**Transcription of Interview 4**

**Interviewer:** Thank you again for agreeing to be interviewed today umm like I said in the beginning this interview is about understanding your experience with MND and just a couple of things, if you want to take a break at any point to stretch your legs or…

**P:** Sure

**I:** (...) Just let me know and we can pause the recording and umm if you find any topics difficult or challenging as well, we can just skip over if you feel you don’t want to answer them. Another thing to say is that all the information that you tell me will be confidential, so, if you say any names of people or hospital or things like that it will all be confidential. So, I guess, first just ask you what your experience was with MND and you can start wherever you like, really.

**P:** Well I am sort of an unusual case in that I’ve had it for quite a long time. I was diagnosed in 2003, so, 15 and a half years ago and the early signs without knowing that’s what they were. Actually, started probably a year and a half prior to that. Umm, and it started off with feeling extreme fatigue and I was starting to find it difficult to walk upstairs. Then, I started to develop a limp in one of my feet, in one of my legs. It took a good year and a half and three visits to my GP to finally get a referral but that was to physio. He referred me to physio, and it was the physio therapist that picked up on the fact that I really needed to see a neurologist. It is, you may know this, it is very difficult to diagnose MND because there’s no test for it. They have to eliminate other things and if you got certain forms like say bulbar or more aggressive form of it, it can be diagnosed quicker because it is advancing so quickly. But the form that I have is referred to as lower motor neurone disease and because the symptoms could have been indicative of a number of different things and it was so slow, very very slow progressing. That’s why it took so long to diagnose. At the time I was diagnosed, so this would have been the summer of 2003 and this was by the professionals at the MND clinic at [name of hospital]. They estimated life expectancy of 5-10 years, so, here I am, 15 years later... more than 15 years later and though I have got considerably worse since then, by MND standards, I’m still reasonably umm in good condition, [laughs] I guess. It’s the best way to put it. Umm, early on shortly after diagnosis, I was referred by my GP to a… at that time I was living in [name of place]. I was referred to a local charitable organisation called the [name of centre] which is in [name of place]. They provide help and support and counselling to people with life limiting illnesses. They deal often lot with cancer patients but MND falls under their umbrella, so, I was very very fortunate to get some excellent counselling. It started off with one-to-one session which probably went on once a week for about 6 months and then I was able to join a group session for another… I probably did… I’m trying to remember maybe another 3-4 months, once a week and that counselling made all the difference between being able to live with MND and not. And I have never looked back since. I haven’t had to get talked up, if you’d like. Prior to that experience, I was sceptical about counselling. I had [hesitant] had not such a great experience years prior to that and umm, I kind of… like I said I was sceptical about it but you know, it’s like with anything, there are good and bad doctors, good and bad paint decorator, there’s good and bad teachers and there’s good and bad counsellors but this woman that I had was excellent. You know, I felt comfortable with her and like I said, it made all the difference.

**I:** What was the situation that led you to seek counselling?

**P:** Well, I was devastated by the diagnosis and I was only 45. I come from a long line of women who live well until their 90s so I thought that I have been robbed off half of my life. I had been up until then, very fit and healthy, and active and umm you know, it was a devastating diagnosis and umm, it was difficult to come to terms with initially. I went through a roller coaster of emotion, went through a bit of denial and then depression and you know, it was sort of going through all of that, struggling to deal with it that I was then referred to the [name of centre].

**I:** How did the counselling help? I mean you briefly touch upon it, could you tell me a bit more?

**P:** Well, I had come into it thinking it would be specifically about dealing with the diagnosis. But actually, there was a lot of [pauses and hesitant] it… I don’t think there… there was no prescribed way of going about it but it enabled me to deal with a lot of issues from the past that umm, I hadn’t previously dealt with, emotional issues and umm, I guess it sort of helped put those things in perspective and to get over certain things that you know, some emotional baggage that had been holding me back throughout my life. But I wasn’t, I guess really aware that it was holding me back but it was stuff that was umm [pauses], causing unhappiness in my life. And so… I remember the first session speaking to this counsellor and I remember saying to her this was when I was feeling quite down about it, I felt like my life had been reduced to well, I had a shit childhood, a failed marriage, now I got MND and then I die. It’s like suddenly that’s what my life felt like it… it just one big great negative and that’s what sort of opened up you know, obviously there’s other issues there and it was being able to deal with these other things that it enabled me to deal with the present situation, and move forward with it.

