**Transcription of Interview 19**

**[person with MND]**

**Interviewer:** Okay, brilliant. So I guess, I’d like to start with wherever you’d like to start really about your experience with MND. Uh could either be about diagnosis or if you noticed symptoms before.

**Respondent (P):** Okay, right? Um, six years ago, more than six years ago I noticed symptoms. Umm I was not walking properly. I’d fallen over. Um, I started getting twitches all over my body. I went to the doct- to the doctors and they thought it was a trapped nerve. Umm, I was sure it was MND because I googled these symptoms and that’s what came up every time. My husband did loads of research, trying to find anything that it might be, other than MND.

**Interviewer:** Yeah.

**Respondent (P):** Um, I then [Pause] second time I went to the doctors, I got an appointment for an MRI scan, which didn’t bring anything up, and then they sent me for nerve conduction test. That was in the March of 2014. Um, and I knew then that the guy who did it knew what it was. I said to him is it MND? He said I’ll get the results to your doctor tomorrow and make an appointment and he’d discuss the results with you. So, I did that, and they said it could be MS or it could be a virus. Um, and we’re getting appointment with a neurologist. It will be 88 working days before I could see a neurologist, so I said no way I’m going private. I’ve waited a year and I want to know what it is. Um, so, I made my own appointment. Went with my husband to a private, um, private appointment. I think it cost about £200 and um he, it took him 15 minutes, no more, to diagnose me. And I literally came back, went to work, I had a business, told them. Then tell my best friend. Went to tell my both my sons and then went to my mum’s and told her. I got all that out of the way. I was at work the next morning seven o’clock, and I’ve since then tried to get on with life. [Pause]

**Interviewer:** Okay.

**Respondent (P):** And that’s how I dealt with it.

**Interviewer:** Okay. Um, and how has your experience been now ‘cause you’ve had it for so many years now.

**Respondent (P):** Well, I can’t walk at all.

**Interviewer:** Mhm.

**Respondent (P):** Um, I my last step was probably in November last year. I battled and battled [Swallow] trying to walk, but it was getting too dangerous, so I haven’t walked since November. Um, I’ve got a brilliant social life. Uh, a brilliant husband, um and I’ve got business. Which I make food for people. We adapted my, our garage into a kitchen. There I sit on a chair and I can work. Um, so, I try to keep life as normal as possible. My voice now is affected, my breathing is. I’m on a ventilator overnight. Um, but [Pause] I want [Pause] I want to live.

**Interviewer:** Yeah, yeah. And, um, ‘cause also when you were first diagnosed with um MND, I know it was a while ago, um but what were, what were you thinking or feeling around that time?

**Respondent (P):** I wanted to know what it was.

**Interviewer:** Okay.

**Respondent (P):** I was convinced, I’d been convinced for a long time and that first year before diagnosis was awful [Pause]

**Interviewer:** Not knowing.

**Respondent (P):** Not knowing.

**Interviewer:** Okay, okay.

**Respondent (P):** And it was awful finding out, but [Pause] I knew then and then I thought right, I’ve got to get on with it. Make the best of it.

**Interviewer:** Yeah, and how did you feel after you were diagnosed as well?

**Respondent (P):** Obviously upset, but what could I do?

**Interviewer:** Okay [Pause] and how-

**Respondent (P):** You know I carried on with life as [Pause] as well as I could [Pause]

**Interviewer:** Okay. What were, like, uh some of the things that were particularly upsetting?

**Respondent (P):** Ithought that I didn’t want to die.

**Interviewer:** Mmm.

**Respondent (P):** Um, and I still feel the same.

**Interviewer:** Yeah.

**Respondent (P):** I’ll do anything I can to keep going.

**Interviewer:** Yeah, yeah. That’s a good attitude um.

**Respondent (P):** Well I thought it was the only one I could have.

**Interviewer:** [Laugh] Yeah.

**Respondent (P):** You know, I didn’t have any choice.

**Interviewer:** Yeah [Pause] um and have your thoughts and feeling, did they like change from uh the time you were diagnosed until-

**Respondent (P):** Yeah, far more challenging now.

**Interviewer:** It’s more challenging now?

**Respondent (P):** Uh, yeah because, obviously I can’t walk and the breathing’s affected. Um, but [Pause] I, I don’t know I just [Swallow] try can’t get on with it.

