**Transcription of Interview 3**

**[Beginning of file]**

**Interviewer:** Just to say again, thank you for agreeing to be interviewed. Just a couple of things before we start also, at any point if you want to take a break or just want to take a sip of water or something, it’s fine. If you feel some of the questions you don’t really want to answer, you can just let me know and I can skip through them. Don’t worry about umm people’s name or hospital’s name or things like that because at the end of it we will make all of it anonymous so you can feel as comfortable as you like, telling us about your story. So, I guess that’s the first question, really. I know you have told me a little bit already of the recorder about how it all started but what was your experience umm with [name of patient] having MND?

**Respondent (C):** Well umm to be quite honest, when the doctor, the neurologist told us I wasn’t at all surprised because I know they say you should not look it up on google the very symptoms but I knew in my mind that is what he had but he had no idea, it came as a little bit of a shock. Though he took it quite well mainly just umm said he could still speak at the time when he said to me, “well I am just going to whatever they tell me to do…”

**I:** Okay

**C:** And umm you know, just hope, obviously being not going to get better, but make it as easy as possible really. But umm, I mean I wasn’t at all shocked but I think I was, because we got a daughter-in-law and she has got multiple sclerosis. First of all, I thought it was something like that but then when I looked again, I looked at the swallowing and all that on google. I thought no it’s not that, I am sure it is MND.

**I:** So, you were sort of prepared?

**C:** I was, yeah, more so that [name of patient] was really.

**I:** And that was 2006?

**C:** 2016

**I:** Yeah, sorry yup. I thought it was 2016, I just said it wrong [laugh]. Umm, so since then, umm have your thoughts and feelings changed about MND and just living with it?

**C:** No, to be quite honest, most people don’t really know very much about it. I mean, but then people ask what’s wrong with him and then they automatically think he has had a stroke. Umm, when I said no it’s not that, and I said what it is, they immediately think of Stephen Hawking and I said no he is not like that at all. There are different types but most people don’t understand at all and realise what it is. But it can be very isolating because of the umm, the mobility problems. Once we had to give up the car because [name of patient] did all the driving and I hadn’t driven in years. But umm, now he is on the wheelchair all the time obviously we need to have transport that the wheelchair can be wheeled into, so that is quite hard, umm quite expensive too if you want to go anywhere.

**I:** Yeah, especially together as well.

**C:** But that is the worst bit, feeling a bit isolated really. I mean we are coping with symptoms alright.

**I:** Okay

**C:** Umm obviously you get bored at times because it been so cold, so we haven’t been out much, but we try to get out. He has got a powered wheelchair now, he just got it for Christmas, so that would be helpful when the weather warms up.

**I:** Hmm okay, so he can operate that himself?

**C:** Yes. That’s the worst problem, really. The mobility and the fact that he can’t do anything, any personal things for himself. Anything he wants he has to ask me for, if he wants a cup of tea if he needs the commode, and you know, if he wants to move from the bed to the chair or anything. He can’t obviously do on his own and I think that’s hard for him, not having your personal freedom, really. But yeah, I mean we are coping, aren’t we? We obviously get down in the dumps sometimes. The other thing, the silly thing like not being able to go out for a meal because [name of patient] can’t eat. He is tube fed with a syringe umm we can’t go out like we used to go out for lunch every couple of weeks or something. Things like that, or we used to go for a drive in the country and stuff like that you miss, really.

**I:** And what are umm your main worries or concerns having to look after someone with MND as well?

**C:** My main worry at the moment really is moving him from there to there because his knees and lower legs are getting weaker and I’ve got that that [points] to move him, but obviously the straps go around him..

**I:** It’s like a hoist?

**C:** Yeah you have to stand as upright as you can but where his knees have got weaker so he’s going like that and the thing tends to go over so there actually looking to see if there is some other way that we can move him umm that’s [name of person] at the [hospice] looking in to that for us. But that’s the hardest bit really, because we got carers coming in all in evening do the washing and dressing him up.

**I:** Okay, that was gonna be my next question, so how do you cope on a daily basis? In terms of …

**C:** I do all his medication, his feeds, myself. They do the washing and dressing him in the morning and the reverse in the evening. I mean apart from that, it’s just really the two of us. If he wants anything, I’ll just do it and that’s it really.

