**Transcription of Interview 1**

**[Beginning of file]**

**Interviewer**: okay, I’ll just put this here so it captures everyone. Thank you again for agreeing to be interviewed, um, I explained previously that this interview is about understanding peoples experiences, just a couple of things as well, um, if you want to take a break at any point during the interview, just let me know, we can stop the recording, take as many breaks as you like. Also, if you feel certain questions might be slightly difficult to answer, we can skip over them or you don’t have to answer, um, and also this information will be anonymous at the end of it so please feel free to say anything about your experience so if you happen to mention, say, a hospital name or a doctor name it’ll all be anonymous in the end so.

**Respondent (C):** okay

**Interviewer:** so you don’t have to worry about that, do you have any questions or anything before we start?

**Respondent (C):** no no no, you go ahead

**Interviewer:** okay, so I guess the first question is if you could tell me your experience of living with MND, and you can start from wherever you like really

**Respondent (C):** [pause] well it’s progressed over the years, it’s very difficult, really, living with MND as you can appreciate.

**Interviewer:** ‘m’huh’

**Respondent (C):** but um its, as the years go by, you gradually know and understand how to cope, cope with it

**Interviewer:** okay

**Respondent (C):** in the beginning, I think the worse part is the diagnosis [referring to wife] would you say, you agree?

**Respondent (P):** [breath heavily]

**Respondent (C):** which on our part, from our point of view was horrendous. Absolutely horrendous.

**Interviewer:** can you tell me a bit more…about that

**Respondent (C):** well in as much it was just um, you have MND, which we knew nothing of

**Interviewer:** okay

**Respondent (C):** so, we ask the consultant what we could do and where there any treatment, and the answer was no, no treatment.

**Interviewer:** okay

**Respondent (C):** which there isn’t really, is, there’s no operation. Un, we asked them about medication, he said there’s, uh, a drug called Riluzole, which you can take, which might keep you out a wheelchair for 6 months. See you in 3 months, and we were out in the corridor. [pause] our life was shattered in 2 minutes. And I felt that was cruel, very very cruel.

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

**Respondent (C):** [pause] there should be a, there should be a way of discussing it with you and saying well look, you have such and such a condition, but hey, this is what we can do. Not just you’ve got this and throw you out, and so we had to find our own way round this problem. Gradually through the years, we’ve not got used to it, but, uh, we have to accept it. We joined the [charity organization], and they gave us more help than anybody.

**Interviewer:** yeah

**Respondent (C):** and so, well, when [name of patient] was first diagnosed, of course she could walk…

**Interviewer:** okay

**Respondent (C):** ..and talk, well, even though her voice was disappearing then

**Interviewer:** okay

**Respondent (C):** and over the years, it’s got worse and worse

**Interviewer:** and, how how have things changed from that point of diagnosis to now and how you, you think about things and how you’re coping with things

**Respondent (C):** well we cope the best we can, we have a routine and we know exactly uh what [name of patient] is capable of. And I care for [name of patient] 24 hours a day, and frightening thing is of course if I go down, is our main worry. I know we’ve got 2 carers in the morning to help us but that’s only for one hour [pause]

**Interviewer:** okay

**Respondent (C):** so our lives really been turned upside down, because I have to do everything,

**Interviewer:** yeah

**Respondent (C):** [name of patient] doesn’t want me to do it, but what can you do? Its, you need a lot of help with MND…

**Interviewer:** yeah

**Respondent (C):** …a lot of help, and its difficult to get it, its difficult to know where to go..

**Respondent (P):** [heavy sigh]

**Respondent (C):** and through the years we’ve learned.

**Interviewer:** can you tell me a bit about what it’s like on a daily basis, what kinds of challenges, you face, um

**Respondent (C):** urm, well [sighs] we just have to work all the time, from early morning, I cook [patient’s] breakfast, but it’s a question of routine, all the time, and to get [patient] up in, I don’t get her up, the carers get [patient] up because I can’t do it, we used to use a machine, we used aids and we have a gantry hoist, um and so we have to do everything, all meals are prepared..

**Interviewer:** okay

**Respondent (C):** ..modified, it’s a continual, it it really is a continual struggle, isn’t it, would you say [name of patient]? [referring to wife] would you agree, it’s a..