**Interviewer:** Okay, okay. And even now are there any emotional concerns or worries?

**Respondent (P):** Well, about a month ago, my MND nurse put me on a mild antidepressant, and I think it’s been really good.

**Interviewer:** Oh, okay.

**Respondent (P):** Because I was getting emotional. I was crying quite a bit, and I’m not a crying person. Um, but that’s stopped now.

**Interviewer:** Okay, okay. So mainly because of how MND was um

**Respondent (P):** Yeah.

**Interviewer:** Affecting you and things like that.

**Respondent (P):** [Crosstalk] Yes.

**Interviewer:** Okay, okay. And how do you, how do you cope with that? Is it mainly the medication?

**Respondent (P):** I’ve just taken one of these tablets today, and it seems to have sorted it.

**Interviewer:** Okay, okay that’s good. Uh

**Respondent (P):** It is.

**Interviewer:** Yeah, that’s really good [Laugh]. Um and also how, what other uh challenges do you tend to face in your daily life? I know you mentioned a couple of them because of how it’s got worse, but could you tell me a bit more about that?

**Respondent (P):** [Sigh] Um, the breathing.

**Interviewer:** Mhm.

**Respondent (P):** I get a bit more tired, but I do, I’m up all I don’t sleep during the day and I’m still working. I think the biggest challenge is uh my voice.

**Interviewer:** Your voice, okay.

**Respondent (P):** Yeah, it’s hard work talking.

**Interviewer:** Okay, okay.

**Respondent (P):** But I’ve always been really chatty, and maybe I don’t have the same confidence that I used to have, in everyday life

**Interviewer:** Sorry, this must be a bit challenging for you as well to

**Respondent (P):** [Crosstalk] Yeah

**Interviewer:** Give an interview over the phone

**Respondent (P):** No, it’s okay, it’s fine

**Interviewer:** That’s okay. Okay. Okay. Um, yeah, if at any point you feel tired or anything you can always…

**Respondent (P):** Yeah, no I’m okay

**Interviewer:** Okay. Um, yeah and you mentioned as well before um that sometimes you’d get tearful and things like that. Um, how did you usually cope with them before, say, you had the medication?

**Respondent (P):** Umm, [Exhale] try to think positively. Try to think about all the young people that have this horrible disease and, I mean I’m 58. You know, my kids have grown up and these young families I think if I get down, how awful it must be for them and I try and think positively.

**Interviewer:** Yeah.

**Respondent (P):** And I try and occupy myself. You know I’m working. I do three full days, at least, and that helps.

**Interviewer:** Yeah, that’s good, that’s good. And, um, do you also get any support from say family or friends or things like that?

**Respondent (P):** Amazing support.

**Interviewer:** Okay

**Respondent (P):** Amazing, with fundraising, general support. My MND team are fantastic [Pause] and so yes I get am-m-mazing support

**Interviewer:** Uh who is in you MND team? Is it healthcare professionals or?

**Respondent (P):** Yeah, it’s um my MND nurse, neurologist, dietician, um physio, OT um language and speech therapist and I see all them people every three to four months.

**Interviewer:** Oh, okay, okay [Pause] and-

**Respondent (P):** I also go to [Pause] two MND group coffee afternoons

**Interviewer:** Oh, okay

**Respondent (P):**  And so I am quite involved in fundraising as well

**Interviewer:** Does that help, then, to be quite involved with MND activities also?

**Respondent (P):** Absolutely. Yeah, I’m on MND groups online and that helps [Pause]

**Interviewer:** Um, in in what way sort of? Just um

**Respondent (P):** Oh, just helps knowing that other people are going through a similar thing. They can understand what I’m going through and, yeah, it just helps.

**Interviewer:** And you share your experiences on these groups and that

**Respondent (P):** [Crosstalk] Yeah, yep. And I’ve spoken to quite a few new, newly diagnosed people and hopefully given them a bit of hope

**Interviewer:** Yeah, yeah. How, how did you, how did you do that? What did you say to them?

**Respondent (P):** Just, you know what, I’m five years down the line and I’ve led, last five years have been good. They’ve been hard, but they’ve been good. I’ve done, you know, I’ve done tandem bike rides, I’ve done parachute jump, all sorts.

