**Transcription of Interview 20**

**[person with MND]**

**Interviewer:** Okay, that’s good. Um, great so I’ll start with my question then. I guess it’s, um, more of a general question, um, about what your experience is like with MND and you can tell me either from diagnosis or before that if you noticed symptoms or wherever you’d like to start really.

**Respondent (P):** Well I mean I’d, I’d started umm [Deep Breath] I was diagnosed just over 4 years ago because I couldn’t recall having weak arms for maybe three of four years prior to that. Umm and since diagnosis I have slowly uhh, my arms have got weaker and now my legs are also getting weaker. Uhh, so now I um I have a powered wheelchair, and a push along wheelchair and I go, don’t move anywhere in the house now without uhh a walker uhh I don’t have to use a wheelchair in the house still, I can still walk a little bit.

**Interviewer:** Okay.

**Respondent (P):** But, uhh, otherwise, you know, it’s just arms and legs weakness at the moment.

**Interviewer:** Okay, okay. Umm and it was about how long ago did you say it was, your diagnosis?

**Respondent (P):** Sorry?

**Interviewer:** How long ago was your diagnosis, did you say?

**Respondent (P)** Just over four years. It was four years in February.

**Interviewer:** Four years, okay. Umm and what were your thoughts and feelings around that time, when you received the diagnosis?

**Respondent (P)** [Sigh] Well, I don’t know really its uh, it wasn’t unexpected. Umm my wife is a nurse. Umm, so we’d uh, you know, we, we had a a fair idea of what to expect. So I, I wasn’t uh, you know, obviously its [Deep Breath] it’s not nice to be told you’ve got this, umm, but I am, well, I am I was then 73 then so you know it its [Pause] you’ve got to expect something to start failing by that time. [Laughs]

**Interviewer:** [laughs], yeah. Umm and how [Pause] how have you felt now after having it for four years?

**Respondent (P):** Well, I mean, just you know it’s frustrating umm you know you can’t do things you’ve got to rely on your wife to to help you all the time. Umm [Pause] But, you know, uhh umm I’m still healthy in myself and my uhh fit and well, apart from the weakness, umm so we, we enjoy our life as much as we can.

**Interviewer:** Okay, okay. So it’s mainly the weakness in your arms and-

**Respondent (P):** It’s just a weakness in the arms and legs, you know, just not being able to do anything. Not to get around really. Umm [Pause]

**Interviewer:** Okay, okay.

**Respondent (P):** [Crosstalk] Need so many things to help me get up off chairs, and all that uh and fortunately we’ve got uh my daughter and son-in-law came to live near us [pause] three year two years ago. Umm so they’re very helpful. You know it’s, it’s having people to help and uh do find, you know, lots of the neighbours have been very helpful an- and friends, you know, gather around and uh help me up. In January I had three falls, so I had to, you know, once I’d fallen down, I’m really a dead weight, I can’t do anything really to help myself get up so I have to rely on neighbours then to come in and uh and lift me back on my feet.

**Interviewer:** Okay, okay [Pause] umm and, so, I know you mentioned umm some of the things but on a daily basis what are the main challenges um that you have to?

**Respondent (P):** Main challenges for?

**Interviewer:** Yeah.

**Respondent (P):** Well [Laugh] Every-everything becomes a bit of a challenge. Umm, you know, I mean you can’t get washed, can’t get [Pause] you know got to get off, get off the toilet can’t get to the toilet myself or um [Pause] its um you know every- everything [Short Pause] everything about life is, is a, is a bit of a challenge ha.

**Interviewer:** Yeah.

**Respondent (P):** You know even using the computer it uh tires me out, you know, I can still use the mouse and things, but uh its uh gets tire- my arms get tired.

**Interviewer:** Okay, okay. You still able to use a mouse and, or is it like a special kind of device?

**Respondent (P):** Well no, you know, just the ordinary mouse on the computer, you know on the main um the um desktop.

**Interviewer:** Okay, okay. [Pause] Um, so every, every single activity requires help and is a big procedure is that that-

**Respondent (P):** Sorry, say it again.

**Interviewer:** So, every, every activity is sort of you need help or it’s a long procedure.

**Respondent (P):** Yeah, that’s right. Yeah, you need, you need help all the time. Umm, I mean obviously there we have a [Short Pause] a, a rise and recline chair which enables me to get out of my main arm chair.

**Interviewer:** Mhm.

**Respondent (P):** Um [Clears Throat] I have special things on the, on other chairs that uh push me, push me up to help me get up, umm, but every, you know, I have uhh an iFloat (electrical arm support) to, that helps me to eat, umm to help me get to my put food to my mouth.

