**Transcription of Interview 7**

**[Beginning of file]**

**Interviewer:** This is interview 7. Just a couple of things before we start the interview, just some instructions, so the main purpose of the interview is to talk about your experience with MND and also to talk about how you cope with things and the challenges and things like that. So, some parts may be a bit difficult so if you feel… I’m happy to stop the recording or skip a question or take breaks whenever we like. The other thing is, the information you tell me will be confidential so supposed you mention a hospital name or a doctor’s name or something, don’t worry about that because it will all be treated confidentially.

**Respondent (C):** Yeah that’s fine.

**Interviewer:** I know you’ve already given me a bit of background before we turn on the recording, but could you just tell me what’s your experience with MND was, from wherever you want to start, whether diagnosis…?

**Respondent (C):** Well I mean the start is really, no warning we got a healthy person [name of patient] was really healthy nothing wrong with her, working full time as a civil carer looking after the elderly and people with dementia. Just one day, she started walking funny. Literally just started walking strange and then within, three months of that it just progressed worse and worse until the fact she fell out of her work, and bosses told her that she really needs to get seen, because she can’t carry on working like that. She went to the GP, GP examined her, he was quite concerned and got her to hospital that day. She was in there a week, and after the week various tests, numerous tests, it was diagnosed she got Motor Neurone Disease. So, simple as that, quick as that. Shocked, yeah. Totally turned your life upside down.

**Interviewer:** What were your feelings at the time of the diagnosis?

**Respondent (C):** Just shock. Total, total shock. We knew there was something but we didn’t realise it would be that severe because you know, and not knowing anything about Motor Neurone Disease at the time. You then start reading up about it and see all the horrific stories about it. So, it is a shock. I think the early thing you know about all people now about Motor Neuron Disease is Stephen Hawking because he’s such a well-known guy, but then everyone we’ve spoken to in the MND circle say that he was really a bit of a freak of nature because no one’s ever lasts that length of a time. So you know it’s difficult, it’s just a difficult situation.

**Interviewer:** What did you do after the diagnosis?

**Respondent (C):** Well, [name of patient] obviously had to stop work so, apart from the shock of what she’d being diagnosed with, we then had the financial burden because [name of patient] was the main earner. We then… her incomes stopped and from an income of £600 a week plus, we were then put on benefit, sick pay which was £80 a week. Of course, we had bills to pay, we had finance agreements that were in place and everything else. Apart from the fact that she got this horrible disease, we were left with financial burden and the financial side of it with benefits and everything else was just a nightmare, absolute nightmare trying to get form filling. I mean I noticed the [charity organization] got a thing going through parliament to try and get people with MND fast tracked. Well luckily the GP that we had at the time was absolutely brilliant and he did sign the 1500 form which is the fast-track form because otherwise it is ridiculous… they wanted to send her for… she’d just gone for all these hospitals been diagnosed, tested and everything else. And then the benefits department wanted to send her for assessments with people from agencies that go no real medical experience which is ridiculous. But thankfully the GP signed this 1500 form and it was fast tracked, all of our benefits was fast tracked. When he signed that, we got everything sorted out within a week, but I feel sorry for people that don’t, haven’t gotten a GP that will sign that because if they don’t it takes months to get all this. They have to go for interviews and… well hopefully I know it’s not like that, the [charity organization] have lobbied Parliament to try and get this people that got MND to get fast tracked. because it’s bad enough to be diagnosed with the disease and then having the added burden of finance. Because it’s not her fault, it’s not my fault. I mean I’ve worked all my life, I’ve never been out of work, I’ve always paid income tax and everything else, British citizen... Yeah she’s got this horrible disease, we should be able to look after her you know, as simple as that. But it is a mine field, the benefit system is just a mine field. It’s a good job Lynn had me because I’ve always had financial services business, so, I do know about form filling, about the technicalities of everything. I mean if she was on her own, she wouldn’t be able to do it, no way on this planet! It’s too complicated for a majority of people and I’m sure there’s many people out there that aren’t getting what they’re entitled to because it’s just a nightmare, the form filling. Absolute nightmare! But anyway, we got it all sorted in, didn’t we? And it continues to be sorted because we still get bits of “[name of patient] owes £70 income tax from 5 years ago.” “Hello. Are you sure? Why haven’t you taken it from our earnings? It has been 5 years.” “Oh yes our mistake. I’ll wipe it off for you. Thank you”. But you know it’s just one thing after another, honestly. But the benefit system is terrible, it’s just a mine field. The government wastes so much money like for PIP, people have to go for assessments.