**I:** Are there any, you did mention a couple of people like [hospice] and the carers, but where would you say you get your support from? Is it by doing certain things or from certain people?

**C:** The biggest support we’ve had has been from [hospice]. Yeah, I mean the occupational therapist, they have been brilliant I mean it’s them that set up all the equipment we needed, and they keep in touch and come out and see how things are and if we need anything else, they’ve been… The carer support, but obviously they just do what they are paid to do, um, the district nurses come in once a month just to check his bedsores and skin damage, but the carers check that daily anyway. But apart from that, all the support we get really is from [hospice].

**I:** How do you all usually cope with the isolation and things like that?

**C:** Probably just get used to it. We both read a lot. Um, I mean we try and get out, when it’s not too cold. We try and get out to library or [name of patient] goes down to the barbers to get his haircut which is not far off but it gets him out and goes to day care once a week, on Thursday.

**I:** Is that the [hospice]?

**C:** Yes that’s the [hospice]. But you only get 6 weeks at times so after 6 weeks they review and you may get another 6 weeks or they may say we got other people that need it so, sorry. Your 6 weeks is up for the time being. We’ll review it again in the future so... And obviously, we go to the coffee meetings twice a month, the MNDA.

**I:** All of these little bits help?   
**C:** Yeah that’s right.

**I:** And how do you feel, like um, was there some areas where you may have needed help but there wasn’t anyone available or wasn’t offered?

**C:** Umm, no [P coughs in the background] A couple of times when he’s been bad, I mean he’s had Pneumonia a couple of times, it was a job to get to the doctor out, he wasn’t keen about coming out at all, and we phoned 111 and they sent the paramedics and they’re very good. But we don’t really get that much help from the GP surgery do we? I feel that when you’ve got something like this that they know it’s obviously not bound to improve, I think they… when you phoned and ask a question or um speak to someone, it should be flat up that you know what your health problems are and um, but they don’t seem to know. You know, when you phone up, with a query to ask something or ask for a visit or anything. And they sort of say why can’t your husband go to the hospital or surgery and I think they surely, they should be [written] … it’s things like that but… So the most help we got was from the [hospice] and they’re really good.

**I:** It’s… you to have to repeat your story again and again. Have you had any support with... like any emotional concerns or how to cope things?

**C:** Not really, everyone that comes to me always asks you how are you, are you okay? But yeah that’s all, really. No, we just really take each day as it comes.

**I:** Did you feel like you needed any help with that?

**C:** Um no, not at the moment, really. I mean sometimes, not so much now. But in the early days, when [name of patient] wanted moving about more often than he does now, because he likes to rest more now. I used to get so tired that sometimes when he had gone to bed in the evening I did just feel like standing there crying, and I could have done with someone to talk to then. But now he’s not being moved about so much about because he’s resting more, it’s not quite so bad.

**I:** Was this sort of earlier on?

**C:** Yes, this is in the first, when he first wasn’t able to walk and that sort of thing.

**I:** Okay, so a bit of support with that?

**C:** Yeah it would have been nice then … but I don’t think at the moment we need it as much as we needed it then.

**I:** Yeah, I see. Umm, I guess is there anything I missed out about your experience that we haven’t talked about, umm or even your experience looking after [name of patient]? Or have we covered everything?

**C:** Hmm, I don’t think there’s anything else really so…

**I:** Not too much [laughs] Umm, so what we’re doing is from people’s interviews and when they tell us about their experience, at the end of it we will be trying to develop some kind of support tools online. Umm, you mentioned me that you initially used the internet to Google things and stuff like that, I wondered whether you think something like that might be useful in your situation? Maybe not now, maybe earlier?

**C:** Yeah, we could’ve done something more support earlier I think. You know, it would have been nice to talk to someone else about going through the same thing or maybe a professional who could give advice to make things easier. But I say now, after 2 years … you sort of got into a routine and you do it your way and … you just get on with it, really.

**I:** Um, okay. So in the beginning, there were times you didn’t know how to manage or were searching for…

**C:** That’s right. It was really hard at first…

**I:** Sorry I’m going back again but where did you get your help or information from that point just after diagnosis.

**C:** In the beginning, we had an occupational therapist from [name of county], but she was based in [place]. She came down and spoke to us and she helped us with getting a higher carer’s allowance and umm, talked to us that we should get a stair-lift fitted and tried to get help which we didn’t get, anyway. And umm, talked about having a bathroom because [name of patient] couldn’t get into the bath, having it turned into wet room which she tried to get us help with funding for that which we didn’t get...