**Interviewer:** Okay.

**Respondent (P):** Umm, lots of things like that. I’ve a, we have a hospital bed which helps me get out of bed and things like that.

**Interviewer:** Yeah, so lots of equipment. [Pause] Yeah, so lots of equipment and things like that.

**Respondent (P):** A lot of equipment, yes.

**Interviewer:** Yeah.

**Respondent (P):** Which my wife [Laugh] keeps saying we’ve got so much equipment, and no room for us.

**Interviewer:** [Laughs]

**Respondent (P):** [Laughs] [Pause]

**Interviewer:** Umm, okay, okay. I think I can, sort of get a picture of things without being there [Laughs]

**Respondent (P):** [laughs]

**Interviewer:** Um, some people who have MND also find um you know the emotional side of things a bit challenging as well. I was wondering if that was the case for you or?

**Respondent (P):** I haven’t really, no. I mean, I suppose I look at it philosophically and, uh, think that there’s uh other people much worse off than me. Uh, one other thing about MND well, for for me anyway, is that there is no pain involved.

**Interviewer:** Mhm.

**Respondent (P):** Um, you know, things are much worse if you’ve got some something that involves pain umm [Pause] I think, you know, the other thing that, that mainly concerns or worries me is uh the effect on my wife. You know she’s, she’s also in her mid 70s umm and really, she’s having to do more and more looking after me. Uhh not, not good for her.

**Interviewer:** Yeah [Pause] Yeah. Do you have any other help, um I don’t know any other more professional help or things like that?

**Respondent (P):** Not at the moment. I mean we cou- we, we probably will have to have more professional carers in the future, but at the moment my wife can manage me um so we’re, we’re just managing on our own. But, um, yeah, I’m sure the time will come when uh we’ll have to have carers in, yes.

**Interviewer:** Okay, okay. Um and I guess besides your wife and I think you mentioned some, some of your family as well um, do you get any help and support from anywhere else?

**Respondent (P):** Well, from neighbours and friends [Pause]

**Interviewer:** Okay. Umm this is more for what, what sorts of things?

**Respondent (P):** Sorry, say it again

**Interviewer:** For what kind of things would they give you help?

**Respondent (P):** Oh. I have a friend that comes and takes me out on a Tuesday evening. We go up to I go out in my powered wheelchair and we go up to the uh, to the pub for a couple of pints.

**Interviewer:** Oh nice.

**Respondent (P):** Um, I have a friend well, two people that come and sit with me for a little while, have a chat.

**Interviewer:** Okay.

**Respondent (P):** Umm, my neighbours, I’ve uh said it before have, have helped me get up off the floor when I’ve fallen down. Umm, and we have friends that come and help in the garden ‘cause we’ve got quite a large garden which uh I used to do, but my wife is having, you know, finding it a bit of a strain doing the garden as well, so we have friends that come in and do weeding and general garden maintenance.

**Interviewer:** Okay, okay. Uh, so lots of people popping in.

**Respondent (P):** Yeah, lots, lots of people help, yes.

**Interviewer:** Ah that’s good, good, and do you find that um that’s an important part of coping with MND as well to have that support around you?

**Respondent (P):** Oh yes, absolutely. Yes.

**Interviewer:** Okay. Um, yeah, and also on a more personal level, are there any things you sort of tell yourself or any attitude that you have that kind of keeps you going?

**Respondent (P):** Well, that is to try and do as much as I can, get out as much as I can. You know, we, we go out, we’ve we’ve bought we’ve got rid of the car and we bought ourselves a wheelchair accessible vehicle so I can go in my powered wheelchair in the back of that and uh move to different pl- go to places to for a walk and things. Um, so so I’m in my wheelchair [Laughs] you know, sort of walk. Um [Pause] and we go out for coffee three or four times a week. Uhh we go out for meals. Umm, [Pause] you know generally just keep active really.

**Interviewer:** Stay busy. Yeah, yeah. And, um, for how long have you been using a wheelchair now?

**Respondent (P):** [Deep Breath] Well I’ve had the powered wheelchair for just about a year.

**Interviewer:** Mhm, okay.

**Respondent (P):** You know, and, uh, we had a push along uhh before that which I used occasionally, if my son-in-law was around to push me when I if we were going for a a particularly long walk but, you know, I try to use the walker as much as possible just and that just supports me and uh and enables me to walk okay. I’ve got a one of, oh yes I never said that before but one of my uh problems I’ve got foot drop in my left leg, so my foot hangs down, umm and I’ve got a splint now that which pulls it back up again and uh that helps tremendously to to for walking.

