**Interview 5**

**(person with MND)**

**I:** You should see some kind of message saying it has started, yeah? I mean, yeah. (says it’s recording) Yeah, just like that...

**P:** This year with technology my, it's improved immensely. Not you know, I mean, it's still not there but yeah, I'm learning new tricks all the time.

**I:** Yeah, yeah. So I guess just to sort of understand a little bit of background about also just when you got your diagnosis as well. And whether you had any kind of things you were struggling with mentally either before or now?

**P:** No, I don't think so. I'm, I'm quite savvy, you know. I mean, I was in the army I suppose they prepare you for life, you know what I mean? And when you’re tired in the army, you just get on with it, you know? Umm…no, as I can say when I got diagnosed with it, I didn't really know what it meant apart from the fact my uncle had it. And I see him in a wheelchair and so on and so on, you know. So then you think, ‘ooh is that what the future holds for me?’ But then who knows I could get run over by a bus tomorrow so I'll never get to that stage, you know what I mean? So there’s no point in getting down on it.

**I:** Yeah, and you mentioned before when we were chatting as well, that there's no major issues but like sometimes there's you know, frustration with doing things or something like that. Yeah, what are like, when does that usually happen and how do you kind of overcome it?

**P:** I just started going over things in me head now, I used to get really frustrated. Then I've got family and friends around to help me out with things. But if that's not possible at the time, it was hard, but I just I think we’ll will wait until tomorrow then, we'll sort it tomorrow, you know what I mean? We'll put it off, we'll put it on the back burner, you know, and things, you know what I mean?

**I:** Yeah, yeah. Yes, also, I guess when you saw the advert on the MNDA website or something like that, what came across to you that this website was about really?

**P:** It didn't, that’s what I'm saying, until I actually sort of looked into it. Like I said to me it was more focused on the mental side of it, not the physical side of it and the financial side of it, because that has an impact, you know what I mean and all the different things that go with the condition, like you know, being able to do things, falling down, and choking at night, you know, all these things. It didn't really give me anything that I didn’t already know, you know.

**I:** Yeah, so uhm. I think I briefly saw you had a look at some of the sections so you’re saying things like when they spoke about anxiety or anger or all of that, that was not really relevant to your situation?

**P:** No, not really. I think… when I was out of the army and I was a lorry driver etc, and I met a girl and she already had a son who had Duchene's muscular dystrophy, and her husband and she was caring for him. Yeah, I mean and I could see the frustration on his face and he was in a lot worse position than me, you know? So I think it's learning from other people and things that have happened, you know. Like I said, my uncle had it, but he also had COPD etc, you know what I mean? So different circumstances, different situations and so on. I know me Auntie, she used to put him into respite care and because she couldn't cope with the daily, you know, cleaning and all the rest of it, I mean…

**I:** Yeah, yeah.

**P:** When I…should I reach that stage, I don't know what’s around the corner for me. I was hoping there maybe something on the website that could tell me.

**I:** OK, so sort of how to manage practically when you get to that situation…

**P:** I mean, obviously there's different people at different stages, and it be nice to know how they have like, overcome the barrier, you know what I mean? Or how they cope with you know? 'cause I live alone now, you know what I mean. I've got my daughter, she helps me out, you know, just helps clean and stuff like that. You know as well there’s always something, it’s a degenerative condition so things are gonna get worse.

**I:** OK, OK, I see so you were looking for something that showed how you'd overcome barriers especially once it got worse...

**P:** The way different people have coped and managed, you know different situations, things like that. Not the case of you know, listening to calm music, doing this, doing that. I'm not saying it doesn't help some people, I'm sure it does, you know. Like I say to me it’s more of, well if I'm gonna try this out, what would be in the best way to do it. And somebody might have already been and done that and succeeded, you know. And then I could follow that step and be ‘yeah, that's a good idea.’ You know what I mean?

**I:** Yeah, I mean yeah yeah. I'm very interested in this because we’ve got a couple of like mixed opinions about this as well. But would you be OK with hearing stories and examples of people where they're kind of worse off in a sense, or you know, it's gotten bad and how they've overcome that?