**Interviewer:** Sorry, PIP is…?

**Respondent (C):** Personal Independence Payment, it’s for disabled people. But they sent people for an assessment to a little office in the industrial estate where there is an agency worker, probably an ex-nurse who’s about 70 years old and retired and she got to assess someone like [name of patient]. When [name of patient] has already been assessed by consultants, neurologists, specialists. Why is the government wasting money sending out for assessments when it all has been done anyway, it’s just crazy. I mean they obviously pay these agencies a lot of money but thankfully [name of patient] never had to go through that because I went to see the GP and he signed the 1500 form which is the fast track. So now you don’t need to go to all these assessments but there’s a lot of people out there with MND that have to go through all of this and it’s just crazy. Taking someone like [name of patient] to a retired nurse, who hasn’t got a clue about MND and she’s meant to do an assessment on her for benefits when [name of patient] has been with neurologists, specialists and all of this and they’ve said yes, she got Motor Neurone Disease.

**Interviewer:** It was up to you I guess, to sort this out?

**Respondent (C):** I mean, I did it all didn’t I? Did all the paperwork, got all the stuff sorted out, phone calls and this and that and eventually got sorted out. But we still have hiccups sometimes because obviously I got power of attorney for Lynn’s finance and health. Some weeks I check our bank account and I haven’t paid it so you phoned out, “oh yeah our mistake, sorry. We’ll get it out in the next couple of days,” but you can do without all that.

**Interviewer:** And you were clearly new to all this system.

**Respondent (C):** Yeah I’ve never claimed a penny in my life.

**Interviewer:** So how did you feel having to suddenly…?

**Respondent (C):** The fact that I was a financial advisor for 30 years, I used to have to advise people. So, I kept my knowledge of the benefit system because obviously I was dealing with people that needed to know about it. So, I was lucky, but I can imagine people, normal run of the mill people who hadn’t had an idea. They must be in turmoil trying to get it sorted. I’ve spoken to a few people that have said that we just gave up at the end, yeah, I mean, it’s just crazy. But yeah, I mean know it’s going to Parliament, and it has a few sits already about the fact that people with MND should be fast tracked to… should have their benefits sorted out.

**Interviewer:** Yeah, right from diagnosis…?

**Respondent (C):** Yeah because you know otherwise… well, it’s the government wasting money sending them for reassessments, when they’ve already been diagnosed by specialists. It’s just crazy but anyway, all sorted, we got it through in the end. But it was hardship because one minute you’re… this is how quick it worked, one minute she’s working £600 a week, bang can’t work anymore, you got MND £80 sick pay a week, and there’s a big difference and of course you still got to pay all these people. I mean, I had a little boat which was my hobby, I had to sell that because I knew it’s gonna take time for all the benefits to come through. I mean they did come through in the end but as I said you just worry initially because you still got to pay all the bills. But here we are, we sorted it didn’t we [name of patient]?

**Interviewer:** Is that how you all generally cope with things?

**Respondent (C):** I’m very much sort of an optimist, I’m a fighter. I used to be in the royal marines I’ve been brought up to be strong and you gotta be strong with it. You can’t…you know because it’s horrible we know that. But we just make [name of patient] as comfortable as possible. You’ve got to be positive, otherwise you just sink and go under but I can imagine there’s a lot of people that would just go under because they won’t be able to cope really. But you know, I’m lucky I’ve always been a financial environment because I own my own business, you see. Dealing with mortgages, financial problems with people, debt management and all that sort of thing, I’m used to dealing with it. But we were lucky in that aspect.

**Interviewer:** Did you have to give that up as well?

**Respondent (C):** Well, prior to [name of patient] getting diagnosed I was diagnosed with… I’ve got vascular problems. So, I’m registered to disabled as well. That’s why I had to give up work as well. I think I was about 59, 60 when I was diagnosed with it. What happened was I had a financial service business for about 30 years but then I gave it up simply because of all the legislation, I mean if you go down the high street, you don’t see insurance brokers anymore. It’s just the big building societies that deal with everything now. So I gave it up, and I took a totally different direction in life, I took my heavy good vehicles license, big lorry, passed that and I drove HGV lorries all over UK out Southampton docks, the big containers. So, I used to be away all week, all over UK driving that. But then I was diagnosed with this and I just couldn’t do it. Simple. Which was a bit of a shock for me. So, [name of patient] was working as a senior carer and I was like a house-husband. I was just doing the chores and everything else and [name of patient] was working. So, of course when she was diagnosed, we were both disabled up the creek without a paddle [laughs]

