**Transcription of Interview 16**

**[family member]**

**Interviewer:** Recording this interview, um.

**Respondent (C):** Okay

**Interviewer:** With an audio recorder, so are you happy for me to do that?

**Respondent (C):** Yeah, no problem.

**Interviewer:** Okay, okay.

**Respondent (C):** Yeah

**Interviewer:** Uh, okay. So, I guess my first question really is what your experience is like living with someone who has MND and you can start from wherever you like really, whether it’s diagnosis or before when you noticed symptoms. Wherever you’d like to start.

**Respondent (C):** Okay, so, probably start, um you know, over two years ago when he, when we first met, and he was using a cane. So, he had um some small mobility, just small mobility issues, and he had been to the doctor, and when we first met, he had just barely started going to the motor neuron. Um, he had been referred to the motor neuron doctor, and um we went with, we were visiting him quite often and had several MRIs, had X-rays um and several [name of test]. So, he had he had gone through a whole gamut of uh [Pause] um [Pause]

**Interviewer:** Uh is it like-

**Respondent (C):** Tests, tests yeah. A whole gamut of tests to try and find out and everything came back as you don’t have motor neuron, you don’t have motor neuron. And even though his two brothers had died of it and his sister had motor neuron, you know, so two brothers and a sister, and they had all died of motor neuron, he was insistent that he wasn’t. And we were pushing just because um his mobility [Pause] but it it it didn’t it, wasn’t like it was going downhill really fast, but, you know, there was an issue with pain, mobility and w- we just knew something was wrong and so we were trying to find an answer about what it was. And we actually went with the doctor and we said, you know, we, you know, we appreciate what you done, we know what it’s not, but we don’t know what it is and we want we want a second opinion. And so, we went, actually he did send us to another doctor, we went to another doctor. He examined him and did, you know, similar things and looked at his past record. He referred us to another doctor, and they were looking for water on the brain and saying that that was it. And we went to [name of hospital] and had a spinal tap and it came back as that wasn’t it. It was, he wa- although he was borderline on the water in the brain because his symptoms became worse rather than better, better when they got rid of the water they knew that that wasn’t what was wrong with him. Still, we were back to square one again, even after getting a second opinion and seeing another doctor, we went back to the doctor again. Then in last summer, um, I’d actually been away and right before I went away in July, I had to go back to [name of place]. Um, we had noticed there was muscle deterioration in his hands. And so we had made an appointment with the doctor and it takes it takes so long, you know, to get in that I had I had been away for six weeks and, you know, when I came back we still hadn’t we we still had two weeks ‘till our first appointment. [Inhale] So by the- in that two months that it took to get an appointment, he not only had muscle loss in his hand, but he also has muscle loss in his arm and twitching. The twitching was the real noticeable trait and so was the muscle loss, and so when we went to the doctor at that time, he just said he looked at him as he says oh, now you have motor neuron. And so we were, yeah, we were kind of upset and I said you haven’t done any tests or anything and I said you look at him and he has it. After looking at him for two years and telling us he doesn’t have it, he absolutely doesn’t have it and having a dozen tests, you know, and he didn’t have it. Now you look at him and miraculously, you know, you find out what’s wrong with him. So we were we kind of lost a lot of um respect and a lot of trust with the doctor at that time, so we haven’t worked well, we didn’t work well in the first place ‘cause we were always pushing, but you know when you’re going for two years and they say no, no, no and then, you know, miraculously it happens one day that you have it, you know you just lose it. And they say it takes it’s hard to it’s hard to um [Pause] find, it’s hard to you know define it. But he ha- I mean when you have brothers and sisters dying of it, we had asked for genetic tests for two years, they refused it, and you know, he just didn’t, according to them they had no findings of it and so, you know, they never found out what was wrong with him. There was never anything wrong with him either. So, anyway, then he had it, that was September, and um we’ve were [Pause] it was kind of like okay you have it, thanks, and there’s but there’s nothing we can do for you [Laugh] you know. We’re going to send you to the motor neuron clinic, you’ll be in charge here. We had been to the pain clinic and they had said, you know, you’re doing good, we’re going to discharge you, you don’t need us. You know, you’re not a candidate for us so the pain clinic, we went to the speech clinic and the speech clinic he said well, you know, you should record your voice and then they didn’t get back to us for a couple of months, like three months. And then when we went back his voice performance, his voice was too, had deteriorated to the point where they couldn’t record it, where it wasn’t worth it. So, we missed out on that opportunity because they didn’t get around to it, and then, um, then we had asked they said okay. Um, nothing’s happening, nothing’s happening, we’re just like okay, so we changed our lifestyle. You know, we’ve had to change our lifestyle so we’ve had to- we were doing simple things like, okay he needs slip-on shoes, we’ll only do slip-on shoes ‘cause he can’t tie his shoes. Okay, we’ll do we’re gonna do, um, that um zipper pants ‘cause he can’t do the button on his waist anymore. Okay, we can change that. And then, um, his first shirt, I put Velcro on ‘em, you know because he w- he couldn’t button ‘em, so he could do the Velcro. And then we bought a zipper tie so he can zip up, you know it’s already tied, and it sits on. And then, you know, his coat has a bigger zipper on it, so he can, you know, do it more himself other than a small zipper. And so, you know, you kind of you you your- we bought um lifters to lift our couch, raisers, raisers, to raise our couch so that it was easier for him to, you know, get up and down on.

