**Transcription of Interview 8**

**[Beginning of file]**

**Interviewer:** Okay, um, thank you for agreeing to be interviewed today, um just a couple of things before we start, um, I’ve explained to you what the whole purpose of the interview is about, but also if you have, if you want to take a break or you want to pause during the interviewer that’s absolutely fine, I can just press stop and start, very easily. And um, if there are any questions you find maybe to difficult to answer or you don’t want to answer them you can just let me know and we will skip over.

**Respondent (C):** yep

**Interviewer:** there’s no obligation, and yeah whatever information you tell me will be confidential so say you tell me about a certain hospital or a certain doctor or something like that, all of that information will be confidential so you can feel comfortable sharing as much as you want to. Uh yeah so, I’d like to just start, so basically I don’t know your story as well, so what was it like, um, when your wife got MND? And that whole experience.

**Respondent (C):** Right, she showed symptoms in June 2017, her voice started getting slurred, and uh I knew something was up, so I actually left work um beginning of November.

**Interviewer:** okay so you retired?

**Respondent (C):** yeah well I knew something was up so I didn’t want to leave her on her own or anything. And uh she wasn’t diagnosed until the 28th November, which was 2 weeks after I left work.

**Interviewer:** yeah

**Respondent (C):** So uh,

**Interviewer:** it was quite soon then?

**Respondent (C):** yeah, so really she sort of shown symptoms is June but was diagnosed in November. And it gradually got a lot worse, she ended up I think around January/February she lost her voice completely. And uh, uh she’s having now fork mashable food, um even that was difficult when it got to about [pause] about May June time. And uh what she ended up having then was um fortified supplement drinks.

**Interviewer:** okay

**Respondent (C):** um and yoghurts, that’s all she could have then. It wasn’t until December the 12th last year that she got um aspiration pneumonia,

**Interviewer:** oh gosh okay

**Respondent (C):** and went to hospital, she was in the [name of hospital] for about 8 days then she was transferred to [hospice].

**Interviewer:** oh okay

**Respondent (C):** and that’s where she started getting worse and her um her mobility had started getting worse before she went into hospital but she was still going about, I had to help her up the stairs and everything. And then um [sigh] 25th January she passed away.

**Interviewer:** oh gosh, okay – that’s quick

**Respondent (C):** [mumbling] the aspiration pneumonia when she was in [hospital] and transferred her to [hospice] was in there for, well since, from the 20th December until the 25th January. So about 5 weeks on. The day before she passed away she got the aspiration pneumonia back again, she choked on some, a yogurt.

**Interviewer:** oh my goodness

**Respondent (C):** the last um, 4 weeks, I could only feed her with a syringe. Because she couldn’t move her tongue or.. she couldn’t um uh move her chin up and down for chewing motions, to actually get the food to go to the back of her tongue down.

**Interviewer:** and she passed away this year?

**Respondent (C):** This January , yeah.

**Interviewer:** okay so this, 2017 to now, okay so it’s quite quite sudden. Yeah. Um, also just how were your feeling when they diagnosed her and things like that, did you know a lot about MND or?

**Respondent (C):** Not a lot no. I didn’t know a lot about it no. But uh, I looked it up and looked all around, they said that uh with the Bulbar MND the life expectancy is 6 months to 3 years.

**Interviewer:** okay yeah

**Respondent (C):** Normally it’s the other way round, people get it in their legs first, their arms and then..

**Interviewer:** it moves up

**Respondent (C):** yeah,

**Interviewer:** it’s so different for different people isn’t it

**Respondent (C):** she had the uh front-temporal dementia as well

**Interviewer:** oh okay

**Respondent (C):** to go with the MND, it don’t effect everyone, everyone don’t get that but she did. So it affected her, well her reasoning, because she was offered the feeding tube – she refused that because all she could pick up on was the bad effects of it, not that it would help.

**Interviewer:** so she had already had the dementia at that point yeah?

**Respondent (C):** yeah well, she [mumbling] was diagnosed with the Bulbar onset MND and the frontal-temporal dementia at the same time.