**I:** Okay, so it was more general?

**P:** It was quite… yeah holistic, it wasn’t right now you’ve been diagnosed with this terminal illness, let’s talk about that. It wasn’t that at all, it was dealing with whatever it was that I came to the table with and it happened to be that there was other emotional baggage going on in the background.

**I:** Yeah and have your thoughts and feelings change since the diagnosis?

**P:** Oh tremendously. That counselling enabled me to like I say, find a way to live with MND, in a positive way. It also, I guess it became a bit of a liberator. This might sound strange but once the worst thing that can happen to you has already happened, it’s like everything else just becomes small. Small for I. So, I don’t get stress about stuff very easily now. I used to be a stress head and I don’t, now. So what? What’s the worst that could happen? Oh right that already happened. It also umm, I got a newfound confidence because I didn’t care what anybody thought. I didn’t care about consequences, and I don’t mean… I don’t mean like I was just going to go out and do reckless things and commit crimes or anything like that. It was… I guess maybe consequences of, “oh don’t do that, you might hurt yourself”, and so? You know [laughs] or [pauses] I didn’t care what people thought of me. It was their problem, not mine and it also umm, [pauses] I guess I had been a lot more shy prior to that, like lack self-confidence and that kind of went out of the window. Maybe that might be that the counselling kind of lifted that emotional baggage and cleared all of that and that might have been, you know affecting my self-confidence. So that might have something to do with it, but umm, like I say it was just a kind of a liberator, so I’ve pretty much ever since then just got on… try to get on with living as much as possible. I am someone who is living with MND, not someone who is dying of it.

**I:** How is it like living on daily basis? What is that experience like?

**P:** It’s jolly hard work at times. I mean, I’ve been lucky in so far as because the progression has been so slow, it’s easier to get used to the changes whereas someone where it is progressing quickly, you know the deterioration can often be tracked from one week to the next. They you know, get worse and worse whereas I’ve had… I’ve gone through plateaus where maybe I go for 18 months without anything getting worse and when it does, it’s a gradual decline so I’ve been able to get used to it. But absolutely I’ve had to make major adaptations in my life. I do find it extremely frustrating the things that I can’t do anymore, that I used to be able to do. You know sometimes, I try not to let it get to me but sometimes, occasionally I might feel a little bit down about it if umm, if there’s something I can’t do but I’d like to do. And disability can also be extremely isolating. For example, of my local friends, there’s only two of them whose homes I can physically get into because there are not accessible so then, you get situations where you know people that I regularly have around to my house. You know if they have a party or something, I don’t get invited because I can’t get into their house and you know that kind of thing happens a lot at Christmas time. You know, they don’t want to hurt my feelings so they don’t tell me about it but then I find out like and I had quite an awkward one this past Christmas, where a mutual friend said, “Oh you’re going to [name of friend’s] on Friday night” and I’m like, “Umm, no. Haven’t been invited” and she’s like, “Oops” you know. So yeah, living with it is challenging at best [laughs].

**I:** I guess, you mentioned at certain times you do feel a bit down. Can you tell me a little bit more about those experience?

**P:** Sure, [pauses] I think a classic… a typical thing would be for example, I … a number of my friends frequently go on umm, holidays abroad or you know travelling here and there everywhere. It’s very very difficult to travel when you’re a wheelchair user and it has got to the point where the last time, I flew was probably about 10 years ago and it was such a nightmare. It’s put me off flying ever since and you know, just all the physical, practical aspects of trying to do international travel when you’re a wheelchair user and disabled to the extent that I am. It’s just too difficult and I had always thought because I used to work all the hours that God sent and ran my own business, when I was able to get time off I would usually go back to the States because I have family there and my parents were getting older and older, I kept thinking well…and here I am living at the Europe doorstep and really wasn’t able to travel and see very much of it. But I kept thinking well you know my parents aren’t going to be around forever and you know, there’s that kind of feeling of obligation to go back and visit them and stuff and I thought well I’ll do all my travelling in my retirement. Well, that’s not going to happen now. So, it’s like a great sense of loss. It’s something that all these places that I would love to go on to, you know, my son and his girlfriend just left this morning to go travelling for 6 weeks to Sri Lanka and the Philippines and it just, you know, I feel quite jealous about it. Another friend is off to New Zealand for a month, umm, and another friend just gone to India for a month. I feel like yeah great here I am in [name of town] [laughs]. So, it’s that kind of thing that can make me feel a bit down. I don’t let it, I try not to let it drag me down, try not to dwell on it. But things like, like I mentioned about, not being able to… being excluded socially because of my disability. Umm, that’s the kind of thing that’s probably more likely to get me down. If I can’t go to something that a group of friends are going to because it’s not wheelchair accessible. You know, that kind of thing would make me feel would get me down because of that isolation. It excludes you.

