of where we are in that matters and how we see things also. So, who knows, maybe Covid has helped me and other people to see that as well.

**P:** Yeah, but it is just, it's just, it's recognizing that. However awful diagnosis is, that there are always worse, people worse off than yourself… people given two months to live or in a car crash and that’s it their life is gone. There are people every day in a worse position than me, and so it's recognizing even though it's a horrible diagnosis, it could be worse.

**I:** OK. Yes, you mentioned briefly about making a list of positives and things like that. So, you did try to do the exercise for yourself. Yeah, how, was that difficult or easy or was also the level of instruction, I guess on the website OK to just go out and do that for yourself?

**P:** Yeah, no it was fine. As I say the website was fine I think that my only criticisms are perhaps just a few things that you could add to it, but I think the actual website was well-worded, it gave examples, gave other people's experiences. I think all of that is useful. So I've got it here, I've got about 2/3 of the page of positives, so that's quite a lot really…

**I:** That’s really good, yeah

**P:** So, but it's very linked into your values and goals, so you think about your values and goals, and then it's actually having time to do them..

**I:** Can I just ask about examples as well? With using exercises like the values and goals and how, I guess it relates to if you have MND or certain symptoms as well, like how did how did you actually put it into practice?

**P:** Sorry, I'm not sure if I...

**I:** The values and goals, I'm just trying to look for examples of sort of how you put it into practice. So, if like MND or symptoms got in the way of doing certain things that you have to work your way around it…

**P:** I think I said before that everything I used to do I can't do so. So, for me it was a question of finding new values and goals. I mean, one thing I thought, obviously I don't know about you, but I've got oodles of photographs that are just on my phone or sort of on my laptop. But it's one of those things I've meant to do for years is to go through them, print them out and put them up on the walls or put something into albums that I would like. And it gives you an opportunity to do things like that, that I have wanted to do for a long time, but I've been so busy doing other things that I haven't got time to do it. So that's the value and goal that I can work out. I've got children so I’ve got albums for them and things like that so. We’re doing a lot of work in the house lately, but I want to focus on the garden now, there are a lot of things which I can still do. That’s something that I can be focusing on which again, I’ve had less time to do before, so that's the positive is that I've got more time to do things that perhaps didn't have time to do before. I can focus on different things that needed, but still things I want to do. Does that makes sense? And I think it's like listening to music, I can still do that I’ve got lots of music. So, you can go through and listen to CDs I've not listened to for ages and get more music on Spotify. And yeah, things like that I can still do so. Yeah, it's, I like watching documentaries, again, I’ve got time to read more and more and do stuff like that. Learning, I guess, I have more time to learn things, sorry if I’m bragging. So, is that, is that what you meant?

**I:** Yeah, yeah. I basically wanted examples of how it looked like in real life, but yeah, you gave me plenty.

**P:** yeah for me, it's finding things that aren't too physically active, but all of my life used to be quite geared around physical activities, so it's finding things that I can still do like and still enjoy.

**I:** OK, so is more than finding new goals rather than modifying something that you were doing…

**P:** I think they've always, I mean things like my photographs and like my gardening, listening to music, they are things I've always wanted to do or I've always enjoyed, but it's having more time to do things like that because I… Other things in my life have stopped so I have now more time to do the things that I put on the back burner. But now that comes to the fore, does that make sense or not? They're not new things now, just things that were parts bit more on the back burner.

**I:** OK, OK, I see

**P:** Things I can focus on now, with alternatives to what I used to do

**I:** OK, yeah. That's a really good way of phrasing it. Uhm? Was there anything else about this section? Before we move on to another section…

**P:** No, as I said. I think it was very good. I mean there's a couple of things I mentioned that perhaps you could incorporate as well, but I thought what was there was very good. Just couple of ideas of things you could add. Yep, so the actual activities were very good and very positive.

**I:** OK, OK. So, the adjusting to changes section. I think you had a look at all of the different emotions in there, so anger, sadness, frustration. And each of them had a technique and I think an example, and practical tips. Did you mainly look at the techniques or the tips?