**P:** Yeah, I think it’s about what may happen, it's not necessarily going to happen, you know. I mean, you get an insight as to what may happen and how they’ve coped or have managed and got over that, you know what I mean? I mean I attend the MND Clinic up at [name of hospital] and I see people there obviously a lot worse off than me, you know. And I always wonder how do they cope with things? Maybe that's when the men outside of it will kick in with me, I honestly don't know. But at the minute I'm fine that way, you know.

**I:** Yeah, that’s absolutely fine. And a lot of people have said as well, like the information is fine, but I may have, I mean look at it maybe later or maybe earlier on or something like that, so that's fine. Uhm, I was just wondering was, 'cause there was a section on positivity, I don't know if you remember, but just encouraging you to do more and more sort of positive activities so it's more for doing things, but it also improves your mental health I guess.

**P:** I always set myself a challenge. It's like I said to my brother at the minute I've got a C4 grand Picasso car and I’ve had it for a long time now, since 2010 but it’s new on motability. It was fitted with a hoist in the boot so I can lift me scooter in and out. And to me it's all about keeping me independent, yeah. Now I've come across a nice scooter, where I live the practicalities of getting a scooter in and out of the house are, I mean, they're not great. So I can’t go for a big scooter because it won't get in the bungalow, yeah. So going for a medium size scooter with suspension, you know what I mean? But I can't get this in the car it’s too big to fit in the car. So it’s a challenge now, and I've been looking around at different opposition [options] you know, how I can get over that barrier. So I think you know, I mean, I would have to change me car for another one. I can't go too big 'cause I can't get in and out of a big car, you know what I mean? So this is what I’m coping, I’m dealing with at the moment, is how to solve that situation. There's no rush, I'm happy I've got my small scooter that’ll go in the boot. I can use a big scooter for going round local, not a problem. So well, if I can get it, if I can get a big scooter in the car, it’ll be happy days you know. So it’s just little things that you know.

**I:** OK, OK, So you kind of already have that kind of mentality, but you were probably looking for more practical tips and how to do it?

**P:** Yeah.

**I:** No, that's fair, that makes sense. I guess you mentioned also support groups and or I don't know what they're called coffee mornings maybe? Do those sorts of things also help?

**P:** It’s all online…

**I:** It's online because of covid stuff…

**P:** It’s online and all a bit awkward, you know what I mean? I mean this online stuff, this is all new to me now, I don't…I don't do Facebook, I don't do Twitter, I don't do any of that, you know what I mean? One, I can't handle some of their rubbish that’s on there, and another it just goes right over my head, you know. I can do the phone and WhatsApp.

**I:** OK, that makes sense. Just out of curiosity as well, if you did have any concern, sort of with emotions or things like that, would you know whom to contact or how to get help with that kind of thing?

**P:** I’d probably approach family first before anything else and then go from there. But like I say, you know people come to me with their problems at the minute, you know what I mean? But maybe that'll happen in the future, but like I say I'm a, I'm a I'm practical sort of person. I always try to find a solution to anything, you know what I mean? I don't get down on things, I don't…like I say it's more frustration, yeah it's more frustration than anything. I mean, you know when people say, ‘oh you're coming down there’, I can't go down there 'cause of the steps. Right but they don't see it you know what I mean? It's, you know…

**I:** Yeah yeah, that's fine. Just trying to work out like if you would have liked any more information or anything like that, but it seems like more of the practical…

**P:** Yeah…or how other people, I'd like to know how other people have experienced. Like for instance I’m experiencing the issues with my car and my scooter at a minute, how they have, you know, coped with different things, you know what I mean? I mean obviously some people will have a partner, who can help them out more. You know, I mean and then obviously some people in the same position as me and won't, you know so. Yeah like I say, it is what it is and you just have to get on with it.

**I:** Yeah, that’s a good attitude to have. Yeah, uhm, I just wondered if there was anything else you wanted to say it or can I stop the recording?

**P:** Yes, stop the recording if you want, that’s up to you, if that’s the information you wanted…

**I:** Yep, but just generally anything else in terms of, I don't know, how you cope with things or where you get support from, but I think we've covered that?

**P:** Yeah, OK.

**I:** I'll still be on the call, but I just stopped the recording.