**Interviewer:** oh I see, okay okay I see now

**Respondent (C):** I knew something was up because she was doing um funny things, well not funny things um we’d be out in the car, her sister was in the car with us and it was on her birthday, 2017, before she was diagnosed. We were going to um take her on the [name of place] railway, the steam train for her birthday and they were driving down towards that way and she said ‘where are we going?’ I said ‘funny farm’, I just being funny and she says ‘where’s the funny farm, where’s that? Where is it?’ She said [name of husband] where is it? She didn’t sorta get what I meant you know.

**Interviewer:** yeah so you knew something was up then

**Respondent (C):** and she was getting up at weird times, she’d get up at 4 o’clock in the morning and go into the bathroom and I’d wake up and say ‘what you doing?’ and she’d come downstairs, get her breakfast and start eating her breakfast at 4 o’clock in the morning or 3 o’clock in the morning. It’s uh, it was just um silly things like that she used to do.

**Interviewer:** and how was that for you also just um living her, looking after her with all of those symptoms?

**Respondent (C):** It was difficult because I didn’t want to leave her on her own, for the occasion I had to, like If I wanted to go shopping or something or or if we were out in the car and I went shopping while we were out she used to stay in the car, so I was aware that she might get out and walk off or something.

**Interviewer:** yeah

**Respondent (C):** but she just wanted to go out every single day, exactly the same thing every single day, she just wanted to exactly the same thing it was just, you know, it was difficult.

**Interviewer:** and what was the difficulty like, in terms of how you used to look after her. Just roughly the kinds of things

**Respondent (C):** uh, well she couldn’t actually climb, she couldn’t get into bed or out of bed, I had to um, I got her um, I bought it in the disabled shop, there’s a step with a big hand-bar on the front so she’d stand on that and I had to guide her down to sit on the bed and I’d life her legs in. Cause she, she started dragging her right leg, her toes were always pointing down, she kept and she tripped over a couple times, one time she fell down the stairs backwards and fractured her wrist but um I bought her a doorbell, it’s over there [laughs], I said that if you need anything just press that, I was actually already upstairs, and she didn’t bother pressing it and tried to climb up the stairs and fell backwards.

**Interviewer:** oh gosh

**Respondent (C):** so that made it a bit worse but uh, she couldn’t do as much, ah ha, she could do even less then, she couldn’t even get dressed herself. But uh before she went to hospital she couldn’t dress herself at all.

**Interviewer:** so you had to help her with pretty much everything

**Respondent (C):** yeah

**Interviewer:** okay, and uh I know as well not just for the person with MND but also for the family members, sometimes just not knowing what it is and things changing so quickly can be quite um an emotional challenge as well. So, can you tell me a bit about how it was like for you.

**Respondent (C):** [tears up] It’s sort of frustrating really, I was sort of uh [pause, cries silently] yeah trying to cook her meals that uh she might be able to eat but uh she just couldn’t…

**Interviewer:** that’s quite difficult seeing her like that, and um it was just little things like..

**Respondent (C):** yeah she lost so much weight, her clothes were, well they’d fallen of her so, when I bought her a pair of jeans and stuff like that for her, even when she went into hospital she was in size 10 clothes, size 12 clothes when she went into hospital, but when she was in [hospice] um, she was down to size 8. She just lost so much weight.

**Interviewer:** probably with the diet and..

**Respondent (C):** yeah, but it was difficult because the ward she was in in the [hospital] was in the respiratory ward, so most people in there either had viral pneumonia or COPD. So I don’t think the nurses knew, she needed mashed up food and yoghurts and stuff, so for the whole week she had nothing to eat at all.

**Interviewer:** oh my gosh

**Respondent (C):** they kept bringing meals into her, but you know, they were normal meals. I started taking yoghurts in but uh, till she got transferred to [hospice] and they, there she had the um the fortified yoghurts as well so, she was having them as well in there.