**Interviewer:** yeah

**Respondent (C):** it’s a struggle, hum, yeah, don’t think that’s too harder word to use, it is..

**Interviewer:** yeah

**Respondent (C):** it is quite a struggle at times.

**Interviewer:** and does..

**Respondent (C):** ..tire very quickly

**Interviewer:** and for you as well, in terms of having to do all of this..

**Respondent (C):** yes

**Interviewer:** its gets quite difficult

**Respondent (C):** very difficult,

**Interviewer:** yeah

**Respondent (C):** [stutters] luckily, I’m a person who is um, domesticated, quite domesticated, it doesn’t particularity bother me about cooking an doing pots and pans, and it’s it’s the toileting as well, you’ve got to do everything, and that doesn’t bother me. [pause] so, but, uh aaaa, some other people it would, they wouldn’t cope.

**Interviewer:** and, what has been your strategy to kind of help you cope with things, because it was quite a difficult diagnosis…

**Respondent (C):** very

**Interviewer:** and then, how did you [pause] how did you come to a place where you started looking for help and managing things.

**Respondent (C):** [sigh] well, as I say, it, it was gradual, and when, when [name of patient] was first diagnosed she could walk and do most things for herself, and then her legs started to go and she fell, in the bathroom, and broke her collarbone [pause]

**Interviewer:** okay

**Respondent (C):** and, that’s, when really it got difficult, she had to go to hospital and have an operation [pause] and um, [name of patient] was in a, [name of patient] was in a convalescent home, uh, for 5 weeks..

**Interviewer:** okay

**Respondent (C):** and in the mean time I had to have a knee replaced, which was very very difficult, so she went from one home to the other, I couldn’t do a thing, in those days because I had my knee replaced, and that was about 5/6 weeks, wasn’t it [name of patient] [referring to wife], coming up to 2 months, and then [name of patient] came back here, and the occupational, occupation.. occupational therapist set us up with the bed and the things we have, so we learned then, the occupational therapist was the key to getting things,

**Interviewer:** yeah

**Respondent (C):** and this is how you gradually learn, the occupational therapist can get the equipment, which she did, also Hampshire county council gave us equipment, but we didn’t know this..

**Respondent (P):** yeah

**Interviewer:** yeah

**Respondent (C):** it’s a question of asking, as things got worse, it was fairly gradual you see, so we had to change our life to fit [name of patient].

**Interviewer:** okay, so you most stumbled on the occupational therapist, and then..

**Respondent (C):** well..

**Interviewer:** they pointed it out…

**Respondent (C):** well, yeah we stumbled on her when [name of patient] went into um, the home

**Interviewer:** [at same time as respondent C] the home, yeah. And then, they pointed you out to all the other.. support..

**Respondent (C):** yes, yes

**Interviewer:** okay

**Respondent (C):** local support and um, so so it was gradual in what [name of patient] could eat, and in those days of course [name of patient’s] eating was better, and has deteriorated

**Interviewer:** okay

**Respondent (C):** in as much as we have to modify and um um mash everything, spin everything, blitz I think is the word, we blitz everything for you don’t we [referring to wife], to rather like a porridge consistency

**Interviewer:** okay, okay

**Respondent (C):** and so it goes, do her the food, I mean, do the toileting, and, and we, of course we have the chair which is essential...electric chair

**Interviewer:** yeah, and um, so, in terms of how you coped with things, with all these, was there anything that was particularly helpful like, any people that were helpful or anything that helped you cope with things better?

**Respondent (C):** well, as I say, uhh uh, the occupational therapist, the hospice was very good, [name of patient] went to the, we we were, our case, our case was transferred from [hospital], in London, we used to go there, once every 6 months, to see, to see the uh specialist up there, but because the travelling is so difficult, in the beginning we used to go up by train, and stay the night in a hotel, but [name of patient] was walking then, and then we used to go to the hospital didn’t we, and then come home, but as things went on uh in the end we couldn’t do that, so they sent a car for us, they used to transport us, up there, but it got so difficult, in the end they decided to transfer [name of patient’s] case to [hospice], in [name of place], well as you know…

**Interviewer:** yeah, where I met you, yeah

**Respondent (C):** and so, we went such to go there and [name of patient] went to day care there, so we learned a lot from them