**P:** I'm just sort of reading through my notes, but I think kind of most of it I already knew, you know, sort of focusing in the present, sort of mindfulness. Not focusing on the things, you can't change, but then focus on what we can control. And I kind of recognize all of that, kind of know most of that, but it's always really, really good to be reminded when things are getting on top of you so it’s very good. I think my only… yeah and using distraction when you're feeling strong emotions, I’ve been using music to try and change my mood. I think my only negative thought is the, the audio, sort of exercises. I don't know I’ve done yoga before and I've done sort of guided meditation before, but I don't know, they just didn't really work for me. I don't know whether I was in the wrong place or the wrong head space, but I don't know whether it was the person's voice I couldn’t really get on with. I mean, I think what they were saying was good, but they just didn't really, didn't really work all that well for me. I couldn’t stop my mind from wandering, I wasn't really focusing on what they were saying, they weren't the best exercises for me

**I:** I don't know if you can remember which ones they were.

**P:** I think the most…(overlapping speech) Go on sorry.

**I:** I think a lot of them use the same, but there were just a few that were different…

**P:** So yeah, there was a there was a lady did, one of them, didn't she think that the body scan with the lady..

**I:** Ah yeah. That was me actually (laughs)

**P:** oh, was it? I didn’t know. I think most of them it was a chap so whether for me it would have been better for me if it was a lady doing that I don't know. Maybe I just didn't get on with his voice, sorry, I'm not sure. I mean, I'm not saying they're awful I just. They said a lot of the right things, it's just somehow it didn't quite work for me. I don't know why, maybe I just wasn't in the right space.

**I:** That is an important component of the exercise, so yeah.

**P:** But I think a lot of it was written, I mean. Also, it depends, it's different with some people take in written comments better, some people take in audio things better, don't they? So, it is good to have both. But, yeah, I think for me the written work is better. What was written on the website was good, you know, a lot of it is that the mindfulness and focusing on the present common idea and living with your emotions… accepting them.

**I:** yeah, yeah, and I guess. Yeah, I'm keen to ask you cause you've probably done lots of these exercises before as well. Do you feel they were particularly relevant to having MND or…

**P:** The audio exercises or the things that were written down?

**I:** The mindfulness exercises, I can't remember which ones. I think its compassion break and three-minute breathing space…

**P:** Again, correct me if I'm wrong, but on things like the body scan or compassion break and… Obviously for me, parts of my body don't work properly, not all of it, and maybe that would be the same for some of the MND sufferers, depends what stage you are I guess. But for me it's mainly my left arm and my right leg. And you know, exercises focusing on those parts of your body that are not working so well and kind of giving them a hug, you know, either I should be physically or just mentally, you know, it's showing kindness to that part of your body that’s not working. I don't think that was really covered. I think it's, as somebody who's got motor neuron disease, it's like parts of your body turning into aliens that just don't work anymore. And it is being kind, not getting cross with them, but ‘it's OK,’ ‘it's not your fault.’

**I:** OK, so that that's a helpful angle.

**P:** Yeah, I'm just thinking of it from the point of say motor neurone disease. It's easy to get very angry with your body that doesn't work. That's not helpful, but it’s about having kindness and compassion towards the parts of the body that are failing.

**I:** Yeah. Yeah, just in the as you know as well, there are many different kinds of mindfulness exercises. So yeah, it was a question about choosing which ones as well. Did you find any particular one more relevant to your situation?

**P:** I'm just having a little look through. I think they’re all useful, let me think. I mean, I think things like you know, the self-kindness letter and compassionate break, they’re all linked to what I was saying really, it's about being kind to yourself. I guess for some people like the Safe Place meditation would be useful. I don't think there's any that stuck out to me as being particularly you know, and I thought they were all good, I just, just don't think they were exceptional. I think, yeah, they're all useful but not amazing so…

**I:** So, was I guess in the whole list of different activities with the mindfulness ones, probably the ones you kind of least looked at when you were having some sort of emotional struggle or anything like that. It was more you were looking at it from the research point of view, I guess…

**P:** I think so, I think when I'm upset and, I've done this all my life, I've always sat down with a piece of paper and I've actually done, I think you actually did mention this in one of the activities, to sort of actually write down what the problem is, you know. I think being open about it and really say it like it is. And then the next stages is to accept, that’s how you are feel however - angry, sad, frustrated, you’re feeling that kind of feeling. And then kind of accept it and then hopefully you then move onto what can I do about it? Do I just have to accept it or is there something I can do about it? Is there something I can change or do I have to just accept? Or is there some way I can make it better, and I think you went through that process in one of the audio activities.