**Interviewer:** So, what it’s like on a day-to-day basis just living?

**Respondent (C):** It’s alright now because we got it all sorted but originally it was a bit… I think the thing is as well is that [name of patient] has stabilised a lot now she’s got to a stage where she is what is. But, before that she was eating properly and she was still managing to walk. So, it’s the decline you’ve got to change everything I mean, she’s now hoisted to go anywhere whereas before she was using her walker, weren’t you first of all when you were walking about yourself? So, it’s the decline, it’s the same with eating, she used to eat a lot of stuff, now she can’t. It’s through the PEG feed. That’s quite a challenging thing, the fact that it’s a decline. And you can’t stop it. She’s on medication which helps with the pain. Your pain is pretty controlled now, ain’t it? But she’s on quite a lot of medications these days which I have to administer to her. But I think the thing about it is the way you decline… it can be… each decline can be quick or it can be long, so, you don’t really know do you. But at the moment yeah she’s stabilised…

**Interviewer:** And that’s the tricky bit I guess not knowing how…

**Respondent (C):** Not knowing… yeah you just don’t know what’s going to happen next? It’s the unknown, really. The problem is I mean, I can understand from the drug companies’ point of view… I don’t think there has been a lot of research done into MND. The drug companies aren’t really interested because there’s only about 1000 people in the UK any one time one got it. So from a financial point of view, it’s not worth for them spending money to research it because they’re not going to get too much back. They’re only getting about a thousand people, different (??caps?) or something like that so that’s the difficult part as well. I mean, you know all these years they’ve literally haven’t come up with anything. No drug at all! To suppress it, to stop it! I mean they’ve got one drug you know in all these years, Riluzole but all that does was prolong for about a week. She took it for a couple of days and was violently sick and we said no more. All the money that has been spent and for them just to come up with that, it’s a little bit you know..

**Interviewer:** Did you want to say anything about how you felt about the decline and things like that or have we covered it?

[pauses – carer offered a drink to the interviewer and make patient more comfortable] [part 2 begins]

**Interviewer:** So, I guess you’ve kind of covered some of it but in terms of the emotional side of things as well for both someone going through the disease and someone looking after. It can be quite challenging, so if you could tell me a bit more about those sorts of emotions

**Respondent (C):** You go through a mixture of emotions. I think again, we’re lucky we live in the area where we got the [hospice] because they have been brilliant. They’ve got a MacMillan nurse that comes to see [name of patient] once a month and she’s brilliant. If you got any problems about anything, she will sort it out. I mean, the other problem we had when [name of patient] was diagnosed was the fact that she needed a wheelchair. Wheelchair services provided over the electric wheelchair but where we were living [name of place] at the time, it was a two bedroom flat, it was so tiny. She couldn’t move around in it. So, the MacMillan nurse and the OT, occupational therapist from the [hospice] obviously they’ve looked after people with MND before and they said there’s no way this place… you wouldn’t be able to stay over here. We had that flat through… it was social housing…. Through umm, a housing association anyway in [name of place]. So, we got in touch with them and they said “well we can’t really do anything, you need to go to [place] Council.” So, I went down to the Council and told them about our situation and within two weeks we were offered this brand-new property purpose built, disabled-friendly flat. Just lucky, we were lucky this was available. It was brand spanking new. It has wide doors so she could move about in her wheelchair. The bathroom has all been adapted with the shower room so she can have a shower and you probably noticed the doors are all automatic. They all fitted especially for [patient]. All of the other residences have got keys but we got fobs so [patient] can get in and out. We also got a key safe with the fob in there so the carers can…. So, we were lucky from that point of view that they sorted the housing out for us pretty quick. But that was really down to the [hospice], MacMillan’s nurse and the occupational therapist writing letters to the council to say, look, you really need to sort this out because if you saw the bathroom it’s like a … it was no bigger than the toilet. You can’t get two people in the bathroom.

**Interviewer:** The old one?

**Respondent (C):** Yeah, and that would be impossible because [patient] has two carers four times a day. Can you imagine if we’re still there? It would just be a joke isn’t? We got two carers; it would be full up. So I mean this lovely, absolutely lovely area you get the deer walking pass the window, she calls them Pixie and Dixie 3:51.