**Interviewer:** Oh, that’s amazing

**Respondent (P):** I’ve learnt about, well between me and family and friends since diagnosis it was really just about, I think somewhere between 40 and 50 thousand.

**Interviewer:** Oh, wow.

**Respondent (P):** So, I hold, I hold a big dance in our village hall every February and every time it’s about, somewhere between three and a half and four thousand. I’ve done all the cooking for it and we’ve had a 145 people at every one.

**Interviewer:** That must keep you busy then [Laughs]

**Respondent (P):** Yeah, I am busy, really busy. I don’t drive any more, I had to give up driving. But my husband, he’s only working part-time, so it’s not a problem.

**Interviewer:** Okay, okay. [Pause] Um, so staying busy like this is also quite helpful?

**Respondent (P):** Absolutely. I will go mental if I had nothing to do. Once my arms go, I don’t know what I’m going to do. I’ll have to find something.

**Interviewer:** Okay, okay. Do you, do you find yourself thinking like that about the future or preparing for it?

**Respondent (P):** [Crosstalk] Yeah, yeah

**Interviewer:** Yeah. Um, does that help, or?

**Respondent (P):** Umm, pfft I don’t know whether it helps or, but I think you’ve got to a little bit.

**Interviewer:** Think about the future?

**Respondent (P):** Yeah.

**Interviewer:** Yeah [Pause] and sort of plan for things

**Respondent (P):** Yeah

**Interviewer:** Yeah

**Respondent (P):** And [exhale] I, I mean, obviously the biggest hope is for a drug [Pause] to stop the progression

**Interviewer:** Yeah

**Respondent (P):** Um, and I’m holding on to that.

**Interviewer:** Yeah [Pause] and um, yeah, so those kinds of hopes for the future

**Respondent (P):** [Crosstalk] Yeah. You’ve got to, you’ve got to hope.You’ve got to want to live [Pause] otherwise you probably won’t

**Interviewer:** Yeah

**Respondent (P):** You know?

**Interviewer:** Yeah, no I understand what you’re saying, yep. Um, yeah, and you found this helpful and you’ve spoken to other people about having this kind of attitude as well?

**Respondent (P):** Yep, yep

**Interviewer:** Okay, okay. Um, are there any other things that help you. I mean, i- it already sounds like you’re quite busy, but uh?

**Respondent (P):** Um, obviously support from others. I mean my husband’s brilliant. You know, he moves me around and into the car and [Pause] I don’t know, without that I don’t know what I’d be like.

**Interviewer:** Yeah, family and friends.

**Respondent (P):** I’m pretty lucky that I’ve got, you know, such good support. And I think I live in a good area where I’ve got a lot of support from the MND team.

**Interviewer:** Okay, okay that’s good [Pause]. Um, did you, did you at any point get any support, it doesn’t even have to be professional support, but um for when you feel say a bit worried or sad about things?

**Respondent (P):** Well, I only really speak to my husband and best friend about things like that

**Interviewer:** Okay, okay. And talking to people also helps in some way?

**Respondent (P):** Yeah

**Interviewer:** Yeah [Pause]

**Respondent (P):** Yeah. Otherwise you just bottle it up.

**Interviewer:** Yeah [Pause]. And did you feel at any point that you may have liked someone professional to talk to about those concerns?

**Respondent (P):** Yeah, I’ve spoken to my MND nurse and I’ve spoken to my neurologist and that’s when he put me on the um mild anti-depressants.