**I:** Was it a thought distancing one that was for unhelpful thoughts. Which is I guess, a similar process you’re identifying which ones are more problematic and just working out why they are that way and giving yourself a bit of space. So, you can think of either an appropriate solution or let go of. That troubling thought, that sort of thing. Is that what you were thinking?

**P:** That's what I've always tried to do. When I first started just writing it down somehow distances yourself from it, but it's there, it’s out there instead on paper. But it somehow, you can then look at it a bit more objectively and see what helps it or deal with it. But it's also just, it's like I put it out there, you know, it's a bit like talking to a friend, you could be completely open about this. It’s only on a piece of paper, it can go in the bin. It’s just between me and the piece of paper, but somehow it’s a way of writing it down, stating how you feel. It helps to calm you down really.

**I:** OK, so that was more you're go to technique or something like that?

**P:** It’s similar to a lot of the other things that you've mentioned.

**I:** No, that's absolutely fine. I'm just trying to work out how different people use it because everyone is different and their kind of strategies they use. Sorry, I'm kind of mixing up the different techniques now, but…

**P:** Well, anyway, I think you really asked you about the different exercises, and I probably haven't really answered. I think none of them really stick out as being particularly useful I suppose as well. They were all good, but none of them really stuck out yeah.

**I:** You mentioned the self-kindness exercises, compassion break and self-kindness letter and all of that. I'd love to hear what you thought about that self-kindness section really?

**P:** You know, I thought that that was good, and I think that's important, you know, I was saying from the motor neurone disease point of view, it’s accepting that your body is failing and, yeah, not getting too angry with that part of your body and being accepting of it, being kind to it. You have to be kind to yourself, it’s an important thing when you go through something difficult. So yeah, I thought that was good.

**I:** OK, thank you. Did you try the self-kindness letter?

**P:** I didn't actually no. A lot of the other things I did, I did I didn't actually do that, but it does make me think that I need to be kind to myself more.

**I:** Yeah, I'm just asking, not a lot of people do use it, but I thought maybe since you like writing down stuff…

**P:** However, the fact that you don't do it doesn't mean the thought hasn't gone in yet. It is putting that seed, it's good to be kind to yourself cause what you're going through is horrendous, so don’t beat yourself up for it.

**I:** Yeah yeah, no it is quite… you have to be in the right headspace as well, and so difficult one to do I guess yeah…

**P:** Even if you don't write the letter, you can still think about it. It has still planted a seed, a thought, which is good.

**I:** I wondered if you looked at any of the practical tips or were they stuff you already knew really?

**P:** Are we, still on adjusting to change?

**I:** Yeah, so within each of those specific emotions there was a suggested activity and then there was also practical tips, mainly because I just know that some people prefer to do things rather than you know, maybe do an activity about an emotion or that sort of things. So, I just wanted to know how that information was conveyed and whether it was relevant?

**P:** I mean, I think I wrote some of them down because I didn't want to forget that. You know, for anger, you know distraction going out into the fresh air, watching TV, music, relaxation. All practical tips which I think is very good. You know, it's sometimes you’re just full of emotions and you just need to just go and go out to garden and watch some TV, put some music on or lie down and be calm. Sometimes there’s just not that you could do, that's how you feel, so distract yourself. So, I was gonna go on to sadness, I've got here lots of practical tips for sadness. I mean, I thought they were very good, you know, expressing your feelings, focusing on the things you can control rather than the things you can't control. I think that's really all about the values and goals and setting those. I mean, I always remember Stephen Hawking saying that the best thing to do for motor neurone disease is not focus on what you can't do, focus on what you can. And I’ve adopted that kind of phrase, you would drive yourself mad thinking about all the things you can't do.

**I:** No this is all really useful stuff. So, it almost served as a reminder to do when you were feeling down or something like that, OK?

**P:** Lots of very good practical tips I think of things to do and as I say I've written them down, so you know I’ll have them there in the future as well.

**I:** OK. Yeah, was there anything else with this section?

**P:** I don't, I don't think so. I thought, you know, I think there's a lot of good points that were made, I thought it was good.