**I:** Oh okay...

**C:** So, we did get the stair lift and we did get the wet room done, but we paid that for ourselves. We did get a grant funding from [charity organization] for the help towards the bathroom about £1000 I think but unfortunately now, it really was a waste because he only used it for 6 months. He can’t get up there to use it because of the way our stairs are set up at the top. They say it’s not safe for me to try and move him from the stair lift to the bathroom.

**I:** Oh, it’s upstairs?

**C:** Yeah. So, really, we got 6 months use out of it, but we could’ve really kept as it was, couldn’t we? But never mind.

**I:** And how did you hear about the [charity organization]? Or was that also through your neurologist?

**C:** No, that was umm, actually through the speech therapist, [name of person]. We saw her every couple of weeks in the beginning to check [name of patient’s] swallow and try to help him with speech and all that sort of thing and it was her that suggested or asked us if we thought we would like to go, and we said well you know, we’ll give it a try. So yeah, that’s how it started off. She’s another one that was really helpful, she did a lot to help us in the beginning, [name of speech therapist].

**I:** The speech therapist, yeah?

**C:** Yeah.

**I:** So, it was from the doctor, the occupational therapist and speech therapist... from there you learned from everyone else how to get support?

**C:** Yes, but to be quite honest, the neurologist, you just go and see him, and he checks you out and says can’t believe it was a year ago I last saw you and I diagnosed you. See you in a year’s time sort of thing and that’s it really. Well, at the beginning he was uncertain whether it was really actually MND. Umm, that’s why it took so long to actually tell us what it was. He wanted to see [name of another neurologist] first before he would actually tell us what the problem was, and because he said somethings point to it and somethings are completely different from what I would expect. But when we saw [name of the other neurologist], she said yes I do think it is MND and then he accepted it, and said yeah obviously that’s what it is. If she says that’s what it is, that’s what it is.

**I:** So, it took a bit of time to just get the correct...?

**C:** That’s why it took a while to...

**I:** Okay, I think I sort of understand the whole story now. Is there anything that we have not spoken about?

**C:** No, obviously you know the other hard thing for me is that I have to speak for [name of patient]. Although he can write it down and understands everything that we say but another thing that’s hard umm, some people sort of talk down as if he’s got mental problems.

**I:** Oh okay.

**C:** You know, they sort of, all talk to me and say “how’s [name of patient] keeping?” instead of saying to him “how are you?” They sort of talk through me, I know it’s difficult for people, but then other people treat him like a child, you know what I mean?

**I:** It must be quite frustrating as well…

**C:** Yeah, even a couple of carers, a couple of them are quite young and they sort of treat him and talk to him like a child. We said to their supervisor that we don’t want to get them into trouble or anything, but he doesn’t like being talked down as if he was a child because mentally, he’s the same as he’s ever been. So umm, she said, actually we’ve had a couple of other people anyway comment on that, so it is not just [name of patient].

**I:** I guess that’s the similar thing to what you said in the beginning as well about people not understanding what MND is?

**C:** Yeah, no they don’t, people don’t. I mean I know; I suppose it is quite uncommon, I don’t know. Although when we got over to the wheelchair place, the chap over there, he said it is becoming more common in [name of county] for some reason. He said that more people that they’re getting sent to them got MND, more than what they used to get. I don’t know why that is. I mean, apart from that, I say we just take each day as it comes, really.

**I:** Okay.

**C:** If he wants to go out, we get togged up in our clothes, keep warm and go out, don’t we?

**I:** Yeah, that’s a good attitude.

**C:** If he doesn’t want to, then he stays on the bed, or he stays in the chair reading.

**I:** Is that how you cope with stuff by reading?

**C:** Yeah, he reads a lot. But he don’t do jigsaw or something, but he never has done [laughs]

**I:** [laughs] If you’re happy, I can stop the recording unless there is something you want to say?

**C:** I can’t think of anything else.

**I:** Happy to stop it, yeah?

**[End of recording]**