**I:** Okay. What do you do in those situations to help you…?

**P:** There’s a very good friend I have who umm, I can talk to just about anything and so, he’s very helpful about being supportive in situation like that. I might you know, it might, get me to a point where I get a little bit cry or you know, feel sorry for myself for a little bit but I try really hard not to lapse into deep depression. One strategy that I have learned which has been quite effective and this came out of that counselling was, I used to think about what I used to have, my physical abilities, what I used to be able to do before MND and I would get down about that. Almost like mourning the loss of it. That would get me feeling bad about I can’t do this anymore, I can’t do that anymore, and then on the other side, there’s the worrying about the future because you never know exactly what course the disease it would take, it takes a different course for everyone. You just don’t know exactly what’s going to happen and when, so, I realised there’s absolutely no point in dwelling on the past because there’s absolutely nothing I can do to get that back. So, it’s waste of energy and there’s no point in worrying about the future because there’s absolutely nothing I can do about it. There’s nothing I can do to control that and again it’s wasted energy, wasted emotion. So, what I kind of taught myself to do is try to live in here and now because I do have some control over that and if I find my mind wandering towards dwelling on the past, or worrying about the future, I mentally picture that those things are in a room, so, there’s a room of the past and a room of the future and I just close the door on it and I walk away. I felt fine like I kind of gone into that room, “oh stop! Come on, just leave the room, close the door”. That has been a very very useful strategy.

**I:** First time I’ve heard about it, that’s really interesting.

**P:** It wasn’t specifically something that the counsellor taught me, but it was a result of talking about umm, dwelling on the past you know, you can’t… you got no control over that worrying about the future, I’ve got no control for it. So, I just kind of just developed that strategy for myself about giving myself a mental image. So, what I have been able to do as a result of that is try to make the most of what can I do now, and that’s what I concentrate on, is doing what I can do now and not dwelling on what I can’t do anymore. That’s been an extremely powerful strategy that has enabled me… I believe, keep fairly busy and active.

**I:** Yeah, umm, just because I find this interesting. Are there any other strategies that you actually used, maybe were not as effective or were better?

**P:** Umm, [pauses] nothing immediately comes to mind. If something comes up, I’ll say. But I can’t think of anything straight away. I mean that has been my… my really go-to way of dealing with it.

**I:** This is the main one you used?

**P:** Yeah.

**I:** I’m just going to look at the questions… and I guess you mentioned, your friend and a couple of other strategies you used. Are there any other things that give you support?