**Interviewer:** okay

**Respondent (C):** they helped us didn’t they? And then of course we go once every 5 months to see the specialist at [hospital]

**Interviewer:** okay

**Respondent (C):** anybody else helped us [name of patient], I don’t, can’t remember, no doctor, well, you see the doctors, there’s not a lot of help they can give you, they’re very good on the drugs,

**Interviewer:** is this the…

**Respondent (C):** we, um, [patient’s] going to write something, we gradually built up the drugs, Riluzole was the first one, and because [patient’s] uh, we had another great problem was the saliva, continuous saliva, which you have to try and stop, so uh, they decided to put [name of patient] on a drug called glycopyrronium, which is a drug that uh, dries up, tend to dry up the excess fluid [pause] but there’s no, there’s no drug for MND. Riluzole, is just, they think it works a little bit on the brain but, I’m not sure [pause] but it is uh everyday, I would say I would class it as a bit of a battle, everyday, because you never know what’s going to come next.

**Interviewer:** yeah

**Respondent (C):** its, uh, very very hard

**Interviewer:** and how do you deal with that?

**Respondent (C):** well, I don’t, I just carry on, I I get over most problems, we have 2 sons who help, who help us with certain things, but they can’t be here all the time. So I just have to cope, with it, whatever [patient] wants [pause] but getting her to the dentist and that sort of thing, it’s all very difficult, you have to go to a specialist dentist because you can’t get in, we go to a specialist dentist, that um, [hospital].

**Interviewer:** oh, okay

**Respondent (C):** that’s a specialist dentist, they deal with cases like [name of patient] when there’s a wheelchair

**Interviewer:** okay

**Respondent (C):** so we go there [pause]

**Interviewer:** so, then its making your way there and all of that

**Respondent (C):** oh I, we, we have a converted car, we have transport, we have, uh umm, that’s another thing you see, we had to get rid of the car, a cars no good to us, [patient] can’t get in a car, so we had to sell the car and buy a wheelchair accessible vehicle, so [name of patient] goes in the vehicle, and um, then you come up against things like benefits, and that’s another world, that’s a horrendous world, so you gotta battle for everything, I mean it’s unbelievable that [name of patient], with her condition, cannot get a mobility car.

**Interviewer:** really?

**Respondent (C):** because, you are over 65 [pause] and once you’re over 65, you’re not allowed to have a mobility car, so you’ve got to be ill before you’re 65, otherwise you won’t stand a chance, so we could do, well we have to provide our own transport, we have to pay for that.

**Interviewer:** oh gosh

**Respondent (C):** but normally you just see those cars going about with mobility on, you can’t get one once you’re over 65, doesn’t matter what condition you have, they come up against all these sorts of things, and then we had to apply for extra benefit, so [name of patient] gets a thing called attendance allowance, which helps us a bit, so we buy the bits and pieces da da da…

**Interviewer:** yep

**Respondent (C):** um, and and [charity organization] helped us with the chair, that chair was £10,000

**Interviewer:** oh gosh

**Respondent (C):** that’s a lot of money

**Interviewer:** yeah

**Respondent (C):** most people can’t afford that, and that is so, because [patient] wanted to, that chair rises up, we need that to get [patient] up to the commode, so it rises up, but the the uh, the um national health won’t provide that, they only go to a certain standard, otherwise its expensive for them. But [name of patient] wanted one that came up so that you can get her up on the commode, and the tilt, so [charity organization] helped us with that

**Interviewer:** the [charity], yep okay

**Respondent (C):** they gave us a grant, paid, come on [name of patient]

[scuffling – movement]

**Respondent (P):** information by talking to other people at coffee mornings

**Respondent (C):** yes that’s a good one [name of patient]

**Interviewer:** [to patient] that’s what helped you?

[patient nodded]

**Respondent (C):** yes, we go to the coffee mornings at [hospice], as you know we met you there

**Interviewer:** yes

**Respondent (C):** and we’ve been going there a long time, as [name of patient] says, you talk to people, the same condition, and we’ve got ideas that have been very helpful, you’re right [name of patient], yes. Did you know so and so? Or did you do this? And did you know that? We’ve picked a lot up from there,

**Interviewer:** yeah because, initially you didn’t get that support and then you had to find..

**Respondent (C):** no

**Interviewer:** ..find out

**Respondent (C):** no, we never knew what motor neurons was about [sigh] it was very difficult, and still difficult but uh not so difficult know because we now know who to go to, but as [patient] said, you’ve got people that go to coffee mornings who are in the same boat as you so to speak, and they have the same experiences..