**Interviewer:** Do you actually?

**Respondent (C):** Yeah, you get deer walking pass because this used to be an old mental hospital here. So the deer has always been here, so now all they’ve got it’s that a little field at the top there so they must think it is strange all these houses. So yeah, that was a bit of a strain on it because obviously we had to move all the stuff. You know what it’s like moving, it’s a lot of hassle. But once we got settled in here, it was nice wasn’t? It was nice.

**Interviewer:** And then you settle into the new space and new routine and things like that.

**Respondent (C):** Yeah and then obviously because [patient] was… she got PIP, Personal Independence Payment for mobility and for care because it’s two elements of it, so, she got the top rate for mobility and care. The mobility allowance we used to get her a van, which we got that she can use… so her wheelchair can go in in the van with her. You know what I mean? A proper wheelchair van. So we used that part of the personal dependence payment for… which gives us a little bit of freedom because basically we can get out. We haven’t taken it out much in the winter because she doesn’t really like the cold do you, but in the summer, we’ll be taking her out in the beach for an ice cream.

**Interviewer:** Looking forward to that.

**Respondent (C):** It’s nice down there. There’s a nice café down there.

**Interviewer:** Were there any other organisations that helped you?

**Respondent (C):** The [charity organization] helped. They were good. Very good. Umm, I mean again, initially we didn’t know who to turn to because you know, you’re just diagnosed with this thing and then you think “oh my god what do we do?,” And all of a sudden, we were, after a couple of weeks it’s all quiet after [patient] came out of the hospital, we didn’t hear anything. We thought ‘what were we gonna do?’ And all of a sudden, we were bombarded with people, phone calls, speech therapists, hand therapists, occupational therapists. Ahh, honestly, we were bombarded with people. Constant! It was every day of the week.

**Interviewer:** Was that good or not so good?

**Respondent (C):** It was a bit of an overwhelming, to be quite honest because to start with, because all these different people some made appointments and some just turned up, knocked at the door. It was literally everyday wasn’t it? The phone was ringing, “hello this is so and so… we want to make an appointment to see [name of patient],” “[name of patient]! what about me? Come and see me.” So yeah, that was a bit challenging because of all these people coming into the house and we just moved in and all this. Umm, but then it started to settle down and I mean now it’s all on a level playing field but as I say, it’s quite shock to start with because you got all these people. You know, there’s quite a lot of people that got involved with it. Because we had speech therapist, hand therapist, respiratory therapist, neurologist, both at [name of place] and [name of other place]. So I had to take her to all these appointments at the hospitals and we were going every other day, wouldn’t we? And then over here to this hospital for the speech therapist, dieticians...

**Interviewer:** Sounds like a full-time work?

**Respondent (C):** Honestly, I’m [patient’s] full-time secretary [laughs]. It was wasn’t it?

**Interviewer:** Well now you’re settle into a routine.

**Respondent (C):** Yeah now it’s calmed down quite a bit. We still get MacMillan nurse once a month, she comes around. Speech therapist comes about once every two months now, and then of course we got the carers four times a day. So, two of them four times a day, necessary? Yes. Intrusive? Sometimes, because you lack a bit of privacy and you feel like every day because it’s 7 days a week. You know, they’re coming in, I mean they come at 8 o’clock in the morning for an hour [ring bell at background]. Excuse me.

[part 3 of the recording begins here]

**Interviewer:** So professional support. Do you get any support from any other things or people or things like that, rather than professionals?

**Respondent (C):** Nah, not really. Say [charity organization] do that meeting once a month but we don’t go there anymore because it’s a long way for [patient] to travel. She doesn’t like travelling that far in the van. It’s a bit too far, it’s quite a long way from here to [place]. So no, there’s no one else is it? No non-professional. They’re all professional people that she sees.

**Interviewer:** Personally because it can be quite, as you imagine well quite a lot of work and just quite challenging on a daily basis. How do you cope with things?

**Respondent (C):** [Laughs] I just… get on with it, to be honest. I mean it’s not nice and I just want to make sure [patient] is comfortable, I wouldn’t like it you know. Even though I’m a bit peeved because I thought she’d be looking after me but it’s the other way around. I mean, touch wood, apart from my vascular thing which I do cope pretty well, don’t I? I’m pretty healthy apart from that. So yeah I mean the only thing is obviously, we’ve just had a review because [patient] gets continuing healthcare through [name of place] Council and we’ve had a review recently and they said that I should, I need to have a whole day away, 8 hours so they agreed it. The funding was put in place and everything else but the care company haven’t got the staff to do it. So I lost out on my day off, which is unfortunate.