**Interviewer:** did you have to go quite often to the hospital?

**Respondent (C):** well I was going everyday, I was going there for 10 o’clock in the morning, well half 9, 10 o’clock, until 8 o’clock at night. Even Christmas day

**Interviewer:** oh yeah it was around Christmas

**Respondent (C):** [tears up again] needed to eat properly..

**Interviewer:** yeah yeah,

**Respondent (C):** so there was rubbish stuff to eat

**Interviewer:** yeah it must have been quite difficult for you to manage also both stuff here and there. Um, how and also these experiences does it, do you usually, does it kind of depend on when the difficult parts are, is it certain times like when she has a fall or things like that or does it happen everyday where there are these sorts of emotional challenges?

**Respondent (C):** Well almost everyday yeah,

**Interviewer:** okay, okay. Um and how do you usually cope when you have these sorts of concerns/worries?

**Respondent (C):** Grin and bear it I suppose,

**Interviewer:** okay okay, is there anything…

**Respondent (C):** well if the carers come in for, they weren’t worth paying for, but it’s mainly for in the morning to help her get washed and dressed, but um she was getting upset because in the morning she wanted to get dressed straight away, course they were coming half 9 ten o clock, and so she’d already dressed and washed and so they were doing nothing so I cut it down, because it was £25 a day, costing for 7 days a week, well I don’t have many come in but the carers at the moment, and [name of patient], my wife was only getting the um uh standard living part bit, I applied for the mobility bit but that took months and months to come through, in fact it came through, I got the um DS 1500 from the doctors

**Interviewer:** okay, DS1500?

**Respondent (C):** 1500 yes, that’s when someone’s got a terminal illness that they um the prognosis that um they won’t last longer than 6 months, uh some people with MND, one of the guys said that he’s got DS1500 and he’s got to have it renewed because it’s 3 years old now, but once you’ve got it you can get it renewed every 3 years but its getting it, finally got that, sent that off and she got the um enhanced living and mobility at PIP, week before she went hospital. Course then it stops once she goes to hospital so.

**Interviewer:** oh okay

**Respondent (C):** She didn’t really get it anyway.And the disabled badge arrived the week before she went to hospital as well, so we never used that [laughs]

**Interviewer:** but did all this sort of help or make it easier in some way, for you as well?

**Respondent (C):** yeah

**Interviewer:** okay. Um besides these bits of help um, see from professional carers or these allowances and things like that, is there any other things you did or people that helped support you in any way?

**Respondent (C):** [pause] well, only the um occupational therapist that came in, um well there’s certain things like the mattress topper, to stop bed sores and stuff like that and the cushion for the seat.[mumbling] lift and tip chair but I never used it or anything, couldn’t stand it. So I phoned the company that installed it they said we need the person, order number from the [place] Council, before they can take it out. So I don’t know who to phone, in [place] council.

**Interviewer:** and how did you know who to go to and how to figure out what equipment was needed and things like that?

**Respondent (C):** Well they just came and said, ‘this would help, this would help’. The occupational therapist and um, [pause] uh the physiotherapist that came because she said about the leg supports to keep her foot up when she’s walking or trying to walk, but she wouldn’t wear them either so.

**Interviewer:** did they, did anyone suggest any kind of help for um you as well or was that not offered?

**Respondent (C):** well they said that if I uh need anything that I can phone anyone.I just thought I could cope..

**Interviewer:** I see, so you didn’t try call any other support that they did offer?

**Respondent (C):** nope

**Interviewer:** um did you feel you needed any or, were you okay?

**Respondent (C):** well I thought I was okay,

**Interviewer:** okay, alright. Um and also just from, I guess before diagnosis, when you noticed things were starting to um have some effect and then things changed and got worse, I guess you have to keep dealing with things as they change as well. Um, so just what was that experience like with just coping with things constantly changing?