**Interviewer:** Okay, okay. Um, so it’s been like a gradual change of different kinds of walkers and wheelchairs?

**Respondent (P):** Yeah, you know, just have to have everything you know. I’ve got, I have a walker inside for for inside the house and a another one which we keep in the car for when we go out. So.

**Interviewer:** Okay, okay. How was it like first, um, adjusting to the fact that you had to use a wheelchair and things like that? Did [Pause] was that okay for you or?

**Respondent (P):** Yeah, no problem. Um [Pause] no, you know its uh, I don’t mind you know. I know my mother-in-law, when she was uh getting frail, she refused to go out in a wheelchair because she didn’t want people to see her but, uh, I don’t have that problem. [Laughs]

**Interviewer:** Okay, that’s good. Um so you accept help quite easily. [Laughs]

**Respondent (P):** Yeah, absolutely. You’ve got to yep.

**Interviewer:** Yeah. Umm I guess are there [Pause] I know we did mention people who’ve helped you and um how you, how you go out and keep busy and things like that is there anything else that kind of helps you cope with MND on a daily basis?

**Respondent (P):** Sorry. Can you?

**Interviewer:** Um, I know we’ve spoken about people who’ve been really helpful and you going out and staying active and things like that.

**Respondent (P):** Yeah.

**Interviewer:** But is there anything else that we’ve missed out that helps you cope with MND on a daily basis?

**Respondent (P):** Umm, no, just keeping interest, you know. I, uh, I play a lot of chess on the computer against people around the world.

**Interviewer:** Oh, do you?

**Respondent (P):** Umm and that uh always keeps me interested. I um I’m even still doing a little bit of uh consultancy work from uh the company I used to [Pause] be part owner of.

**Interviewer:** Oh, that’s good.

**Respondent (P):** So, you know, that keeps me interested and things like that. I read a lot.

**Interviewer:** Okay, okay. So finding things that interest you and pursuing that.

**Respondent (P):** I keep, you know, don’t sit around being bored. [Laugh]

**Interviewer:** Yeah. [Laugh]

**Respondent (P):** Something to do.

**Interviewer:** Yeah. Oh, that’s good, that’s good. Get a chance to work as well.

**Respondent (P):** Yep.

**Interviewer:** Okay. And um, have you, have you felt that you’ve had enough support from health care professionals and organizations and things like that.

**Respondent (P):** Oh yes. I mean we’ve got we have a very very good GP who sees me once every three months just to have a a general chat about what things are doing. My consultant at uh [hospital], [neurologist], uh is wonderful. You know we see her about every every six to eight months, um then I go to [another hospital] to see doctor mm I can’t remember, [name of doctor], I think it is um [Pause] to check on my breathing and everything. Umm, we have a very good OT, we have uh very good support from the [charity organization] um that we have a, a support group that meets once a month um for coffee and uh group of us to have a chat.

**Interviewer:** Oh, nice.

**Respondent (P):** Um, [Pause] so you know in general yes, we’ve, we’ve got a lot of help and

**Interviewer:** A lot of help, yeah.

**Respondent (P):** Yeh and uh very good attention from all the medical people.

**Interviewer:** Oh, that’s good, that’s really good to hear. Um, and even these coffee groups and things.

**Respondent (P):** Sorry.

**Interviewer:** Even the coffee groups or coffee mornings from by the MNDA um when did you start attending them?

**Respondent (P):** Um well when I was first diagnosed uh they told I was told about them at the uh we had a, my cons- uh at [hospital] the consultant had a morning where you, where she introduced you to all the uh different help people uh one of those was the local [charity] rep.

**Interviewer:** Mhm.

**Respondent (P):** And he told this about the coffee mornings, and I suppose we probably started going about six months after that and uh now we go regularly as, you know, whenever we can.

**Interviewer:** Okay, because some people um say initially it’s that they may not want to meet other people who have MND because it’s uh it’s hard to see um people as well, I was wondering if that was a similar situation for you or?

**Respondent (P):** Well, I do- I have never, never found that with other people. I mean y-yeah I mean there are people that we’ve met at this group um over these four years which who’ve who now no longer with us. Um, we’ve seen them deteriorate and, and die, but you know that’s [Sigh] that’s a fact of life you know we, we can’t change that. Um but while they were alive they were happy they we, we had a laugh when we met um and, you know, it’s I think it’s more encouraging than depressing.

**Interviewer:** Okay.

**Respondent (P):** See, see people, you know, how they deal with it.

**Interviewer:** And have you found these groups helpful for yourself as well?

**Respondent (P):** Yeah.

**Interviewer:** Okay.

**Respondent (P):** It it’s been very helpful.

**Interviewer:** Okay, that’s really good to hear. [Pause] Um I guess everyone’s situation is quite different um in terms of how they’re diagnosed and how they manage and things like that.