**Interviewer:** Same level. Yeah, okay.

**Respondent (C):** Yeah, and so, so we were making lots of, you know, little changes like that to make life better and easier here and we weren’t hearing from him at all, you know. [Laugh] He’s just like ‘okay’, we’re not we’ve not a pain clinic, we can’t, you know, we missed our opportunity for the speech and then, one day, and so you kind feel like okay, well they don’t care, they don’t, you know, they can’t do anything about it. It, you know, he diagnosed this in one day and then was just like oh, you know, now you’re done. And then one day we get an email, oh we get a call, and they say, you know, he- we want to make a doctor appointment with I guess somebody and we’re like okay, and they make it in a week. So, we’re thinking a week, oh my gosh that’s so bizarre, everything else takes weeks and weeks or months to get into, and they want to see us in person, they want to see us now. And we had no idea, we had no idea.

**Interviewer:** Which doctor is this?

**Respondent (C):** This is the gastronomy (7.16), yeah, [name of doctor]. We’ve never seen him, we’ve never talked to him, nobody ever called us, you know. And so we, it’s a week and we get, I’ll I say I’m gonna call and see what’s going on, and my husband says no, no, don’t you call, don’t you, you know, just we’ll do it. And so I honoured h-, you know, respected him and honoured him and for a week we were going crazy. And, so that morning, you know, ‘cause we don’t know, we don’t know if a test has come back and it’s bad and he’s sick or he’s ill or what’s going on. And so then, um, we go to our appointment and the doctor says to us ‘oh, do you know why you’re here?’, and we said ‘no we don’t, we don’t even have a clue, nobody has said a thing to us about it’ and he says ‘well, you’re here’ and they wanted to put a PEG in. He is uh, he wanted to put a PEG in for feeding. [Inhale] Well, my husband eats just fine, eats all food, you know. He’s he’s fine and the PEG is for the future and um they wanted to do it while he was still healthy. And I guess, you know, there were two big choices and right now he had a choice of both of those PEGs and, you know, he would he would do well operation, it would be for something down the road. So, he explained everything, there was a nurse there, there was the motor neuron people there, and so we just said yes, you know. He said go home and think about it, we said no, we’ll do this. And then said well, we’re going on holiday, we’ll do it in a month. Okay, that will be fine. And we wanted to, um, I said one more thing okay, we want the nutrition, he can drink it now. There’s, you know, he he might cough sometimes, he might have some trouble with some dry food but, you know, we want to try this, give us some different flavours, let us try it. Well, that didn’t happen [Laugh] and then, you know, two weeks later it was the Friday the 1st and they go oh, you’re supposed to have blood tests, sorry. You know, the nurse has been out, you know, for two weeks so nobody’s talked to you, nobody’s done anything and and, you know, run to the hospital, get you blood test or you can’t have the operation, and we’re like okay. We went to, [name of patient] went to the hospital, he got the blood test, he passed, and so the operation went and um. So, it wa- you know all the times there was this tons of miscom- miscommunication or non-communication. We haven’t we haven’t, in fact we haven’t seen since he was diagnosed in September, we saw our doctor one time, [name of the doctor] one time, and we were supposed to see him [Pause] neurologist, we were supposed to see him once every four months, you know. And we still haven’t seen him since November, and they called the other day and says oh, they called and left a message on Monday, we returned to it on Tuesday, and she says oh gosh the appointment I was going to give you is gone, and we’re like okay, we can’t give you an appointment until June 18th, but she says I can’t book ‘em, I can only book out six weeks, so I can’t book the appointments so we’ll have to call you back. Okay, so it will be seven, eight months before we’ve seen the neurologist again.