**Interviewer:** yeah

**Respondent (C):** with, we’ve tried to discuss benefits with them, it’s a minefield and it’s a thing called continuous healthcare, have you heard of it?

**Interviewer:** yes I’ve heard of that

**Respondent (C):** ..continuous health care, well to get that you’ve got to be virtually dead

**Interviewer:** [slight laugh]

**Respondent (C):** we’ve tried 3 times, to get that, you can’t get it. It’s very very difficult, so you have to pay. And, uh and that’s another minefield because if if she had a condition like, say for instance, um your kidneys fail

**Interviewer:** yep

**Respondent (C):** right, the national health would take you into hospital, they would give you a uh, dia..dia dialysis

**Interviewer:** [at same time as respondent C] dialysis

**Respondent (C):** dialysis, 3 times a week, whatever they need all free, which it should be, the kidney comes along, you may be lucky, you go into hospital, they transfer your kidney, costs thousands and thousands of pounds, fair enough, that’s what they’re national health for. But if you have something like a neurological thing like [name of patient] has, MND [pause] you’re not well but they say to you, well we can’t give you an operation, no, uhh, we can’t give you medication, so the only care you can have is care, really, we’ll give you care, but we’ll also take all your savings away. And that’s how it works, what’s the difference?

**Interviewer:** yeah

**Respondent (C):** so they take your savings away, we lost all our savings in care, it’s unfair, it’s terrible,

**Interviewer:** you mean, err, like having a carer or

**Respondent (C):** yeah, having a carer because we have to pay for it, until you um, we don’t now because all our savings, are gone, all [patient’s] savings, it took a lot

**Interviewer:** yeah

**Respondent (C):** so that’s very unfair, it depends what sort of condition you get, whether you get on the national health or not, the only, the only medicine [name of patient] has, is really care. And we have to pay for it, which I consider outrageous

**Interviewer:** yeah

**Respondent (C):** who knows what we’re going to get in life, you can’t pick and choose. You can’t get to uh [patient’s] age, I mean we didn’t know what’s going to happen in life, it’s not as if though we drank ourselves silly or [name of patient] smoked or anything like that, we lived a normal healthy life, haven’t done anything in excess, and yet suddenly, you get a condition. Not your fault so why are you punished?

**Interviewer:** yeah

**Respondent (C):** anyway, don’t let me rattle on [laughter]

**Interviewer:** no, that’s fine [laughter]

**Respondent (C):** it is a point though

**Interviewer:** no, all of that’s really useful

**Respondent (C):** yes it’s a point isn’t it

**Interviewer:** yeah

**Respondent (C):** people with neurological conditions uh, if they can’t operate, or give you medicine, and they give you care, you pay

**Interviewer:** yeah, but it’s also part of your treatment in a sense

**Respondent (C):** yeah yeah, [name of patient] can’t care for herself, so we have to do it

**Interviewer:** yeah

**Respondent (C):** which is right, I’m her husband [pause] we’re married for better or for worse so [laughter]

**Interviewer:** laughter

**Respondent (C):** in sickness in health as they say

**Interviewer:** [laughter] yeah, umm, did you, um, so in terms of um, professional support you mentioned the occupational therapist and [charity] and all of that, did you get any kind of support to help you with any emotional concerns, or things like that?

