**Transcription of Interview 5**

**[Beginning of file]**

**Interviewer:** um, just a couple of things before I start the interview, you can feel free to take breaks and pauses at any point, um, I can just stop that, um also if there is anything that, may be too difficult a question or you don’t want to answer, I can just skip and move forward to the next question, so, don’t worry about that, just let me know. And also, all the information that you give me will be confidential, so… if anyone’s name comes up, or it’s a name of a hospital, something like that, um when we look at all of it in the end it will all be anonymous, so yeah

**Respondent (C):** okay

**Interviewer**: you can feel free too..

**Respondent (C):** yes

**Interviewer:** tell me the story as it is, so I guess um, I’m happy to start wherever you want to really about what you experience was like, um, when [name of patient] got MND.

**Respondent (C):** okay, um, I had stopped working as a teacher for uh a few years before he was diagnosed. He had his own business, um, which he had built up, um, by himself… really urrr, with a colleague, they’d done a keyboard company, he was the director of that. And, when he was diagnosed at 57, you know, the feeling was that he was going to work until retirement age, 65 or 67 as they shifted it.

[background voices]

**Interviewer:** okay don’t worry

[audio recording paused as participant was seeing a healthcare professional who had been visiting to the door]

**Respondent (C):** so um, 50, so he was 57 and expecting to work until he was retired. Retirement age, but because of the diagnosis, um, he, it meant that within 6 months he folded his business and had to close it down and his urm other, the other director of the firm, he passed all the customers over to him, and they’re still good friends. He still comes to visit [name of patient], which is great, we have that connection still. [pause] so that was a real [pause] you know, huge shock, to us both urm, and then you start to think what will you do financially, ummm, that was I guess one of the biggest things, that hit us first, you’ve got savings.

**Interviewer:** yeah

**Respondent (C):** can you stay where you are, and also the impact of, of that and people saying to you, you can get this benefit, you can get that benefit, so I think that the first [pause] 6 months [sigh] possibly to 12 months, our whole focus was around that aspect of our lives really. At that time [name of patient] was um, he was tripping and um he had a splint, so he was moving about the house and you know, we were doing things within the home, um, and, and he’ll probably tell you that um even before the diagnosis, really, a year before, he was noticing that there were some things that were happening. Tripping up the stairs at work, um that was why he couldn’t continue at the work, because his office was upstairs, and so you know, that just meant that it was too difficult. Everything downstairs was the manufacturing process for the keyboard industry, so all the office work was upstairs.

**Interviewer:** okay

**Respondent (C):** so that was that. Um, and of course you have mentally to put your mind to um, the financial aspects, filling out forms for PIP, and later thinking could he get ESA, being told probably that he wouldn’t get ESA, although he’d worked for 43 years without a break. [sigh] lots of things around um, finance, um, because we’re still paying mortgage on our home. Um, and uh we will be leaving this home, in the not too distant future, we don’t know whether to another property or uh the other aspect is that we’re trying to get planning permission to build a specifically designed bungalow for [name of patient] down the bottom of the garden.

**Interviewer:** oh okay

**Respondent (C):** uh, but we’ve been rejected um by the planning uhhh people, back in October, we’re going to appeal so we will go in April to find out that decision. And then we’ll know what to do, about our home.

**Interviewer:** gosh, that’s a lot

**Respondent (C):** it’s a lot, yeah, um and our kids, we’ve got 3 children and 5 grandchildren, and uh 3 children all live within 10 minutes of our home, so it’s a big thing to be, in the upheaval of it all.. moving. So that was the first real impact I guess, um, and and the medical side, [name of patient] was using Riluzole, and um, it quickly became apparent that it was not suiting him. Umm, he used it, I can’t quite remember for how long, 8 months perhaps, and his liver counts, when they were checking the bloods, it was obviously effecting his liver. So uh [neurologist], at the [hospital] advised not to continue, so he came off that, so the only drug he now takes is his lansoprazole, for his reflux he gets, but uh that’s been a long term medication.