**P:** In what way?

**I:** In kind of coping with MND.

**P:** Umm, well yeah. Actually another one is that umm, I [pauses] I remember right at the beginning saying I don’t want the rest of my life to be about MND. So, I wanted to concentrate on just trying to live as normal life as possible and as a result of that, for about the first 4 years, I didn’t want to have anything to do with the [charity organization]. I didn’t want to get involved, I didn’t want to know about it because it was almost like, if I get involved and go to the local group and stuff, it’s admitting I have MND and then, you know, I kind of, mentally dismissed it and I didn’t want to know. I just wanted to try to, like I say, keep my life as normal as possible, which in the early days because my level of disability was so much less than it is now. To a certain degree, that was somewhat possible but pretty much straight away, I wasn’t no longer able to drive even that, that was a big impact; losing my independence in that regard and I’m a fiercely independent person. So, that was difficult, umm, but then it was, just out of the blue, I don’t know if you’ve heard of this the [charity organization], one of its regular fundraising events is they do walk to defeat of the MND. Well, you know they got all sorts of fundraising things that you can get involved in, but this is one where every year usually during the month of June which is the MND awareness month, they encouraged people to do something, to do a walk to defeat event or some sort to raise money. It could be a whole group of people, maybe walking a couple of miles, it could be one person walking from Land’s end to John O’Groats. It could be a group of toddlers walking around their playground, it could be anything you know, a couple of people. You just come up with whatever it is you want to do, and you raise money. And I decided it was… I was pretty sure it was the summer of 2007, I kind of heard about this and I just… at that point, I guess I decided I was ready to get involved with MND association and I thought I knew of someone else with MND, someone of her friends and family were gonna do the walk to defeat and raise a bunch of money and I’m thinking… the chances of getting my friends to do a walk was gonna be slim but I knew I could get them to turn up to the pub and at the time where I was living, the local pub is literally around the corner from my house and I thought, I was saying this to my friend, he was also my colleague at the time we used to run this business together and I said, “You know what, I’m gonna do a walk. I’ll do it myself because I’m not gonna be able to get anyone else to do it” and he said, “what are you talking about?”, and this was when I can still walk but I needed assistance and I said what if I walk from the house around to the pub, and then we can have like live music at the pub afterwards and barbecue and you know get the pub involved and get sponsors and all of that and he’s like, “oh you can’t do that, you’ll hurt yourself” and I’m like ooh red rag to a bull. So that was it and I thought well I’ll do it and I got him to measure out, you know just kind of pace it out 28:55 we worked out it was about 2225 yards and we have no idea if I’d be able to do it or not and I worked out, I had my son and a friend either side of me and I was holding onto them. And you know, the pub was full on with it, and I was signing up sponsors beforehand and you know, the whole business and I was hoping maybe raise 500 quid or something and I lived in a… it’s just a quiet lane and so I was expecting that you know, friends and stuff would be there waiting at the pub for me. Well, left the house and they were all waiting at the front of my house. They were all waiting in the street and they walked with me [started to tear up]. It was… and the local press came and well one neighbour around the corner had set up a rest station with a chair and a glass of wine for me and you know, and it was great and umm. You couldn’t have driven a car at that road that day because it was just full up with people and it was called the shortest walk and it raised over £5000 and it put me on the map with MND association and I won an award that year for the individual who raise the most amount of money. As a result of that because I’ve been very involved with public speaking and such, prior in my previous life… MND association asked if I would be interested in getting involved with things and so I did quite a lot… I went from not wanting to have anything to do with MND association to being fully immersed in it and became a spokesperson for them and spoken at a lot of different events, either fundraising events or healthcare training events or umm, you name it, talking to corporate sponsors, talking at the MND association, AGM, Houses of Parliament, you name it. I quite revelled in doing that, quite enjoyed it. It kind of a sense of empowerment because it was here something positive I can do as a result of it and I’m still involved with it, not quite as much as before but still involved with doing stuff like that. In fact, I’m taking part in an all-party parliamentary group event at the end of February at Westminster. So, that has been kind of another way of umm, dealing with it. Like I say, one aspect it was almost denial and not wanting to have anything to do with it to immersing myself in it completely.

**I:** How did that change happen, really?

**P:** You know sometimes things… you don’t really understand why and suddenly you’re just ready for it and you know, up until then I wasn’t ready for it and it was almost a spur of the moment where this had been… you know, I was getting the MND quarterly newsletter magazine that there’s one here. Have you ever seen that?

**I:** I’ve seen the local stuff…

**P:** [rummages through magazines] That’s the quarterly magazine they put out. I used to get that and I’d see stuff in it about fundraising events and all about what to defeat news. It just kind of suddenly oh well here is something that I can do and I just was ready. Prior to that, I wasn’t.