**Interviewer:** To be here for the day to look after…

**Respondent (C):** Someone would sit here for 8 hours one day so that I could clear off a day to myself, which I need. But the care company haven’t got the staff to do it. We’ve got a case worker who deals with our case from [name of place], who agreed the 8-hours sit and he’s now trying get another company to do the 8-hours sit once a week, which just enables me to go off and see my daughter or something like that. Because the trouble is at the moment is I only got 3 hour slots where I can clear off and do things. Like 8 o’clock, as soon as the carers come, I can go, but then they’re back by a quarter past 12 so I’ve got to be back by then. Then, they’re back again at half past 3 and then they’re back again at 8 o’clock. So it’s only in between those times that I can quickly shoot out to get whatever we need. What I intend to do once the carers come in the morning I normally slip out to get the shopping done and whatever that’s need to be done. But it’d just be nice to have one day out of seven, because that’s what the guy said to me ‘To be fair, the work that you do with [patient], we’d have to pay someone to do that. You don’t get paid anything.’ I’m still unpaid, I do it for the love, do you see what I mean? And as he said, we would have to pay a lot of money to do, cover what you’re doing, what I’m doing. So, he said you know, I’m sure we can afford to give you one day off out of seven, and that’s what we agreed. So, we got the costings, the funding’s put in place but unfortunately the care company… the trouble is with these care companies is they’re all agency stuff so zero contract… They come and go, come and go and it’s just a major problem with the carer community. I don’t know why the NHS don’t employ their own carers, you know, it would be such, a lot easier and better because these care companies… I mean you can start up one tomorrow, you know. But the problem is, the staff… why should they work for an agency when they can work for a care home and get all the benefits like sick pay and everything else because all these agencies, their staff are on zero contract. They don’t get benefits, so why should you work for that? I mean, [says to patient] you’ve never worked for an agency, you’ve been a carer for 20-25 years. But all the NHS, all the councils and everything throughout the country use agencies. Why don’t they get their own staff and set up their own? It would be a lot cheaper as well? Because he’s yet to tell us what they’re paying the agency for [patient’s] care and it’s a phenomenal amount of money. You can have your own staff and pay a quarter of that money. Again it’s just, it’s the government throwing money away without any real thought. It’s crazy.

**Interviewer:** And did you feel you needed a break as well at that point?

**Respondent (C):** Oh yeah, because you imagine you’re in the environment 7 days a week and it’s the same continuous, repetitive, give [patient] her meds, fags, this, that, everyone needs a break. If I was employed, my employer would be sued for not giving me a break and he agreed. The case worker agreed, you deserve one day off a week, you need it. Just a break, away. Like I said, it was all set up in place we were all excited about it and then the care company phoned up and said “We’re sorry we haven’t got the staff to do it.” I’m still waiting for my day off [laughs] but I’m sure it’ll happen one day.

**Interviewer:** Must be quite frustrating to wait for…?

**Respondent (C):** It was agreed nearly two months ago, I’m still waiting. Never mind. Never mind. But they do say that these care companies they can’t take any more people on because they haven’t got the staff. And there’s people in hospitals waiting to come out into the community but there isn’t the people, the agencies haven’t got the staff. It’s a catch 22 situation and that’s why the NHS or whoever needs to, the councils need to employ their own carers. You alright? Do you want… or anything? What’s the matter? Is it getting a bit too much for you? [asking patient]

[break, talks to patient]

**Interviewer:** So, I think I’ve asked most of my questions about your experience but if I missed any that is that you think should be covered because everyone’s experience is different.

**Respondent (C):** The other thing is all the equipment needed. I mean like bed, hospital bed, the hoist, I mean there’s a lot of equipment, isn’t there? And again, it goes in stages like she has a… what is that hoist called, stand aid. But of course, then, she got to the stage where she couldn’t use the stand aid so then the hoist had to be delivered. So, I mean we’ve had [name of place] Equipment Services outside so many times taking stuff back, picking it up. I mean this bed is from them as well because it’s a tilt bed. So again it’s all the equipment that you have to have. There’s quite a lot to it, to be honest. It’s not just a case that someone just got a cold, we got to look after. It’s a big, big picture. It’s quite intense.