**Interviewer:** yeah… and how have you been feeling with all of this happening?

**Respondent (C):** you get your days where you’re tearful, get your days when you’re angry, umm, but sometimes the anger you can channel, and in a positive way, um as I mentioned about the planning application, that’s been our way of combatting our down days really, just thinking well, we’re looking to the future by thinking we can build a house for ourselves.

**Interviewer:** okay

**Respondent (C):** [sigh] um, and I think with MND it’s an illness where you’re constantly getting problems presented to you, because of the way the disease progresses, sometimes in the beginning [name of patient] used to have quite a few plateaus, where you’d just be going along without any difference in his symptoms. But then it would take a downward turn, and then you’re always thinking how to problem solve the next issue, that’s our attitude, and I’m sure [name of patient] will say the same. [sigh] um, so that’s how we deal with it mentally, we just sort of think okay its rearing its head again, push it back. We’re gonna solve this next dilemma, this next problem.

**Interviewer:** okay, more focusing on the practical..

**Respondent (C):** yes

**Interviewer:** and how to solve that issue

**Respondent (C):** yes

**Interviewer:** okay. Um, and also, I guess it’s hard to say because everyday would be quite different, but what is it like on the day to day basis, living with um, the illness, the challenges that come from it.

**Respondent (C):** day to day, um, it’s 3 and a half years, bit beyond that now, since he was diagnosed, and in the beginning it was not so difficult, he was able to um you know, move about the house, and now we’ve got to the stage where [name of patient] can’t move his lim… lower limbs at all, not even twitch his feet, his toes, it’s progressed to his arms, and now his hands are really not functioning, so that now, even in the last month or so, he’s not really able to use his mobile phone. He was using that to, you know send texts and that, dictating to me what he’d like to say on a message, on his phone, so [sigh] um, that’s..uh, that obviously implies much more input from me, as his spouse, his wife, um it makes us more, um housebound as well, because I can’t leave him because he’s vulnerable. Um, but if I give a sketch of, um, sort of a typical day, we’ve now got um, we’re paying for a lady to come in and help me uh, 3 days in the morning she helps me bathe him, so if I talk about a typical day where she comes in and helps me bathe him, um, I’m up and awake at about 7, I come downstairs and um, prepare a cup of tea, offer [name of patient] his medication, the Lansoprazole, um and he takes a sip of water from the uh sports drink to help it down. Um, he’s in a hospital bed upstairs, um so he does um use the hand control to bring it up to sitting position but often it’s, after a nights sleep his hands aren’t really strong enough, his fingers aren’t strong enough to actually do that anymore. So that’s the first thing we do, and I come downstairs and make him some porridge, take the porridge upstairs, and offer the porridge to him. He can’t obviously feed himself anymore, so by the time I’ve done that it’s about 8:30, and then our lady that comes to help us, she’ll arrive at 9, because she has children at school so she drops them off and then she comes on to us. And, we um get [name of patient] ready for the bath by um, obviously un, un – uncovering everything and uh putting a sling round, a special bathing sling round him, um, and we have a ceiling hoist in the bedroom where we move him from the bed into the bathroom, we can’t access a shower because, we’ve had alterations in the bathroom but, you can’t access a shower so, he enjoys a bath anyway, and it’s more relaxing, we have a um, Vanette cushion in the bath, which is uh uh an air inflated with polystyrene balls inside, a cushion. So he can, which suckers onto the underside, which attach themselves to the bath, so it we just, it contains him within that shape because he has less postural support in his body now.