**Interviewer:** Timing’s important, isn’t it? Yeah.

**Respondent (C):** Yeah. And so, you know, you’re just like okay, they don’t care. So, there, you know, we we have we the, we see the dietitian, sh- well she came, the dietitian came and, you know, we just said we’re frustrated, we’ve got some feed. They gave us only vanilla ‘cause they thought it was always going to go in the tube, he says no, we’re not using the tube to feed yet, we just did it for the future. So, then they changed it, so it was at least a great, a good taste, you know, a better taste so that he could drink it. And, so he has a PEG, he does drink it. He’s taking a supplement ‘cause he has had some weight loss. He went from 81 kilograms to 77, and so we don’t want to see any more weight loss. And, so he has this supplement, um the feeding tube we had, so then we had somebody come out from [Pause] the wheelchair, and that, so we didn’t know with the wheelchair it took us six calls, seven calls to talk to finally get somebody, ended up you had to call your GP and they gave a referral. And they gave the referral, then somebody came out from wheelchair and says yes he does definitely need it, and he’s ordered it, but it they bought it out, the wheelchair out, and it won’t work in our home [Laugh] so they won’t give us one. So, then they had to go to so- the the council and say these people need to move. We had to have an OT, occupational therapist come out, she had to move us from a low band, there’s four bands and we were low band. They had to move us up, up to a band, by seeing an OT that says, ‘yes this person needs to move.’ You know, it’s a medical issue, so we can get uh you know, otherwise it’s when you’re two years out for them to move us. So there, so there’s people who are working for housing to move us, there’s people who are working for wheelchair to move us. Tomorrow, today the supplement gets delivered, they deliver the supplement month to month, he gets one get one bottle of supplement a day, so they deliver, you know, they only deliver 12 but, for some reason there should have been 30 but we only got 12. We don’t know [Laughs], figure that out later. And then tomorrow there’s a person coming out, they’re gonna bring, they’re gonna try to put a bar in the bathroom to help him to hold on and they’re gonna try and give a handle thing to get out of bed, support to get out of bed. So, she was out there the OT when she was here, she was, you know, trying to find some things that would help. He had, he had a a pronged cane that they brought out which never worked, and he’s had some [Pause] crutch crutches, he hasn’t really used them. He still he is just walking with his cane, but sometimes his legs are just so weak, you know, that that it’s just not working. And, um, so, you know, it’s you have to reach out to these people before you need it ‘cause when you, you know, it just takes so long. And so, we’re, we you know and so when people say ‘do you want this?’ we just say yes, [Laughs]. You know, do you want, do you want a respirator, yes. ‘Cause we don’t know, you know, some, this lady said, you know, he does um [Pause] forget some things, you know, there’s some things he forgets. So she says well, you know, there’s a group that will help you remember that the alarms and things, and and no we don’t need that now, but we might and so we said yes. And we got a letter from ‘em and saying well, you know, you’ve been referred to us but we’re out two months, we’ll contact you in two months. [Laughs] You know, you’re just like okay, well I’m glad we didn’t say yes when, you know, when we needed it [Laughs]. So, you know, so it’s it’s kinda you need people, uh, you feel really bad ‘cause you, you know, people say ‘well, do you need something?’ and we don’t need it now, but we don’t ne- know what we’re gonna need in the future and we hate to say no ‘cause then, you know, you have to start over. Like the wheelchair lady says well I have release you I you can’t have the wheelchair because it won’t work in your home. She brought it here and it won’t work, he can’t get to the bathroom and stuff, so she says I have to take you off the list and she says I’ve already ordered the wheelchair, she’s already ordered it and it and so it’s coming and it’s for him, but he’s off her list until we move. And I I need to call her back. Yeah. Because we have a place to store the wheelchair here, there’s a wheelchair you know place, the garage. And he could use it outside, he can’t use it in the home yeah, but he could use it to go to the store and to go to the park. So, he could use it a lot without, you know, but he can’t use it in the home so I’m gonna call her and ask her about that. We had multiple things happening that day so we didn’t get the opportunity to, you know, they say okay we’re gonna do this, can’t do that, then they leave, and you think oh, well why? Why can’t we do this? [Laugh] So, no chair. What else is happening? We don’t have a, so we don’t have an appointment with our doctor, we don’t have an appointment with speech, we don’t have a, you know, they’re all coming. We, you know, you can’t make an appointment yourself. And we have a great GP, he’s super, he listens to all of it. Um, we work with the doctor in [name of country], who has done tons for us. [Pause]