**I:** Was there anything else maybe that you wished was there, that wasn't?

**P:** It would I suppose only just to repeat myself that you know, adjusting to changes, it’s the grief of letting go, which I think have all the mentioned. It's just, sometimes for some people to move forward, they have to actually acknowledge the sadness and grief of what they’ve lost. But I also took your point that you didn’t want to dwell on that because its distressing for people. It's a difficult one I mean, maybe include it or not, that comes down to what you want…

**I:** Yeah. But I think that's that'll probably be useful in this section linked to sadness as well, because you are already talking about it, yeah?

**P:** it’s that letting go and saying goodbye to all my hopes and dreams really.

**I:** OK, I'm what about the anxiety and stress section, I guess some of the techniques will be similar…

**P:** There is quite a lot of similar things, I think.

**I:** Yeah, but maybe anything more about information…

**P:** I'm just having a look at my notes now. (pauses) Yeah, I mean as I say it, I just think you’ve made lots of good points, you know, got here self-kindness, supportive, it's being caring towards yourself, but it’s asking for help as well, changing your expectations of what you can do, accepting that adjusting takes time and then sort of focusing on nice activities, distract yourself, plan ahead, thoughts for the future. So, it's trying to take away your negative thoughts and say, ‘well, OK yes, well all that's true, but focusing on it isn't going to do you any good.’ You've got to focus on nice things and nice activities and plans for the future that you can do. Try not to dwell on the bad stuff, move your thought processes to things you can do and positive thoughts. And that, you know, it's within your control to do that, it's just, it’s a bit of effort. We’re all guilty of swirling around with those negative thoughts, and you have to stop them and try and take charge of them and go ‘no, we could do this more positively’, we could stop thinking about how crap everything is, and actually sort of say ‘well, we can still do this, let's go do that, I like to do that.’ You know, that's really what we've been talking about.

**I:** OK, OK, so almost getting a sense of control over that you can do something about this situation.

**P:** yeah, I think with this, because it's dealing with feelings, worries, stress, frustration that you do have some control over your thought processes, when you are feeling worried and stressed and frustrated, how do you stop those feelings? Or at least put them to one side and then try and, change the record to be more positive. That's what this section is really all about, I think it’s about changing the record. Now that takes practice, it takes a bit of work. I think you’ve covered all the things that would be good to do, nothing else you could do. It’s just focusing on new values, new goals, new ideas, positive thoughts, all the nice activities that you still can-do focus on that, things you can do.

**I:** Ok I guess my next question is kind of through all across the sections really, were there any activities that you have already sort of hinted at this, but some you already did or knew about and some that were new or that you, found particularly relevant?

**P:** I think probably the maybe the best activities for me were you know, the values and the goals and finding the positives which we covered in the previous sections, so I think that's been helpful to me. I think I'm up someone that likes to look ahead, you know, so having some new goals and new values is very useful, it’s a positive thing to focus on.

**I:** OK. I just wondered if you tried things like this as well before or… Not necessarily in an MND context, but I'm just judging like familiarity as well with them, so I know you've tried some mindfulness ones before, but the other ones were fairly new weren’t they?

**P:** Yeah, so I certainly did mindfulness before. I think I'm aware of some of the CBT sort of thoughts.

**I:** OK.

**P:** Send I haven't really actually taken any, you know, courses are all supportive courses, but I think it's just throughout my life I’ve perhaps just picked up ideas like this from different things I’ve heard. So, I don't think any of it was particularly new in that I’d never seen or heard of these techniques before. But that doesn't mean that it wasn't good to use the website, because as I say it's good to be reminded and as I say it was quite a powerful website when I first went on it, it really made me stop and think. So yes, just because you know of something, it doesn't mean it doesn't hurt to be, ‘Oh yes, of course I should be doing.’

**I:** Just typically when you cope with any difficult situation, do you use some of these similar ones anyway?

**P:** Yeah, I think as I said to you before, you know what I've always done when I come up with difficulty is just sat down quietly with a piece of paper. Really a lot of the techniques you said there is just to focus on the present, focus on the emotions, but it's also by writing them down and that actually is putting them over there as well, owning them. But then also separating yourself, and then try to move on, but recognize the emotions, put them over there then think ‘right, what am I going to do about them now?’ I think that’s a lot of the techniques you’ve used in there is acknowledging the problem. And also sort of trying to push it to one side slightly, not that it’s forgetting about it, but it's just that you've owned it, but now you don't have to focus on that anymore. We can focus on what you’re going to do next. It might be dealing with it, might be distraction, it could be lots of different things, but it's like, ‘OK, we've owned the feeling we're going to deal with it now, we’re going to move forwards’. And that’s a technique I’ve used all my life, which is some of the technique that you’ve got there.