**Interviewer:** umm

**Respondent (C):** so we lower him gently into that and he’s able to have a nice relaxing bath, we just fold the sling back off his shoulders and that stays in the bath underneath him. And then we, you know, cleanse him, um and uh leave him for a short while so he has a little bit of a wallow, whilst we get the bed ready with towels, and one of us will go iron the shirt, and then we’ll lift him out again in reverse, back onto the bed, onto the towels, and then dress him on the bed. Um, and then hoist him back on to a um what I call a bath chair, transfer chair. Um, and then back into the bathroom so we can clean teeth, comb hair, and um cleanse his eyes if his eyes are still sticky from the bath, sleepiness, and uh little things like we all take for granted, using an ear bud, just to cleanse your ears after a bath, all of those things we have to help him with, shave him, um adjust his clothing and um and now just recently I’ve been, um with the advice of the hospice we’ve got a convene [device to help urinate], nurse that came to visit us, so some days [name of patient] might say yes to ur having that attached to him so he can, urinate without the need for other people having to empty a bottle all the time, [sigh] so that’s been another transition. So that bathing experience will take us until half past 10, the earliest we’re down, we’re in a 2 story house I ought to tell you, um so we go in to a through floor lift that we had fitted early on, because we wanted to stay in our home, and so we’ve got the through flood lift. Um, so usually he arrives downstairs at around half past 10, so it takes an hour and a half to do all of that, um and then um he’ll either decide whether he wants to use the toilet downstairs which is a bidet toilet, until recently he’s, I’ve been using uh a stand aid to manoeuvre him into the cloak room, which is rather small so won’t allow for another sort of ceiling track, so um but that’s become more precarious so now we’ve converted recently to um using what you would call a commode I suppose, goes over the toilet, and um I stay with him whilst that’s happening, whilst he needs to open his bowels, and um we use the bidet motion to help stimulate bowel movement. And, then that can take an hour also because having been it doesn’t happen immediately, I’m sure he won’t mind me telling you I rock him, side to side, front to back, on this chair, because he’s not feeling so much in his muscle movement.

**Interviewer:** yeah, and that affects the muscles…

**Respondent (C):** although they always say that the, in the pamphlets about MND that they say the bowels are spared, we’re not convinced that MND doesn’t attack that as well. Um, it’s not something that you share with other people when you go to the coffee morning necessarily, you see, so we don’t know whether other people might say the same but it’s certainly, it’s, it’s an issue for [name of patient]. Um, so having opened his bowels and um used the, the cleansing of the bidet toilet, I now have to take him back out of the cloakroom downstairs, and return upstairs. The reason we didn’t have a bidet toilet upstairs, because of space, uh

**Interviewer:** all these little things, put together

**Respondent (C):** yeah, um so and then I have to hoist him back onto the bed, onto a towel so it obviously dries him a little bit more before I then pull his clothing up. And nowadays he wears a pair of pyjama bottoms down below because I used to, up until about um, a year ago, less than a year ago actually, um, underpants, trousers and make him look really smart, because that’s how he likes to appear to others, and I like that for him, [participant got tearful] and um but now the suggestion from the hospice, some people don’t bother to wear anything below, they just have a blanket over them but he doesn’t want that so,

**Interviewer:** yeah

**Respondent (C):** we just use pyjama bottoms, and that works for us. Um, so we have to go back upstairs for that process, because I have to lay him down on the bed, flat, roll him onto a sling, and so, you can imagine, it takes an hour to do all of that, and then come downstairs again.

**Interviewer:** quite tiring for you as well

**Respondent (C):** yes it’s very tiring, and we’ve had uh a gantry hoist, um from the [name of company], it’s uh a free uh, temporary gantry hoist, that is over his chair, his armchair downstairs, and so I hoist him out of that, the transfer chair then into the armchair, and that’s when he begins his day basically.

**Interviewer:** okay, quite a while until..

**Respondent (C):** yes, so you might be looking at the clock and thinking it’s 11 or half past 11 and just getting the day started takes until that time.

**Interviewer:** yeah

**Respondent (C):** and then, we might have visitors and then, mostly visitors come in the afternoon because the whole morning practically is taken up with, getting started, getting dressed, getting cleansed, um you know having your first meal of the day and your first drinks of the day.

**Interviewer:** okay, and then that goes into the evening and sort of repeats

**Respondent (C):** yes, it all repeats, yes we have recently asked the lady that comes to help me with the bathing if she had another friend, because she works in a care home part time, she did say that she had somebody that perhaps could help us in the evenings, so we’re now, paying for that also, for that little bit of extra help in the evening, an hour, just to help him get to bed as well.