**Respondent (C):** no

**Interviewer:** would you have liked any?

**Respondent (C):** [pause] uh, well, uhhh, I’ll say no, we did explain to the doctor that, [name of patient] when we first went uhhh, was first diagnosed that it was very very hard for us, extremely hard, so he put her on a drug called um um fluoxetine,

**Interviewer:** okay

**Respondent (C):** which is uhh a drug that helps you with anxiety and depression and [patient’s] on that, and yeah I think It helps her,

**Interviewer:** okay

**Respondent (C):** but, we didn’t have any specific one to one talk about emotional side and that is very difficult to deal with, very difficult to deal with, there’s been a few tears shed over the years I admit, but, [pause]

**Interviewer:** but do you think if there might have been some support

**Respondent (C):** oh yeah

**Interviewer:** that would have been helpful

**Respondent (C):** yes, we needed support from the beginning, we didn’t get it

**Interviewer:** in the beginning is around diagnosis stage

**Respondent (C):** yes

**Interviewer:** yeah

**Respondent (C):** its such a shock…to you, uh it is a shock when you’re diagnosed with some, some uh awful thing like cancers or, you need help there, there should be somebody there to help you on the emotional side, I mean the worlds turned upside down absolutely, [pause] its very very difficult, [name of patient] takes it very well, and now she’s on the drugs, I’m not on… any emotional drugs…. And uh, emotionally I do go down at times, yeah, it just gets too much for me at times [pause] you know.. just to accept it [pause]

**Interviewer:** I guess the coffee mornings also, help in a certain way

**Respondent (C):** yes they help, and you go and see, sometimes you think you’re the only one in the world suffering this way, which I’m not. There’s about 5000 people in the country suffering, well at one time, approximately, so you go there and [pause] we didn’t, [name of patient] didn’t go at first, she couldn’t bare it, she couldn’t go, I, I went.

**Interviewer:** okay

**Respondent (C):** ..by myself, to see what it was like. And I went there for about a year, and then [name of patient], umm, I decided, um, got round to [name of patient], and yeah we agreed and we’ve always gone and meeting, other people and told other people which is very helpful to have

**Interviewer:** yeah

**Respondent (C):** and [hospice] has been very, very good

**Interviewer:** yeah, they’re a lovely place

**Respondent (C):** sometimes you need someone to sit down and [pause] perhaps, uh perhaps, to deal with us we’re very private people, we don’t really [pause] go out of our way to get attention, but I think there needs to be somebody there, at the early stages.

**Interviewer:** to just check up on you, yeah

**Respondent (C):** yeah, uhh

**Respondent (P):** [through ipad] very tearful at first,

**Interviewer:** hmmm

**Respondent (C):** yes, very tearful at first

**Interviewer:** okay

**Respondent (C):** well we both were, such a shock to the system

**Interviewer:** how did you, how did you cope with that at that point was it..

**Respondent (C):** well we didn’t, we just went on until we got out, I went to the doctors and, [name of patient] was working at the time, you see, she was a secretary to an architect, which is quite demanding work [pause] and, uh, in the end we managed to get this, try to help [name of patient] calm down, and over the years, it’s got a lot better.

**Interviewer:** okay [rustling] um, is there anything more about your experience that I haven’t spoken about in terms of just how you manage or how you cope with things or..

**Respondent (C):** well, as I say it’s it’s continual finds, continually learning things, day by day. There’s no overall thing I can tell you really we’ve learned…

**Interviewer:** no that’s all the information is really useful, it’s important to understand first hand, from…

**Respondent (C):** yes yes

**Interviewer:** …someone living through it

**Respondent (C):** it is, yes, it’s a very good idea, I think you need someone with this sort of diagnosis, who can get help earlier, rather than having to fight for yourself, you don’t know where to go, there should be, should be some way, it may be like [care coordinator], the, uhh that , the MND centre that wasn’t there then, I mean we were going to London, you… and had a multidisciplinary where you’d see the consultant, you’d see the physiotherapist, and then the speech therapist.

**Interviewer:** oh okay

**Respondent (C):** speech therapist got involved [pause] had speech therapy down here, but once your voice has gone, you’ve got to, and we knew nothing about aids. There wasn’t, ahh uhh, over the years it’s got a lot easier, the, when [name of patient] first lost her voice, that was in 2005, started going in 2004, we bought, our first machine we bought was, we didn’t know about these things you see, we looked on the internet, and we bought a machine like this, and it was £2500,

**Interviewer:** for something like that, no?

**Respondent (C):** oh big thing it was

**Interviewer:** okay

**Respondent (C):** because there was no speech, we didn’t even have an ipad in those days, did we? We bought a thing called a dial-a-write horrible voice on it, uh but it was early stages, and we paid all this money for it, and uh, it was useless. And then we went to speech therapist in the end, who gave us our first light writer, didn’t she, but there wasn’t a very good voice, on it, and then they bought a new light writer out, from [name of company]