**I:** Yeah, yeah. Uhm? I guess as well. Did you have a look at the other support section pointing you to other resources?

**P:** I did, which was which was good and then obviously I mean the motor neuron disease association is an important thing to mention there, which I'm a member of. I don't know whether that could be expanded at all, but this is really difficult one. I’ve had no counselling or support since I was diagnosed. I have actually raised that with my support coordinator, and she has said to me that if I want to go out and find myself a counsellor, but it will, you know, I can get some six sessions reimbursed but. The whole focus actually seems to be I've got to go and find somebody. (indistinguishable speech) I mean if I went to my doctors with a physical problem and they said, ‘oh well, you go and find yourself a physio.’ It wouldn't be very good, would it? Thinking ‘oh I've got to research physios on the Internet,’ I don’t know what I'm looking for, what kind of physio I need? That doesn't happen, the GP says ‘alright I’ll refer you to a physio’ and I'm just disappointed that my consultant doesn't have a list of appropriate counsellors, that I wasn't given when I was first diagnosed. Just told you can have six sessions. And I know that's nothing to do with you and I'm having a moan really, it’s another issue. But I think everybody who is diagnosed with motor neurone disease or any other life-threatening disease, should be immediately offered counselling from somebody who is trained in that area. Six sessions, I mean I know the NHS doesn't help in that area, but six sessions would be helpful. But I felt very much I had to go out myself, and if I want to do it, I've got to go out and find someone myself. And they might not be appropriate, they might not be fully trained in the area I need help. I'm a bit disappointed, really.

**I:** Yeah, no this is a very relevant point, and like I'm learning more from people that I speak to than some of the professionals, which kind of goes to showing you how little information there is out there. Yeah, so it differs so dramatically based on where you are and how the different services are linked, so yeah, I was just keen to know whether you actually found any support or used any support?

**P:** I haven’t yet, as I say the last three months have been very busy. So, it is perhaps something I will think about doing. But I think it's a shame, I mean in your other support area it does say ‘oh, look for somebody who is trained in CBT or acceptance and commitment therapy.’ But you know, again, it's still, the onus is on me to go and research somebody and it's an area I know nothing about so… People have specialists in different areas, you know, with the counselling and it… I don't know what I'm looking for, I don't know quite… I guess it's yes, dealing with a serious disease, it's looking at that aspect. I just kind of wish somebody would give you list, so you could just go and ring around and see if you've got a vacancy, or just to get put on a list as soon as they have any counselling available, I don't know. That's what happens with physical problems, isn't it? You get put on the physio or the OT list. You don't have to go find your own physio or specialist, you get put on the list to go and see one.

**I:** This is really useful feedback also for any future iterations of this, to have a bit more practical support actually available there…

**P:** I think if you do sort of give this out to consultants you know, across the country, I think stating that people do need counselling. And I’ve been diagnosed in a rural area with sort of no luxury of supports throughout that. And I think that’s quite appalling really, and I appreciate it being publicly funded, but you can do counselling over a Webchat, there’s no reason why I couldn't have had some counselling, but I haven't been offered any at all.

**I:** And yeah, OK, and back to your care MND care team, I guess they haven't necessarily pointed you in any...

**P:** My area coordinator I mentioned it to her and her answer was if you find somebody we will reimburse you which is helpful. But it’s putting the onus back on me to find something, which isn’t really what I wanted. I wanted to be just there you go, she's been doing lots of counselling for motor neurone disease in the past, you know, she understands completely what the disease involves. You kind of just want to be put on the list for counselling, not have to go research it yourself.

**I:** Yeah, OK..

**P:** It’s probably worth mentioning to consultants, it would be helpful. In conjunction with your website, which is something that people could use for longer. It could be like she wants counselling, or you could have both, not everybody wants to have one to one counselling, some people would prefer the website but it’s having options, isn’t it.