**Interviewer:** Okay

**Respondent (C):** Okay. He, um, [Pause] he he he sends us emails and ideas, we take the ideas, you know ‘cause in [name of country], they in [name of country] they don’t, you don’t hear it but they stopped it, you know, they can stop it. And and this doctor has stopped it and, but our docto- there’s nobody here who’ll do anything, except for he does give a B12 shot once a week, we want it which is great. And we, um, can actually, my doctor in [name of country] found us another doctor here, he had to pay out of pocket 250 every appointment.

**Interviewer:** Okay

**Respondent (C):** That, we’re gonna do that. Hold on one second. [Pause]

**Interviewer:** Yeah [Pause]

**Respondent (C):** (interruption)Okay, alright. Thanks sweetie (said to someone else). And, um, [Pause] so there’s, you know, w-w-we are we are doing everything. I mean we I um just like there, there’s a huge thing with Ritalin, not Ritalin, steroids and helping. You know ‘cause there’s some days he can’t get out of bed, there’s some days when he can’t walk, other days he’s great. After his B12 shot, he is super. But, you know, there’s just bad days and then, so I says, you know, I said to the doctor, I want him to have a steroid, here’s a steroid and here’s how much. I mean I’m very specific and he said and so the doctor called me, he always calls, he’s kind, he says I can’t justify it, I can’t, it’s not a cure for MND. And I go I don’t care, I’m not hearing, we don’t want a cure, you can’t, you know. The things we want, the sad thing is I want a B12 shot every week, it costs 6 pence. He’ll give us all this pain medicine hundreds of dollars. All this, they want, you know, here’s this RX medicine, an MND medicine, it’s 170 dollars, here’s the pain medicine, here’s this medicine, here’s the fibre, here’s this, here’s these drinks that are I think 2 dollars a bottle. They’ll do all of this that we don’t want, and he [name of patient] only takes one pill a day, on pain pill at night just to help him sleep. And we don’t and we turn all these other ones away, we want a 6 pence shot, they won’t do it [Laugh] ‘cause they say that’s not part of the prescribed drugs. And the steroid is so cheap it’s like 13 cents, but it isn’t, you know, part of what the process is and I’m just like ‘but what if it works?’ and my doctor, he ta- we have this B12 shot, he ca- he the next day I made my doctor make us an appointment. I said ‘you see him, he doesn’t need his cane, he can talk better, his strength in his arms better’ and the doctor says ‘I can’t explain it, I don’t understand it and I can’t explain it’ and I say ‘okay, but it works, why can’t we have it?’. And he says ‘well, I’d love to do it for you every day but the fact of the matter is is I have 6000 patients’. ‘It costs nothing for the shot’ he says ‘but it’s the appointment and the nurse to give it’. And he says ‘I can’t, I can’t give, I can’t do that for you’, I’m like ‘okay, give us the shot, prescribe it’ and I says ‘I’ll use an EpiPen and give the shot myself’. Millions of people, you know, um with diabetes give their own shot, everybody can give an own shot. If he used a blood thinner you think he’d give your own shot ‘cause you can’t go into the hos- doctor every day, but they won’t. He says I can’t do it. So [Pause] we know things will help him be better, just feel better, work better, but we can’t we can’t get ‘em. And, you know, like oil, they’re using steroids, we can’t get that, we wanted um Ritalin, which is hugely helping MD um patients, we can’t even get it ‘cause only a psychiatrist can do Ritalin. Our doctor, GP, can’t even write it. Can’t get steroids, can’t get Ritalin. I thought that medical marijuana was legal here, hah that’s a joke. We can’t get medical marij-, not only can we not get some of these things, we can’t order ‘em, we can’t get ‘em delivered here because it’s an illegal substance and my doctor, um, actually the new doctor that we just got that’s gonna do the IV said, you know, be careful because, you know, these are illegal and you can’t get caught with them and, yeah, maybe you can buy them, maybe you can get them shipped here, but you’ll be in trouble. [Laugh]