**Interviewer:** yeah, yeah um you mentioned there were certain things that uh you said, either make you quite tearful or um angry about situations, they’re probably different but do you know generally what kind of things they are, that uh

**Respondent (C):** yeah… frustration about the time it’s taken, and then you look at the clock and think oh my goodness it’s time to get lunch ready. That’s a kind of like, it pulls you up, you think where’s that time gone? That sort of frustration, um frustration with um, um, not getting to appointments on time or being late for things because it takes time, so to go out, hoist him out of the arm chair, and then into his wheelchair, and it takes a long time to get him comfortable in his wheelchair, dressing him, his outer clothing, I have to put the fleece that he wears in front of his lap, and all the, the… it, the collar is away from him, if you can imagine upside down, you put the arms in first, and then you lift the coat over his head, a bit like you might do a young child.

**Interviewer**: yeah

**Respondent (C):** um, but being an adult, that is proving very difficult for me know because um, urr I’m having to try and support his arms, which can’t work for him now, and finding ways of actually putting him on my shoulders so I can pull up the coat over his head successfully, and then pulling him forward and then trying to pull the clothing round.

**Interviewer:** physically, sounds quite demanding

**Respondent (C):** very physically demanding, and, and that also gets you angry yourself, because you’re thinking, you know every, every task is um, you have to think it through. Um, and as I say, and then you might be late for something and you feel like you’re apologizing to people for your lateness, or, ummm and…

**Interviewer:** it’s almost not having control of..

**Respondent (C):** yes, you don’t, you have to, you have to really win back time. Um, and anger, I’m having to feed him [pauses…cries] anger what’s the, what MND takes from you as a couple, [tears up again] I still sleep next to him, so I’m near him, in a ordinary bed, he’s in a hospital bed, you can’t cuddle very easily, although I put a pillow between and try hug him [pause]

**Interviewer:** yeah, must be really, uh things like that that make it harder

**Respondent (C):** yeah, but thank god he can still talk, because you know, this disease could take that as well, so [sigh] those sorts of things. And frustrations about you know, the benefits that might be available and then they’re not, and you know it’s there are other things that get you down.

**Interviewer:** yes, the house and things like that, yeah. Thank you for sharing that, I know it can be quite challenging to talk about.

**Respondent (C):** yes

**Interviewer:** urm, and when, when these situations do arise, what would you find most helpful in terms of how you cope with it?

**Respondent (C):** um, [sigh] angry situations I guess sometimes I think we both take time away from one another, it’s not necessarily anger at each other, it’s anger at the disease, so maybe sometimes it’s best to just retreat for a little time, and we both have a bit of space to think and, and then… because we’ve been married for so long, I think we’re kind of on the same page mostly, and um, you come back and think right well what we gonna do about this problem now. You sort of have had that time to reflect and see what, you know what you can do about the problem, you’re confronting. Um, I have recently since September, begun a course, of um, well my family bought me a 12 week course of ceramic lessons, so I can use the take a break time, I have 3 hours in a week given to me by the council, um I’m allocated that amount so I can just go and do some art, which is a bit of art therapy for me.

**Interviewer:** yeah

**Respondent (C):** I make things um,

**Interviewer:** that’s nice

**Respondent (C):** and uh, um, yes that’s really helpful, that’s another way of um, and my family at Christmas bought me another set of 12 lessons and so I’ve got that to enjoy.

**Interviewer:** so things like that where you can take a break from stuff..

**Respondent (C):** yes, taking a break.

**Interviewer:** okay

**Respondent (C):** but for [name of patient], he’s very static and there’s less for him, I’m lucky because u can go and do something like that, for him it’s much more, he used to enjoy reading all his science books and um I read [name of patient] the science magazine every month. But he can’t turn the pages on the magazine now, and I know our kids have said you can get an app, and view it online, but we’ve got to a stage where, in the last weeks, he’s not been able to use his mobile phone, so now we need some help with electronic device support. We did have um, a gentleman came and he showed us some stuff to do with that, but um, we’re still waiting for him to come back, um with some devices that might be able to help.