**I:** have you also tried any of the support groups I can imagine this might be difficult with not actually physically meeting people with Covid and restrictions and all the that…

**P:** We have a support group in the area which, well that's like a zoom meeting you have once a month, so I don't join every month, but I go along sort of when I can, when I’ve got time. So that's been useful, as I say it’s (name of person) that coordinates that, and it’s once a month, it’s not been happening more. And also we have (name of hospice) in the area which is a hospice, I think that'll start to open up more now as things are opening up. I’m aware that that exists so, as things lift I will get more involved with as things change.

**I:** OK, OK. Yep. I think have we covered pretty much all the sections…

**P:** I think so, as I say on the whole, you know, just sort of in summary, I thought it was very good website, thought it covered a lot of really good things. And my only criticisms really were just perhaps things that you could add in, not to take anything out, just a couple of things you could add. I didn't really sort of bond with the audio exercises so much, but that could just be me or the time, but on the whole very, very positive in the feedback really. And I'm not trying to be negative, I thought it was really good

**I:** Thank you.

**P:** You know you can always put more in, but it’s very good

**I:** Yes, I just wanted to ask you a couple of questions whether has anything changed for you in terms of managing your emotions after having used the website?

**P:** Sorry, I didn't quite catch the end of that.

**I:** Has anything changed for you in terms of how you deal with your emotions after having used the website?

**P:** Mmm, I don't think so. As I say I think I mean the values and the goals and finding positives, and that's really important and that's been a big, you know, quite large importance in life and I think it was very good to focus on those. So that's something that will happen over this year, so I think it's probably a gradual process. I haven't noticed any immediate change, but I think that I've got some new goals and new focus and it’s going to be really positive over the year to help me to stop dwelling on the things I can't do and focus on the things I can. So that’s very positive I think.

**I:** Yeah, I'm aware it's also quite a short time, just about a month, and I'm asking you to probably do a lot of reading, try it out in your life and all of that. So yeah, I just asked in case there was something. Yeah, OK, and just another question, do you think the timing of this sort of website makes a difference, in the sense that would you have heard something like this earlier on, or did it kind of come at an appropriate time for you as well in terms of how far you were from diagnosis?

**P:** Gosh, that’s an interesting question. I think sort of straight away, you know, sort of, if I had it in the next week, I think it would have been too soon. I think you go through shock, I think, to start with. And I think you're not really able to take in very much maybe, for maybe a month or so and you are just going through shock and grief and acceptance of the diagnosis. So I think early on, you're not really responsive to very much, I think apart from this shock and grief, so that's probably not the right time. I think some time needs to elapse until you’ve actually accepted the diagnosis, because that does take time. I think my particular motor neurone disease does seem to be progressing more slowly than someone with another diagnosis. I have been diagnosed a year and I am still just about able to walk a lot of people can’t. So I think for me it came at a good time because I'm starting to feel, things are starting to fail more and walking is getting more difficult. Probably a good time for me in the sense of having to deal with the changes at the moment. I think things are changing more rapidly now than they were before. Initially I really only had a left hand that didn't work, so not a huge discomfort or difficulty with life, whereas now I’ve got a lot more problems to deal with. So it might vary from person to person really as to what stage they’re at in the illness. I definitely think the first month, you just need to, maybe just let people get used to it. The first focus I think is telling people that this was what they dealt with for some months, because telling people is hard. And I think you're so wrapped up in that, perhaps you haven’t got the headspace to deal with everything. It's a difficult one, I think it depends how people's diseases are progressing down the road, 'cause some people are progressing much more rapidly than me, and this would be very useful for them you know, at the times their bodies are changing. I think that time has probably happened for me this year, so it's actually been at the right time for me, to do things. It’s probably a bit of a waffly answer. It’s the difficulty of motor neurone diseases it affects everyone so differently, it’s a hard question to answer. So probably after about two months of diagnosis, is perhaps the right sort of time, and then something like this would be useful.

**I:** Yeah, that's completely OK. You can only answer how it's relevant in your situation, so that makes sense to me though. I think I've asked all of my questions. I don't know if there was anything else maybe you wanted to add to anything we missed, or not spoken about?

**P:** I don't think so. Yeah, I think really up just said my thoughts along the way, I think that’s probably everything I’ve thought about, yeah.

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