**Interviewer:** Yeah

**Respondent (C):** And so, even though we, if we wanted to help ourselves, if we said okay, out of pocket, we want to help our self, we want to try this, we can’t. [Pause]

**Interviewer:** Mmm

**Respondent (C):** So, okay, does that answer that question? [Laugh]

**Interviewer:** [Laugh] Yeah, it just sounds like you’ve been struggling for help and I don’t know if you’ve still got it yet or, yeah. How [Crosstalk]

**Respondent (C):** It’s a, it’s a constant fight.

**Interviewer:** Yeah, yeah. And doesn’t give you a chance to just breath and get on with stuff either is it?

**Respondent (C):** Well, it uh so it becomes a way of life because I’m, I’m emailing, I’m writing letters, well I don’t talk to my uh to our neurologist [name of doctor] he’s, to me he’s completely useless and I feel bad to say that, but he is. And when I took my letters from [name of country] and I says here’s some, you know, here’s what we’d like to do, hear about this. He like turned them over and and and completely voids you as a person, experimental, it’s experimental, we don’t do that here. You know, he takes no input whatsoever. And, yet, when we went to another, he wasn’t there we saw [name of other doctor], I I turned I gave the same letter ‘cause I’m pushing the same stuff every time, and [name of other doctor] says well you can have a B12 shot, I’m like what, are you, you know, really? And he goes yeah, go to your GP, I’ll approve it.