**Interviewer:** okay

**Respondent (C):** and, motor neurones, they gave us one, a much better one, but they, uhh aaaa, it shows how things have improved, do say we payed 2500 for the dial-a-write?, didn’t we, awful thing, and now you can buy an ipad for I don’t know, a couple hundred pounds, and put a program on it for 100 pounds, you’ve uh, got a good voice, a choice of voices for £300. So…communication wise, over the years it has greatly improved,

**Interviewer:** yeah, things are much better now, aren’t they?

**Respondent (C):** oh one hundred percent better, umm but, it’s all mechanical things, up here it’s the same, how can you change your mind, you know

**Interviewer:** yeah

**Respondent (C):** what do you do?

**Interviewer:** that’s true

**Respondent (C):** you can’t [pause] we, we, we survive quite well, I mean really, we’re able to get out and we’re able to go to the hospital when we want to, [hospice], but we’re, we might be luckier than some people, some people can’t, don’t have a car or don’t have a means of transport or someone to help them all the time,

**Interviewer:** yeah, did you um, did you go on the internet a lot for help or support and things like that?

**Respondent (C):** would you say yes to that? [to the patient] Yes, I think we did

**Interviewer:** yeah

**Respondent (C):** yeah we did have that, you see the beginning had no internet, going back to that we didn’t have internet till years and years later, did we? Or a computer [pause] so in that way things have improved for people suffering with MND, a lot, yes.

**Interviewer:** because the reason I’m asking is, um, we’re trying to develop some online support, that sort of talks people through and helps them cope with the illness,

**Respondent (C):** oh right, yes

**Interviewer:** well we were wondering if people might find this useful

**Respondent (C):** yes, I would definitely say yes, if you knew somewhere you could get online and go to, say from us and the early stages, we didn’t have internet, there was nothing like that we didn’t have it did we?

**Interviewer:** and also in terms of um, disability and things like that, do you think we need to pay attention to certain things when, you design it online or for people with MND

**Respondent (C):** well yes because, you see like the gadget [patient’s] using now, peoples fingers go, their arms go, their legs go, now the gadget that [patient’s] using now, that’s that’s been specially made for us, from the arm thing, it was made for us from MND centre at [hospital].

**Interviewer:** okay

**Respondent (C):** so that supplies all these things, you need,

**Interviewer:** yeah [pause] and can you access the internet from there, or

**Respondent (C):** yeah she can

**Interviewer:** she can do that, okay

**Respondent (C):** yes, that was given to us they provided that free of charge [pause] yeah she can get on the internet can’t you [name of patient]? But it’s very difficult for [name of patient] to handle, it’s just uh

**Interviewer:** yeah, takes a bit of time

**Respondent (C):** everything with MND is difficult, so it’s all got to be right, it’s all got to be designed, thinking, how can they use it [pause] people can’t use their fingers, hand, so quickly, you see [pause] it’s a problem

**Interviewer:** okay, I think I’ve asked most of my questions, um, is there anything you wanted to add? Um, before we stop? At all? No?

**Respondent (C):** no, I don’t think so, I mean we’ve told you everything we can. I mean there’s obviously one or two things that come up once or twice and you forget them but [pause] I think I’ve ranted on to you enough [laughs]

**Interviewer:** [laughs] yeah

**Respondent (C):** I tend to rant at times, if I get cross [laughs]

**Interviewer:** it’s okay we want the, we want the rant [laughs]

**Respondent (C):** yes, I’m… we manage, but I understand for some people, it’s difficult, more difficult for us. I manage, but it’s nice to know people like yourself are interested in it.

**Interviewer:** yeah

**Respondent (C):** that’s how we get what we get, people doing research, people like yourself, take interest and we’ve done umpteen research papers, urm, questionnaires, there’s a big one going on at [hospital] we’ve had about 4 of those, haven’t we, or 5 of those…and they were 68 pages long, and I plough through [pause] the system is unfair in many ways, I don’t think people realise, you know, what you go through.

**Interviewer:** mmm, okay, that was really helpful, um should I stop the recording? We can..

**Respondent (C):** yeah yeah

**Interviewer:** I’ll stop the recording