**Interviewer:** oh okay

**Respondent (C):** not eye gaze but something on his glasses that will track where he’s looking, um on the computer, but um I think the gentleman is working on that for us.

**Interviewer:** okay, that’s really interesting

**Respondent (C):** yeah

**Interviewer:** and did you, get any sort of support from organisations or health care professionals in terms of, more for your support rather than [name of patient’s] because I’ll ask him later.

**Respondent (C):** yes, um, well we found out about the take a break, I’m just trying to think how… possibly in the MND booklet, yes I think it was probably was the [charity organization], um produced 2 very good booklets, one we were given when [name of patient] was first diagnosed, which gives you a um, overview of what you might be confronting. And it’s categorising equipment and who the health professionals might be that are helping you, um, various other categories. Another one I was given not so long ago, it’s aimed at the carer as well which is very helpful, so that sigh posts you to things, both produced by the [charity], so that’s been useful.

**Interviewer:** okay

**Respondent (C):** urm, [sigh] but um, I think we’ve had to seek out a lot ourselves really.

**Interviewer:** okay

**Respondent (C):** and to say that when [name of patient] first needed a manual chair, we had to go to the [charity] to get him a chair, because that wasn’t available at the outset, and I think that’s an experience I think you’ll probably find when you speak to others, um people that are going to help you with this research, that that is quite a common feature that you don’t necessarily have a wheelchair [pause] easily supplied to you when you need it, so yes the [charity] we went to borrow one.

**Interviewer:** and then you need to go and search for sources and things like that.

**Respondent (C):** yes

**Interviewer:** and what was your, your point of contact that you knew you had to go to the [charity]

**Respondent (C):** I knew about that because my father had, obviously another problem, but um his mobility was compromised, so we had to use that charity service, so we knew about that.

**Interviewer:** yeah

**Respondent (C):** um, and recently I went to um um a place called [name of company] in [place] which is uh, which caters for holidays for people with disability, [name of place]. And um, was speaking to one of the ladies who was a guest at the um there, [name of company], and she spoke about um, the [charity] and another charity, it’s often word of mouth, you speak to other people that may be suffering or that the carers of those people, I guess a lot of the time it’s sort of word of mouth.

**Interviewer:** yeah

**Respondent (C):** and when we go to our coffee mornings, we all kind of come with the attitude, what tips can we share or what experiences might you have had, and you can put that in the mix.

**Interviewer:** yeah, learn from each other

**Respondent (C):** learn from each other yeah

**Interviewer:** Is there anything you felt that maybe um, I know you mentioned the wheelchair but also in terms of just coping with the illness, any support you may have liked, that you didn’t get?

**Respondent (C):** um, I think if we hadn’t had our association visitor, she’s a wonderful lady, who’s a volunteer, who signed up with the [charity] to help us, if we hadn’t had her support sign posting things that would be useful or making suggestions about things that she knew about, I think that we really would have been floundering, in those early months. And she was the person that encouraged us to go to coffee mornings as well, because initially we didn’t feel, I guess the first year probably um, the feeling of do we really want to go along to that? [pause…begins to get tearful] when, when you’re not, you’re still ambulant and not in a wheelchair, it’s a bit scary perhaps meeting other people that are a little bit further along the road, but actually we [pause…cried again] gained a lot of strength from those people.

**Interviewer:** yeah

**Respondent (C):** meeting those people, and since we’ve been going um, we’ve known 6 people who have died since. [pause…cries] yeah so it, it took a little bit of courage I guess to go along, to that for some support, but I’m glad we did.

**Interviewer:** yeah

**Respondent (C):** I’m glad we did, I guess I’m struggling to think of um, in answer to your question about what else, because we had um, our friend, [name of friend] helping us and she was the one that knew where to guide you, in terms of support um, and we’ve done a lot of things, you know, ourselves, we’re lucky our children are, one’s a computer guy, our son, our other daughter is a nurse so she’s very practical on that side of things, and our third daughter is an OT..