**Respondent (C):** it was difficult, well one of the things was when she started walking funny and dragging her leg, um I only mentioned to one of the, I think it might have been the physiotherapist, yeah it might have been the physiotherapist when they came about um the wheelchair, I asked her if her walking funny was help, they said not really because what she was doing was swinging her leg around, she had a walking frame and she was kicking the walking frame. She’d be more of a trip hazard with the walking frame than without. They said about wheelchair and they said yeah we can order one but it’s gotta be ordered and it will take 16 weeks, um I actually hired, well I borrowed one from [name of charity].

**Interviewer:** oh okay

**Respondent (C):** you can get one from [name of charity], you can get in on a 12 weeks, you can have it for 12 weeks.

**Interviewer:** and the give it back?

**Respondent (C):** And give it back yeah. So got that, it was easier, uh it was in the conservatory, put it outside the back door, walk her, then sit her in it, take her out to the car, put her in the car and the wheelchair went in the car when we went out and then same when we come back, because it took so long to get round um from the car to the back door. So I thought it would be easier if I bought a wheelchair then she could just get in it and put it round and um, because it was getting through the gate, because I had to hold her, the side of her, and 2 of us couldn’t get through the gate at the same time. So either I had to go in front of her or behind her, course with the wheelchair it was easier.

**Interviewer:** course you never anticipate these problems and then suddenly

**Respondent (C):** [mumbling] I did order a wheelchair, it was ready when she was in hospital but um, they didn’t have the cushions, they were waiting for the cushions for her, they were still waiting for cushions when she passed away so.

**Interviewer:** oh gosh

**Respondent (C):** when she was up in [name of place] there was us waiting.

**Interviewer:** things take time

**Respondent (C):** yeah

**Interviewer:** to be processed and things. Okay. Um were there any bits that you found particularly difficult to manage?

**Respondent (C):** well only things like um, getting her to clean her teeth, she wouldn’t do it, clean her teeth. And most days she wouldn’t even wash so, had to remind her after she went to the toilet to wash her hands afterwards, she was she was not doing that. Little things like that that um [pause] where she, I had to do everything for her, when uh once she got up like dress her, bring her down here, um make sure she’s having her supplement drink, course then she wants to go out, straight away. I haven’t don’t anything, I haven’t washed my hair and shaved, I haven’t done me teeth, yeah its – it ended up she wanted to go out in the car, usually she sat in the car I’d come back in and I could have my breakfast, wash me hair and um do my teeth and everything, tidy up and then go out. But she just, well it’s the frontal temporal dementia, it um well the symptoms is they don’t consider other people, they just think about their self.

**Interviewer:** yeah

**Respondent (C):** so she couldn’t um reason that I had to get ready as well. Like she used to, used to go round the [name of place] and then she’d say, well she didn’t say, she had a key board she would type on, or a notepad she used to write on, and uh she’d write on the notepad [name of another place], she wanted to go [another place], we were in the [name of place] and she wants to go [another place]. We’d be in [name of another place] and she’d want to go to the [name of place]. Just driven her all the way to [name of another place] and she want to go all the way to the [name of place]. We’d be at the [name of place] and she’d say she wants to go to [name of another place]. And uh of course when I was working I had a company car, so when I left work, the next day the company car was taken away, so I had no car for well from beginning of November till beginning of March, when I bought a car. So I was going round on buses. And of course when she was in hospital having her tests done for a week, I was going to the hospital every day, 2 busses there and 2 busses back everyday. I couldn’t stay late because the last bus from town that comes here is uh just after 6 o’clock, so I had to make sure I got back in the town for 6 o’clock. So I couldn’t stay late so, it was uh a pain that one, course when I got the car she wanted to go out everywhere and I ended up doing more miles than I was doing when I was working. When I was working I was going up to [place] and you know all over the pace, [another place], but I was doing more miles just driving round locally, out in the car all day, doing 150 odd miles all day, and uh the car had its first year service after 5 months, so uh. I kept saying she was just wasting money on petrol, we’d go to the [name of place] and the going to [name of another place] then coming back, backwards and forwards and occasionally I said no we’re not going, it was difficult.

**Interviewer:** and um, even for yourself in terms of taking a break, or um doing some kind of hobby or something like that, did you do things like that to help you cope?

