Transcription for interview 2

**Interviewer:** Thank you for agreeing to be interviewed today. Just a couple of things before we start the interview. Please feel free at any points to stop or take breaks if you need to, just feel completely comfortable. And if you find any of the questions are too difficult or something like that, we can skip over them and not answer. Also whatever you tell me is going to be anonymous in the end so if you mention say the name of a doctor or a hospital or something like that, we’ll remove all the identifying information in the end, so you can feel comfortable to tell us your experience. So I guess what I first want to know is what your experience is of being diagnosed and having MND, how ever you’d like to tell your story...

**Carer:** A bit of a shock really... It’s a...just a...can’t really say why a...why...what have I been diagnosed with, what’s it called?

**Patient:** (makes sounds in the background trying to speak)

**Carer:** Dementia...dementia...i haven’t been diag...thing yet. (mumbles) still have to take my driving test and go and see the doctor again.

**Interviewer:** Okay. So its like an early stage...

**Carer:** Yeah

**Interviewer:** And [name of patient] got diagnosed last year. So were you there with her?

**Carer:** Yeah I was there...yeah

**Interviewer:** And how was that experience like?

**Carer:** Sorry?

**Interviewer:** How was that experience like?

**Carer:** Bit of a shock...[pause] we hadn't even heard of it to know what it was. So it came as a bit of a shock.

**Interviewer:** (to patient) should I wait till you type? No? That’s okay, whenever you want to say something just let me know. On a daily basis, what are your main worries or concerns?

**Carer:** Couldn’t say really...me, as.. I like walking but I can’t walk so far now as I used to. And apart from that nothing sets? it, nothing’s changed.

(daughter speaks about patient’s MND care)

**Patient:** (through device) [name of daughter] gives medicine

(daughter explains how she gives medicine through a tube)

**Interviewer:** So it’s a combined effort to coping with things on a daily basis... And I guess how do you usually cope? In terms of where do you find your support from?

**Carer:** The [charity organization] they’re very good. The doctors are quite good as well. Everybody’s good. Everyone’s doing really well, can’t fault it at all, can we?

**Interviewer:** Okay, that’s good. And have you had any support for any say emotion concerns or needs or did you need any help?

(daughter explains how carer has been accessing support and counseling and hand massage)

**Interviewer:** How has that been helpful or supportive?

**Carer:** Well, it helps you relax a bit, that’s all...she doesn’t have it

[Pause] (patient attempting to write on I-pad)

**Interviewer:** Okay, it’s related to my question..[pause[

**Patient:** (through device) talking to other people

**Carer:** Yeah that helps yes. Other people who’s got the disease

**Interviewer:** Other people with MND? I know this may be difficult to type, but how does that help, in what way?

**Carer:** She’s not alone is she? It’s not being alone, other people have got it and quite a lot of people have got it as well. That helps.

**Interviewer:** And since the diagnosis last year, do you think your feelings have changed about having MND or has it been pretty much the same since then?

**Carer:** Pretty much the same really, as far as I’m concerned.

(daughter explains how it’s been horrible for the patient but also says that the carer has been affected by the diagnosis)

**Patient:** (through device) He keeps it in

(daughter explains how carer was open about counselling but didn’t seem to think it helped)

**Carer:** Didn’t seem worth it (referring to a counselling service). It was okay talking about it but then, but then it was just talking about it. You can talk about it with anybody.

**Interviewer:** But that’s useful for us as well because we want to understand what support is helpful and what’s not helpful as well. So... you didn’t find that too helpful?

**Carer:** No

(daughter explains that the counselling was in a group)

**Interviewer:** So it was in a group setting?

**Carer:** Yeah it was

(daughter explains the group counselling was for carers of people with different illnesses)

**Interviewer:** And I guess that’s why the coffee mornings are helpful cause you can actually see people with the same condition

**Carer:** yeah

(daughter explains how coffee mornings are helpful)

**Interviewer:** Would you have liked any other help or support? I know it’s tricky not having received something to say what you would’ve liked but maybe something in your experience which you probably haven’t got which might have been helpful?

**Carer:** Nothing really

(daughter explains that it is difficult to know what support is available and the charity organization has been very helpful)

**Interviewer:** So I guess in that sense, like you wouldn’t know what services are out there. But say if you had some trouble moving around and you needed some occupational therapy input. Like from a problem point of you were there any issues but there wasn’t any help?

(daughter explained how they were well supported by different healthcare professionals)

**Carer:** A lot of financial help as well

**Interviewer:** Yeah cause that’s a whole other world isn’t it?

**Carer:** It is

**Interviewer:** Sort talk to me about what it’s like on a daily basis in terms of care. I mean these professionals will come in and out based on whenever they visit. But say from the time you wake up till the time you go to bed, who helps and how do people help and what areas do you need help with?

(daughter explains how different people help with the care, but the patient has got weaker physically to care for herself)

**Interviewer:** Yeah and after the whole hospital thing, weaker isn’t it?

(daughter explains how the patient needs more care)

**Interviewer:** The more help, the better... And you attitude is to take it one day at a time?

**Patient:** (makes sound in agreement)

**Interviewer:** That’s good. Is there anything I haven’t covered about your experience that you wanted to tell me about?

**Carer:** I don’t so. Only the transport to the hospital...

(daughter explains about difficulties arranging appropriate transport)

(daughter explains about the patient using a mobillity scooter)

**Interviewer:** Oh so you can actually control it yourself then? Lovely

(daughter explains how the patient doesn’t use it as much now)

**Carer:** It’s too cold outside

(non-interview related chatter. Helping patient sit more comfortably)

**Interviewer:** I guess one of the reasons we’re doing this study as well is we’re trying to create some kind of support online to help people with what they’re going through and help them cope better. So I gues... (directed to daughter) I know you mentioned you used the internet when you were looking up stuff. Do any of you (directed to patient and carer) also look things up on the internet?

**Carer:** No

(daughter explains how they are not technically savvy)

**Interviewer:** So you get your information from (name of daughter)? Okay, in terms of the information and kind of support you found online is it mainly through the [charity organization]?

(daughter answers)

**Interviewer:** Yeah. They do offer the best and most neatly presented kind of support. I was just wondering if we, from say even a family member’s point of view, just, if we created something where, you know because of the shock of diagnosis, where you don’t really know how and what kind of questions to ask. If there was something that kind of talked you through different stages and you can pick and choose what kind of support you wanted, at what time. Would you find that helpful?

**Carer:** Yes, that would be handy

(daughter explains that patient and carer would access it through her)

**Interviewer:** Okay that’s good to know. I think I’ve finished asking my questions, unless ther was anything you wanted to add? No?

**Patient:** (indicates nothing more to add)

**Carer:** I don’t think so, no.

**Interviewer:** Should I stop the recording then?

[End of Recording]