**Interviewer:** oh really?

**Respondent (C):** so she’s signposted us to a lot of things we might be needing ahead of time, for instance in the hallway you may have noticed the Ergolet, stand aid, and very early on she said, let’s look out for one of those on the internet which we did and we bought that early on. We’re so grateful that she told us that would be useful, um so we’re fortunate in our children also, helping us.

**Interviewer:** they already have that natural health care…

**Respondent (C):** networks are really important and we’ve seen I think other families who have not had family nearby or perhaps, and how much more difficult probably it is for them.

**Interviewer:** okay

**Respondent (C):** that’s only us looking out, from outside looking in, not really knowing for sure but…

**Interviewer:** yeah and you never know until..

**Respondent (C):** we feel fortunate in our family.

**Interviewer:** yeah, and places like the coffee morning, you can see other people and discuss that. Um, so is there anything that I’m missing from your experience that I haven’t covered? That you want to share or..

**Respondent (C):** um, I think, there’s one thing I would like to say about being referred to the hospice. When we first began this journey, the first year seemed to be taken up with lots and lots of appointments, and getting to the hospital became more and more difficult, because as [name of patient] became more weak, it was harder and harder to get to the hospital. And the last um, we’ve had it 2 telephone conversations with [neurologist] rather than an appointment because the time it take us to actually physically get there and um um, as I said earlier about the anxiety about being late for something, and missing your slot, and once or twice we were late and they were very kind and you know, they made room for us, but um, that’s why we said could we possibly have a telephone conversation because in a sense, when you’re on this journey, there’s no cure and in a sense you feel like you’re reporting what’s happening not [pause] if you can see what I’m saying?

**Interviewer:** yeah, rather than solving an issue

**Respondent (C):** yeah, I mean they have helped us to solve issues but um, it’s always something sort of practical or another appliance. They can’t help the, they can’t stop the progressions. Um, and something to say about, I think we were fortunate to know that uh, well we got quickly referred to the [hospice] but maybe not everyone knows that you need to be referred to the hospice, that you need a GP or the neuro team to say okay this person’s a candidate for the hospice. Because, um we’re very very grateful that we were, you know, we’ve been supported by them for this much time, and um maybe there are people that fall through the net because they don’t know about that or they’re not advised to try and get referred early or maybe it’s because they hear the word hospice and they think ah, that’s the end, but it’s not because they’re able to help you for a good, very practical. Good reasons.

**Interviewer:** yeah, that is true.

**Respondent (C):** and they’re very good at um, what I call future proofing, so for instance when [name of HCP] and [name of other HCP] come out to visit us they pretty much sort of on a 6 weekly basis to our home, I think they’re pretty good at picking up what might be the next thing that’s necessary or how tired I’m looking and seeing what, dropping in a suggestion here and there about what you might change, what you might need next.

**Interviewer:** oh okay

**Respondent (C):** in terms of future proofing, so you’re not on top of a problem and floundering about solving it.

**Interviewer:** it makes it easier once you reach that point I guess

**Respondent (C):** yes, so um we’ve, as I suggested just now, um, asked the lady that’s helping bathe [name of patient] if she had another friend that could help perhaps in the evening, I think they noticed that I was getting more tired, when you’re tired you get angry with, not with each other, but with the equipment and the danger of a hoist not being right, a sling might slip, all of those sorts of things. We did have a few instances where I was thinking, ooh that was a near miss, being on my own, getting my husband to bed on my own, and you know something like the clasp wasn’t safe enough.

**Interviewer:** yeah it’s scary to..

**Respondent (C):** yes, but I’m very grateful for them, sort of giving us this advice, the advice of getting some extra help

**Interviewer:** that actually leads me quite well, the technology bit, to the next, my next question, uh because what we’re trying to do is um, I know it doesn’t take the place of people helping each other out but at least in the meantime, while people are struggling to cope, um, providing some sort of emotional support as well, but using a kind of online information tool, to help people work through what they may need or not. And I was just wondering if as a family member you think this may be something, I know its hard to say without it in front of you but um, something like this might be useful or?