**Respondent (C):** no

**Interviewer:** no? okay

**Respondent (C):** I couldn’t even spend much time in the garden because, I mean I cut the lawn in November time, and didn’t want to leave her too long indoors, plus I wouldn’t be able to hear if she pressed the doorbell, I took the thing into the, by the conservatory, just outside the conservatory but if I had the mower going I wouldn’t hear it. It’s things like that. But I didn’t trim the leaves until, well this year, end of January, there was leaves everywhere, normally I’d of done it 3 times before Christmas and then couple times afterwards.

**Interviewer:** yeah there was no time really. Um okay but you felt if someone did offer something you probably wouldn’t have taken any help or things like that at that point?

**Respondent (C):** no

Interviewer: okay, um is there anything I haven’t covered, I know everyone’s story is different so I’m just trying to see is there any aspect of you r experience that we haven’t spoken about or…

**Respondent (C):** umm, no

**Interviewer:** well if you think about it later also we can, we can add it to the recording. But as I was telling you about our study and things like that, uh, what we’re trying to do is, develop some kind of support for people, when they’re going through this, mainly to help with umm the emotional challenges that people go through, but we’re trying to do this on an online platform, I was just curious, would you, do you usually use those sorts of websites or go on the internet for help?

**Respondent (C):** no

**Interviewer:** not really, that’s fine it’s just to get a sense of um you know whether it may or may not be helpful, um yeah so you don’t use any of that and you wouldn’t go online for, to look for help either?

**Respondent (C):** not for that no.

**Interviewer:** no okay, um okay. So yeah that’s basically all my questions, I don’t know if we covered anything you wanted to talk about anything closer to um to when she passed away or maybe even after, about how you got on and managed with that type of thing.

**Respondent (C):** um, I was really just a shock. [cries] I knew it was going to happen but, when it does you don’t expect…[cries] it wasn’t too bad because I’d been on me own at night since beginning of January, since December anyway so, it wasn’t a shock of you know I suddenly had to be on me own in the evenings.

**Interviewer:** is that because she was in the hospital, hospice?

**Respondent (C):** she was in the hospital, in the hospice, yeah, for about 8 weeks or so. [pause] so it wasn’t the biggest shock sort of thing.

**Interviewer:** and even after that, um to now even..

**Respondent (C):** [sigh] well uh it is difficult, you know there’s a lot of stuff to sort out, I’ve got all this equipment taken that had been delivered, its just the stairlift.. and everything yeah.

**Interviewer:** yeah, lots of things to sort out and go through, okay. So you got support from the hospice then towards the end?

**Respondent (C):** yeah

**Interviewer:** you had some of their support before as well. Are there any other people that kind of helped in anyway that we haven’t spoken about? Cause I know you [charity organization] so, it’s them as well, um, there’s no one else?

**Respondent (C):** no sorry

**Interviewer:** and even with like the [charity organization] and going for coffee mornings and things like that, how did you find that experiences?

**Respondent (C):** I found it helped, you know there are other people, what their [mumbles]I managed to get her to go to the last one, that was on the uh 18th January. She was in the [hospice] but I asked the nurse if they could get her in a wheelchair before 11 o’clock and they did, we went round there and uh [pause]

**Interviewer:** I think that’s where I met you as well, yeah.

**Respondent (C):** And I managed to get her hair done as well, on the following day on the Tuesday, from the hairdresser.

**Interviewer:** oh okay. I know you said you missed this last month or do you still go?

**Respondent (C):** well I went to this one

**Interviewer:** oh you went to this one too, okay. Is that um, is that different even after she’s not there?

**Respondent (C):** well no because uh, I’d class them as friends you know.

**Interviewer:** yeah its just like meeting friends again, okay. Yeah is there anything else you may want to add?

**Respondent (C):** uh, don’t think so

**Interviewer:** don’t worry, we have covered a lot but I’m just slowly going through the timeline to see if we’ve missed anything. Okay if you’re happy then I can stop the recording.

**[End of recording]**