**Interviewer:** It must be challenging as well to try and figure out the whole picture?

**Respondent (C):** As I’ve said, I am a pretty strong person, thankfully fairly fit. But I can imagine some people, it must be an absolute nightmare for them. Absolute nightmare, especially because I think a lot of… I mean [patient] is only 46, she had it when she was 43/44. A lot of people who are getting this are a lot older and I can imagine they wouldn’t be able to, you know cope with it or with the change because there’s such a lot of factors towards it. I mean like, your life changes not just from the physical side of it, but you’ve even got to change where you live which can be challenging because you might love where you live. Might not wanna move. Then you’ve got all the equipment that has to be installed, all the professional people that have to come around so there’s a lot to it, there really is and I don’t think enough professional people know enough about it, know about motor neurone because even… I mean we were lucky the GP we had in [place], he was absolutely brilliant but of course because we moved here, we had to change GP. To be honest the one we are with now hasn’t got a clue about it because it’s such a specialist thing. And they’ll admit it, they just don’t know enough about it, you know. If they’ve never had a patient that’s had it before in their books it’s difficult for them because they don’t really know. So, yeah it’s quite challenging all the way through. Have you done many of this surveys or?

**Interviewer:** I have.

**Respondent (C)**: Yeah, well you probably know.

**Interviewer:** Yeah but I guess different experiences are slightly different [overlaps with carer]. I’ll just make sure I’ve covered everything about your experience in that point of view as well.

**Respondent (C):** I think so, can you think of anything else?

**Interviewer:** So I guess, what we’re trying to do also from this research is, you know how you went online to find out about motor neuron disease and things like that, so we’re trying to develop some positive support tool that people can use to help them cope with all of these. Just in terms of whether you both use the internet or would you use something like this?

**Respondent (C):** I do. I use it all the time, [patient] would, I mean she does… she goes on Facebook to see her daughter and that sort of thing. But yeah, I use the computer all the time. So yeah, I’d be into that.

**Interviewer:** So that might be something useful…? And even with difficulties with your hands as well, you can still browse thing on the internet or is it a challenge?

**Respondent (C):** Yeah because she got a little, that thing where her hand is now. That was again, this is a department of the NHS in Oxford that do these visual aids and everything so they came down a couple of times all day showing her different things that she could use, eye gaze and this gaze and that gaze. I mean they had boxes of stuff they’d brought in didn’t they? But again, it’s all intrusive into your home. You’ve got to spend that time with them. You know it was literally all day, you know I think the appointment was about 10 o’clock, they didn’t leave until about 6 didn’t they? They trying out all these different things with [patient] which is good, don’t get me wrong, but it is a lot. But yeah that’s good she can change the television channels with that. She can use it as a phone if she wanted to.

**Interviewer:** Just like a little mouse almost.

**Respondent (C):** Yeah it clicks through and she can speak with it, can’t ya? Type out things, tell me when she wants something [laughs]. But yeah, I think it would be good because if GPs don’t know anything about it, Jo public like us don’t know about it so right from day one it was like “oh she got this”, “what is it”, “what’s going to happen”, so many things you need to know. And with the best will in the world if you look online, it’s very sketchy, not really in-depth. Well at the moment [charity organization] is pretty good with their website but apart from that is nothing really you know, you could say let’s look this up. See, things like the different stages that happens in MND like… because everyone's different and the disabilities happened at different stages with different people like some people, their first problem they get, they noticed is their speech, they can walk for ages – no problem walking. For [patient], it wasn’t it was her legs. You see what I mean? So they’re all different. And then the stages like dribbling and things like that, you know if there was a site that could say “oh yeah that’s quite normal that does happen a bit.” Because the dribbling, the MacMillan nurse got some patches, these patches are for travel sickness but one of the side effects of them is that you could dribble. No, it stops… it dries your mouth up. So they use it for that you see, so although it’s a travel sick, because I phoned up her u, “it says travel sickness”, “yeah but if you look one of the side effects is it dries your mouth up.” So they used that to stop, it’s quite clever but it’s so many things isn’t there? The other thing as well which didn’t help is [patient] of the age umm, but of the menopause. The change… so we think she’s going through that as well so we had that added problems for the fact that she’s going through the change, because she was getting hot flushes and this and that. So apart from MND, she was at that age.

**Interviewer:** It’s tricky to say what is what?

**Respondent (C):** Yeah what is what, is the fact that she is going through the change or is MND. Well that’s quite challenging wasn’t?

**Interviewer:** Okay we’ve covered most of it. Are you happy to stop the recording?

**Respondent (C):** Yeah!