**Interviewer:** Ah, yes, yes. Okay. Um, yeah so that was helpful, and you didn’t use any more support beyond that.

**Respondent (P):** [Crosstalk] Yeah. Well, it’s there if I want it

**Interviewer:** Okay, okay, that’s good. [Pause] Um, I guess everyone’s story is quite different really so I, I don’t know if I’ve covered everything because it’s been a long time as well if I’ve not spoken about some aspects of your experience and things you find difficult or how you manage to cope with things. [Pause]

**Respondent (P):** Erm, I don’t know if there’s anything else.

**Interviewer:** Is there anything we’ve missed?

**Respondent (P):** Um [Pause] eh, I can’t think of anything.

**Interviewer:** Um how did, so when you were first diagnosed, um did you almost immediately think yes, I have to keep busy and stay busy or did that being actively involved with uh the [charity organization] and stuff, did that come at a later point?

**Respondent (P):** Um, it came about six months later. I just carried on with my life as normal as it was before.

**Interviewer:** Okay

**Respondent (P):** And obviously, it was more worrying, but I was able to walk, I was able to work, nothing was very different really. You know, apart from this limp and that fact that I couldn’t walk far. But I could still do 12 hour shifts at work and I carried on with my business. I had a busy tea room and they carried on working for, what two years, then we sold the business and I worked 25 hours a week for the new owner, but that wasn’t the same so I left and we converted the garage into a kitchen and I’ve been running a business from here now for two years.

**Interviewer:** Oh, lovely.

**Respondent (P):** Which is really busy.

**Interviewer:** Yeah, yeah

**Respondent (P):** Um, so, life has gradually changed [Pause] but I’ve tried to keep it as normal as possible.

**Interviewer:** Yeah. Yeah, that sounds good. Um, so uh at at what point did um you access help from the [charity] then, did they start with you?

**Respondent (P):** I think the first thing was [Pause] I had a conformation diagnosis at [hospital] and then I had a phone call from the [hospice], um, asking if I wanted to attend a kind of MND, I think it’s call first contact group. It’s on Friday, it’s all day now, it was afternoons, and so I used to wor- leave work earlier on a Friday at 12 something, have a massage, have a cup of coffee, speak to other people in the same boat and it’s been a fantastic thing and I still go now, maybe once a fortnight.

**Interviewer:** Okay, okay.

**Respondent (P):** And that was really good, really supportive. Um, and I’ve been going there nearly five years.

**Interviewer:** Okay. Er, some people sometimes feel a bit apprehensive about going to groups like this where they meet other people. Were you like that as well?

**Respondent (P):** [Crosstalk] I was. Yeah. At first, I thought why on Earth am I going to a hospice, but eventually I made uh an appointment and have never looked back, it’s been brilliant.

**Interviewer:** Oh, good, good. You just decided to go one day and then.

**Respondent (P):** Yeah.

**Interviewer:** Yeah.

**Respondent (P):** I think what, at first, you worry about seeing people that are a lot worse than you are.And it is a bit of a scary thing, but I understand how people deteriorate and it’s totally different for everyone and it’s, you know, the place on a Friday is a good place to be. But we don’t chart it doesn’t it’s not about MND. It’s just a social.

**Interviewer:** Yeah.

**Respondent (P):** And you can get a massage or relaxation and it’s great.

**Interviewer:** Yeah [Pause] it’s different for everyone isn’t it?

**Respondent (P):** Yeah.

**Interviewer:** Yeah [Pause] Um, okay, um di- did you still feel that we’ve missed any aspects out or have we missed out…

**Respondent (P):** Um, Pfft

**Interviewer:** [Laughs] it’s hard to think back so many years.

**Respondent (P):** I’ve tried to tell ya how it is, um [Pause] uh I think what’s hard is [Pause] is starting to lose something and you realise maybe one day that oh, I can’t do this anymore and it’s upsetting at times and then you get over it.

**Interviewer:** Okay, by just learning to adjust.

**Respondent (P):** Like the first time I fell and couldn’t get back up on my own, and you think oh my God, you know it’s, now I can’t be in the situation where this happens and there’s no one about.

**Interviewer:** Yeah, okay. Those sorts of things. [Pause] And constantly changing and that, that kind of thing, yep.

**Respondent (P):** Yeah

**Interviewer:** Okay. Um, and then you, just sort of uh it’s hard at first but then, you finding it..

**Respondent (P):** Well, you get used to it.

**Interviewer:** Okay, okay.

**Respondent (P):** You’ve got to accept it.

**Interviewer:** Mhm

**Respondent (P):** You know I accept the fact that I can’t walk. [Pause] I hate the fact that I can’t talk. Although I can talk, but it’s a bit drained and doesn’t sound like me. But I’ve done voice banking and [Pause] I think you’ve got to be a step ahead.