**I:** Are there any other areas where you felt you needed support but there wasn’t support available?

**P:** Well, at that time like I said, I was living in [name of place] and the [charity organization] employs regional carer advisor and [name of person] was the one for this region. I never once had any contact at all from the regional carer advisor in [name of place] and I lived there… I moved here 7 and a half, well just almost 7 years ago and straight away the regional carer advisor contacted me and I found that the local support from [charity] has been far greater here than it was back in [name of place], so, you know at that time, I felt a little bit [pauses] I don’t know, it almost just like I have to get on with things umm, it probably would’ve been… I mean the role of the regional carer advisor is to make sure the people with MND in their region in getting the support and help that they need. I have no idea if it is the same person or not, probably it isn’t because it has been so many years ago. Maybe she never got in touch because no one ever told her about me but the way it supposed to work is that if you do get a diagnosis, they find out. So, I don’t know how the breakdown of the communication happened, I have no idea.

**I:** Is it from the time you were diagnosed, after that point, how did you access help then?

**P:** Mainly through my GP, it was through the GP that I got an OT assessment and got the referral to the [name of centre] for the counselling and anything else I think, I think… the district nurse come to see me. There was like suddenly… it didn’t happen by itself, I had to speak to the GP. It was at the time when I was really struggling, feeling down and everything and so, one day the GP and… I think it must have been the practice nurse or something like that or a care coordinator or something. Someone connected to the practice came to the house to see me and we kind of went through things and it was actually this practice nurse or whatever she was who was… who put things in place, she was like oh alright okay referral to the OT, we can refer you to the Beacon centre. She was the mover and shaker and got things going. But it all kind of emanated from the GP practice.

**I:** So, did you feel like at the early stage you needed some help, even for emotional concerns?

**P:** Absolutely, because I was… like I said, I was in a bad way emotionally at that time. Cried a lot, felt really down, felt very isolated, felt… you know… just in a very bad way.

**I:** Okay. I think… have I missed any aspect about your experience that we haven’t spoken about?

**P:** Umm, specific to how I felt about it or just some of the actual experiences of you know, with healthcare professionals or what?

**I:** More of how you felt about having MND and living with it.

**P:** [pauses] There were certain things that actually… certain ways… some of the experiences I had with some healthcare professionals actually made me feel really awful and umm, like for instance, I had a local neurologist, this was up in [name of place] who I would see like twice a year. And then I would see the MND specialist at [hospital] twice a year and the local guy in [name of place] was a very very good neurologist, very thorough with what he did but his bedside manner was… excuse my French, crap, umm to the point where I referred him as Doctor Doom. I remembered going to see him one of this occasion and he wanted to know how things have progressed or whatever and I said well since I saw you 6 months ago, they haven’t really got any worse, I feel like I’ve been on a plateau. He was like “oh no, no plateaus with MND, it’s downhill all the way.” And I left there in tears, it’s like I got to a point I don’t think I need to see this guy twice a year. I don’t need to put myself through that and then I got to the point where I stop seeing him altogether. But it took a while for him after kind of seeing how it was progressing very slowly because he had never seen that happened with a patient, he started to revaluate the way he viewed MND and he took on board that well actually there can be occasions when that happens. It happens differently for different people, but you know in a way he’s the one who broke the initial diagnosis to me which later confirmed by [hospital] and talk about beating around the bush and using medical terms and not coming right out and saying it. It was awful, he made it worse because of the way he did it. In fact, I was seeing him when I initially got referred to a neurologist, he was the one I was referred to and he was having all these tests on one thing or another and at one point he said to me, you know [name of patient], just need to prepare you for the the fact that the more we do these tests and the more it keep coming back negative, the less likely we’re going to find anything that we can treat and I took that to mean they weren’t going to find anything. They would have no idea of how to treat it and that they might have to just send me away and shrug their shoulders and say well we don’t know what’s wrong. But he thought he was trying to prepare me for what, at that point he was already starting to suspect was MND. But his way of communicating it, completely was the opposite so when I got the… when I finally got out of him he suspected it was MND, I was devastated because I thought he’d eliminated everything and he kept using words like oh he’s being all scientific one thing or another. He kept using the term the anterior horn cell disease that’s like ‘what’s that when it’s at home?’ and that’s one of many other names for MND. No one has ever heard of it, not anyone who’s a layperson. I’ve actually heard of MND as it happened and I know a little bit about it, so, when finally, after much questioning and pressing out of him and he actually used the word Motor Neurone Disease. I was just like ‘oh my god’, so the way that he dealt with everything impacted far worse on my mental health because his means of communicating with a patient was so poor. That may well be a contributing factor to umm how I was struggling with it in the early stages. So yeah, that was quite the experience very much stands out in my mind.