**Respondent (P):** Yeah

**Interviewer:** So, I just, I think I’ve asked you some of my questions, but I was wondering if there were any aspects that we haven’t covered or?

**Respondent (P):** Hmm.

**Interviewer:** Anything we’ve missed out?

**Respondent (P):** I don’t think so, I mean you say, everybody is different, and it affects everybody in a different way. Um [Pause] and they’re all, there are some people you know in our area that have been diagnosed with MND who won’t, wouldn’t come to the support group uh where one lady that comes who is the carer

**Interviewer:** Mhm.

**Respondent (P):** Uh but her husband who has got who actually is man with MND won’t come to the support group he doesn’t, doesn’t like the idea of seeing other people with it um which you know is what you mentioned really. Um, but you know I don’t, don’t feel like that, I think it’s uh, it’s good to meet other people.

**Interviewer:** Yeah.

**Respondent (P):** With how they’re dealing with things and you’d get lots of advice there you know there are things that we’ve come across um what people are using or, or help they’ve they’ve acquired which we didn’t know about, and we’ve found things out that uh they, they didn’t know about occasionally you know and so you know you all exchange these things and uh, hopefully you can make your life a bit more tolerable.

**Interviewer:** Yeah, yeah.

**Respondent (P):** You know, it’s good to talk with people. Um because, you know, you find things out much more easily; you hear from other people’s experiences.

**Interviewer:** Yeah, some people find that helpful and others

**Respondent (P):** Yep.

**Interviewer:** Just want to avoid it isn’t it? Yeah. Um but I’m glad that that has helped, helped you and your situation too. Um and is that something in general also that you find just talking to people and finding things out.

**Respondent (P):** Yeah.

**Interviewer:** Is is what helps you cope better? Yeah.

**Respondent (P):** Yeah. It’s, it’s very helpful.

**Interviewer:** Okay, okay. Um I guess, I just also wanted to ask you about, umm, do you, do you look online for help and support?

**Respondent (P):** Yes.

**Interviewer:** Okay.

**Respondent (P):** Yes, we’ve lo- looked online for, found very, lots of bits of different support things, yes.

**Interviewer:** Okay, mainly information or what kinds of support did you look for?

**Respondent (P):** Well, just equipment really.

**Interviewer:** Okay, okay.

**Respondent (P):** Something found… people who’ve um have been [Pause] found bits of equipment that that they found helpful to them, and we’ve tried them out and and some have worked, some haven’t but uh you know it’s matter of uh suck it and see…

**Interviewer:** Yeah, yeah. Um the reason I was asking is um, as part of our project as well we’re hoping to create some online resources as well.

**Respondent (P):** Right.

**Interviewer:** They’re mainly with the focus on helping people cope with any say, tricky emotional concerns that they may face, either when they’re diagnosed or after that and things like that.

**Respondent (P):** Yeah.

**Interviewer:** Um, so I was wondering if um you’d see yourself using something like that or if there is anything we should be aware of when we create help like this?

**Respondent (P):** Um [Short Pause] well I don’t really have any say emotional problems at the moment.

**Interviewer:** Mhm.

**Respondent (P):** Um so well, well you know maybe in the future I will have and I I don’t know you know it’s it’s avai- if it’s available I may well use it.

**Interviewer:** Yeah, yeah. It’s not, it’s not um that everyone will necessarily have it it’s more if if you have difficulties and like you say for equipment if you need help there is help online.

**Respondent (P):** Yeah.

**Interviewer:** So this is just trying to fill that gap in case, in case people need, it doesn’t mean everyone

**Respondent (P):** Yeah, okay.

**Interviewer:** Has to use it all the time. [Pause] Yeah, but um, okay so if you do come up with any concerns then that will be an appropriate format do you think?

**Respondent (P):** Yes, uh yeah. Yes, absolutely.

**Interviewer:** Okay, okay. Um, so I think I’ve asked you most of my questions.

**Respondent (P):** Okay.

**Interviewer:** Um, I was wondering if there’s anything about your experience that you wanted to add or?

**Respondent (P):** Well I think we’ve covered everything really.

**Interviewer:** We have, um okay that’s good. Sometimes some people just look at um, like a timeline more just to check if we’ve spoken about everything ‘cause sometimes it can be quite a long time.

**Respondent (P):** yeh.

**Interviewer:** Yeah. Okay, but that’s good we’ve covered everything.

**Respondent (P):** Okay.

**Interviewer:** Um, I is it okay if I stop the recording. I can continue talking to you, its just um I’ll stop the recording and then chat.

**Respondent (P):** Okay.

**Interviewer:** Okay.

**[End of recording]**