**Respondent (C):** like a forum do you mean? Where people share..

**Interviewer:** more like um, strategies to help you cope with things that make you frustrated or tearful, things like that, um something where you could just access in your own home and in your own time, whenever you need it.

**Respondent (C):** yes, yes. Yes I think that would be very useful, I think um, when you receive a booklet like the MND booklets, they’re very clever in terms of only giving you enough information for you to receive at that moment in time, close from the time of diagnosis.

**Interviewer:** okay

**Respondent (C):** so you’d [sigh] as you go further in through the regression of the illness, and there are more pieces of equipment that come into play, maybe that would be where this this electronic support might be useful. You might be able to say, on a timeline even, perhaps, I’m I’m wondering, because maybe I wouldn’t have looked at an Ergolet hoist if my daughter hadn’t, a stand aid, if our OT daughter hadn’t flagged it up as soon as she did.

**Interviewer:** yeah

**Respondent (C):** um, but that’s because she’s a professional, um you know, a layperson we wouldn’t have known about that. Um, she actually produced us a list of the things that we might need in the future, so that might be something else that you could put online, that people could, a go to list that people might be able to say well, to their OT, what is this?

**Interviewer:** yeah

**Respondent (C):** and they would then have somebody professional informing them.

**Interviewer:** no that’s really useful, because we don’t know much about when and how yet, but it’s useful getting tips from someone who’s been through it, and at what point it might be more useful as well.

**Respondent (C):** and also to talk about sensitivity because perhaps, you, with this illness, you throw up a bit of a barrier, you don’t want to hear something perhaps at that moment in time, because it’s too hard.

**Interviewer:** yeah

**Respondent (C):** you don’t want to think about, you know your husband having to be hoisted in a ceiling hoist, or all those things have to be handled sensitively I think, because it’s quite distressing seeing, to explain when we went to the holiday uh [name of company] place, I had to step back and let the whole purpose was to give me a bit of a break, um, and let others do to my husband what I’ve been doing for the past 3 and half years. And that actually is quite hard, when you’ve been the one person that’s been doing that, from the word go. And to step back and let others do it, and not feel like you can sort of, interfere.

**Interviewer:** were you there or?

**Respondent (C):** yes I stayed the whole week with my husband, we were there together

**Interviewer:** oh okay

**Respondent (C):** um, and letting others take over..

**Interviewer:** I see what you mean, yeah

**Respondent (C):** yeah, it’s a funny play of how control and not control, when you want some respite but at the same time, it’s hard to let the reigns go.

**Interviewer:** yeah

**Respondent (C):** and let other people take on that task, and seeing him, and it saddened me, where you’re sort of doing the job of hoisting and moving, the manual handling, and then you step back and you’re seeing it from a distance, that’s actually quite [pause…cries] hard as well, because he’s got no control over his body and he’s having to have people do that for him, he’s a very [sigh] bright intelligent human being, he’s it’s just his body’s failing him. And, one thing just to also maybe to end with, is I didn’t get any manual handling training, so maybe that’s something you could offer the spouse or the carer, that takes on the role, um because you’re learning on the job almost.

**Interviewer:** yeah, okay, so from a health care professional or someone?

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

**Interviewer:** who’s done these tasks before…

**Respondent (C):** not to say that I haven’t since but, I think right at the outset, if you had a little bit more, um, advise that way as well, you know the carer went to a place with other carers and was just shown the equipment and how to use it safely, with with somebody you know, another person taking on the role in the hoist, or just being hoisted yourself. I’ve never been hoisted myself and I, sometimes wonder what, whether I should feel what my husband feels, and then you could sort of understand, when you’re putting the hoist and sling on the person…

**Interviewer:** how it feels for them

**Respondent (C)**: how it feels for them yeah

**Interviewer:** I see what you mean

**Respondent (C):** and empathy

**Interviewer:** yeah yeah, it’s important. Okay

**Respondent (C):** okay thank you

**Interviewer:** are you happy to end the recording?

[End of audio recording]