**Interviewer:** Yeah [Pause] yeah that helps to be ahead.

**Respondent (P):** Yeah

**Interviewer:** Okay [Pause] okay. Um, I know you mentioned a little bit about um going on these online forums and…

**Respondent (P):** Yep.

**Interviewer:** Um, looking things up on the internet as well.

**Respondent (P):** Yep.

**Interviewer:** Um, so what we’re trying to do is um, trying to develop some kind of resources to help people cope with MND.

**Respondent (P):** Okay.

**Interviewer:** Um, and having this online as well. So, I just wondered what your thought and feelings were about something like this, like would it would it be helpful if it was around when you were diagnosed something like that.

**Respondent (P):** Yes, but there are so many people that are diagnosed that don’t want to know. [Pause] You know they don’t want to talk about MND.

**Interviewer:** Okay, okay.

**Respondent (P):** I found, anyway. I mean I found a brilliant group called MND warriors UK and it’s a it’s a really supportive group.

**Interviewer:** Oh, really. I’ll make a note of that. And what happens at this group?

**Respondent (P):** Well [Pause] it’s just, people will maybe post a question saying has anybody had you know what do people do about not being able to sleep in the night, um getting used to NIV [non-invasive ventilation]. Just different things, and people put their own experiences on, and I find that really, really helpful.

**Interviewer:** Okay, I’ll have a look at it.

**Respondent (P):** You have a look at MND warriors. It’s a really good group.

**Interviewer:** Okay, I made a note of that [Laughs]. But, um, so so you’re saying that information online might help but for some people they may not want to access it because..

**Respondent (P):** Some people may not want to.

**Interviewer:** Yeah, yeah. Okay.

**Respondent (P):** Yeah, I mean there’s the MND forum which occasionally I put things on. Um, I’d write in the early days about [Swallow] footwear to able to use with (???) (27.35) um just practical tips. You know, they’re the main things. If, you realise if you can’t do something adapting things to be able to do them.

**Interviewer:** Okay, like practical tips and solutions, okay.

**Respondent (P):** [Crosstalk] Yeah, practical things.

**Interviewer:** Okay, and that you usually find out from other people and things.

**Respondent (P):** [Crosstalk] Yeah.

**Interviewer:** Yeah.

**Respondent (P):** It may be things like what holiday insurance you use.

**Interviewer:** Oh, okay.

**Respondent (P):** Where to find adaptive accommodation [Pause] abroad, you know, and things like that.

**Interviewer:** Okay, yeah.

**Respondent (P):** It’s all the practical things.

**Interviewer:** Yeah there’s so [Crosstalk]

**Respondent (P):** To enable you to live your life as normal as you can, for as long as you can.

**Interviewer:** Yeah [Pause] there are so many aspects to it isn’t it?

**Respondent (P):** Yeah, I mean I got myself involved in a lot of things and I think that really helps.

**Interviewer:** Mhm [Pause] Just to keep busy and yeah.

**Respondent (P):** Keep busy, keep informed. Try and get a step ahead. You know [Pause]

**Interviewer:** Yeah. [Laugh] All sounds good.

**Respondent (P):** And that’s all I can tell you really.

**Interviewer:** No that’s, that’s all really useful, um, because it’s different with different people and..

**Respondent (P):** Yep.

**Interviewer:** Yeah, learning [Crosstalk]

**Respondent (P):** I mean it is an absolutely horrific disease, but to me, I’ve got to make the best of it.

**Interviewer:** Mhm [Pause] Is that an attitude you’ve sort of always had?

**Respondent (P):** Yeah it is.

**Interviewer:** Oh, that’s good.

**Respondent (P):** I’ve always, yeah.

**Interviewer:** [Laugh] Um, okay. Um, are you happy for me to stop the recoding?

**Respondent (P):** Yeah, yeah, that’s fine

**Interviewer:** I can still chat with you, but I’ll just stop recording it. Okay.