**I:** When you initially did get the diagnosis and the shock of that, being delivered by this person, how did that made you feel? What was going through your mind at that time?

**P:** Well, my close friend was with me and this was half an hour with this guy as he keeps saying anterior horn cell and one thing or another. Finally get the word MND out, Motor Neurone Disease out of him. We leave his office, at that time I was walking with crutches and umm, we leave the office and we get out of the building and I was hysterical and my friend, [name of friend] was like, ‘what what what’s the matter?’ and I was like ‘it’s f\*cking MND, that’s what the matter is.’ He’s like ‘what do you mean, what is it, what is it?’ I said, ‘it’s a bloody death sentence.’ I happen to know about it and I was just like I said, hysterical and crying and in a hell of a state because the previous appointment with him was when he said, you know he said we’ll probably won’t find anything that we could treat and so he… unwittingly set me up for one thing, my expectation was something quite different and then suddenly it’s like oh my god. I haven’t yet given a life expectancy at that point, and what I knew from what I have read about MND was typically 2-5 years, bear in my mind I was only 45 at that time. So yeah, huge impact. That was like June and it wasn’t like until the end of August that I was able to get an appointment at [other hospital], he was gonna refer me which he did to the MND specialist. It took that long to get an appointment, so, I’m kind of in limbo. This wasn’t a confirmed diagnosis but he’s saying that’s what he believed it is and refer me to a specialist and they’ll probably wanna do another test or something. So, I got the confirmed diagnosis two months later. For those two months, it was horrendous. It was pretty horrendous afterwards but you know, it’s still pretty horrendous because at that point, I’m think 2-5 years, at the end of August when I got the diagnosis 5-10 years, that was like a little bit better. Now, I just don’t put a timescale on it, part of me kind of hopes I die of something else because I don’t really fancy the end stages of MND. So..

**I:** Before I move on to my next question, is there anything else about your experience… just to make sure I’m covering everything? It’s different for different people so…

**P:** I think that’s kind of like the highlights, really.

**I:** What we’re doing which I explained a little bit in the beginning is we’re trying to develop some online support tools so, particularly to help with the emotional challenges and kind of umm, talk people through and help people through these different aspects… I was just wondering if you have any thoughts about, if you had to use something like this, do you think...?

**P:** Personally, I think I’d be less inclined to. I think when you talking about emotional support, I think the most valuable thing comes from other people, being able to engage with other people. Whether they are professionals or good friends or family that you are able to open up to. I think, the other thing is though MND isn’t strictly an older person’s disease, typically more people with it tend to be older and I know this is a generalisation but I’d be inclined to think that fewer people of more senior years would be inclined to look to online support. I think it’s something that you know, a younger person with diagnosis might be more inclined to do. And we are starting to see more younger people, people in their 20s-30s to be diagnosed with it, and I think that’s just the differences between how different age groups use the internet.

**I:** Yeah, how different people cope as well. Is there anything you think we might need to keep in mind if we do develop this? Specifically, for MND.

**P:** Umm, so what exactly you envisage?

**I:** It’s easier for me to show you, really. It’s hard to explain. It’s offering a little almost like you had in counselling, few tips and techniques to help people cope on regular basis just so it delivered online rather than face to face.

**P:** Well, the thing is some people would prefer that because some people find it really difficult to open up to someone. Maybe they’re not used to talking openly and honestly with someone. Particularly if maybe it was a professional counsellor who they don’t know. Some people find just couldn’t deal with situation like that, I wouldn’t want to know like ‘ooo not for me’ and they might find it may be more suitable for them to access something online or to be able to talk anonymously with someone like for example, if they were able to do a webchat with someone.

**I:** That’s fine. I just thought I’d get your views while I’m here.

**P:** From my personal point of view, I would much rather talk to live human being.

**I:** That sounds absolutely fine [laughs]. I think I’ve asked all of my questions, if there’s nothing more to add, we can stop the recording?

**P:** Sure yeah.