**Interviewer:** Yeah, I don’t think it causes any harm either, so.

**Respondent (C):** Nothing, nothing. And, um, [Exhales] It frus-, it took me and it took me weeks because I’ve requested a B12 shot. Called the doctor, right, called the GP, ‘I want a B12 shot’, ‘oh come in’, go in, ‘well you can’t have a B12 shot because you haven’t been approved for it’, I says ‘well, my doctor says’ ‘well it’s not on the screen, well we have to do a blood test first’. Okay, we’ll take the blood test, take the blood test and get the B12. ‘Well, you’re not really short on B12’, I know it [Laugh] you know. That, you know, then they says ‘well we couldn’t’. Then we got back with our doctor, I mean six weeks later, we met with the doctor and then we’re just like we just want a B12 shots, and he goes ‘is that what you want?’ and I go yeah and he goes ‘okay’ and he gave it to us and it was a miracle. And then we says we want another one and I wrote to him, I wrote to him and my doctor, [doctor in another country], I says ‘you won’t believe what happened over night with my husband, he is walking without a cane, I can understand his speech’. All of this stuff happened over night, he feels, he was dancing, he was doing the hula hoop, he feels different. And I says ‘can we, you know, can we do it again?’ and they’re just like ‘oh, oh, oh we don’t want him to go that good’. [Laughs] What, [Laugh] what. And so then I did, I made an ap- I, we had a shot and I says ‘okay’, I says ‘you’ve got to, you have got to see it for yourself’ and we went in, he had his shot, we went in that day and the doctor is the GP. He’s like ‘oh, well’ he’s stre- testing the strength in his hands and arms and goes ‘well it’s really hard to tell’ you know ‘cause he tested him the day before. I said ‘it’s hard to tell?’ and he says ‘but I can tell his speech is better’ and I says ‘okay’, I says ‘okay, now get up and walk for him’ and he walk- so he walks down the hall, down the h- up and down the hall, no cane, no nothing. And he came back in the room, I mean seriously his eyes were big and sausage like, ‘I can’t even explain it, I don’t understand it’, and I went ‘okay’. [Laugh] And this is my point, you know, I says I don’t think B12 can cure motor neurone, I think there’s something else wrong with my husband. I’ll be honest I think there’s something else. And when I, when we just talked about the steroids, he says, you know, ‘that’s not motor neurone’ he says ‘they’re using It for motor neurone to make him feel better in the pain, but ultimately it’s a fibromyalgia or a, um, polymyalgia’ you know, some type of myalgia that they’re using for that. And I says ‘I think my husband suffers from that’ and I says ‘it, with the steroids, you know overnight. You give them the steroids that they have for myalgia and the next day they see improvement’. I says ‘just give me one dose of, let me try it, let’s see if the next day he has it’. He wouldn’t give us even one pill, not one of this steroid. He made him come in today for a blood test, and he says ‘well take the blood test and see if there’s inflammation and if there is then we’ll look at doing it’ and I says ‘are you really’ I said ‘how much is that one steroid pill?’. [Laugh] And he goes ‘it’s it’s pence and pence’ and I go ‘would one steroid pill hurt him?’ ‘No’, can do one steroid... But in one one pill, well we’d probably have to take four pills in one day, is what the internet says, four pills, some people take up to fifteen, but I had asked for four pills, one day. And we should see results the next day. Now, if there’s no results I don’t want anymore.

**Interviewer:** Yeah

**Respondent (C):** You know, we don’t want any pills and we don’t want to take ‘em, [name of patient] hates taking pills. I mean he takes fifteen vitamins, he’s on a vitamin regimen of fifteen a day, he doesn’t need any more.

**Interviewer:** Okay

**Respondent (C):** Yeah. But he, you know, but if it worked we- yeah we would take it.

**Interviewer:** Yeah.

**Respondent (C):** [Crosstalk] Yeah, so

**Interviewer:** So, it’s just about trying and seeing what what works and what doesn’t but being taken seriously about your suggestions and things like that.

**Respondent (C):** [Crosstalk] Right. He’s terminal, I know that. But will this doctor, okay so my doctor in [name of country] found a doctor in the UK finally for me. Finally, we’ve been looking for months, that would do an IV feed with these vitamins and stuff that he’s taking, ‘cause we’re trying to get it better into his system. Finally found someone, I wrote, he says contact this [doctor], I contacted [doctor] and told him everything and [doctor] came back and says ‘oh, oh, you know, I’m not, I can’t touch you [Laugh] you know, I don’t want to play with you, you’re terminally, terminally ill, and I don’t want to do it.’ And I say, and I was and I was just shocked and I went back and I says [doctor], my husband is no different than any other patient

**Interviewer:** Yeah

**Respondent (C):** All he wants to do is feel better. You do, he does a whole arrangement of different IVs, with vitamins, vitamin D, uppers, downers, and there only to make people feel good. I says ‘all my husband wants to do is feel good, we’re not asking you to do anything different that what you do to people who are not terminally ill every day’.

**Interviewer:** Yeah, yeah.

**Respondent (C):** And he and he said yes. He says well let’s try it. [Laugh] But there, you know, and I was so I was at least he was willing.

**Interviewer:** Yeah

**Respondent (C):** Now it’s gonna cost us 250 dollars every time he’s going to do that, but, you know what, if it made a difference, if [name of patient] doesn’t have to take fifteen pills every day and can just do an infusion once a month, and not take all, you know, we’ve we’re buying vitamins, we’re doing all this other stuff, if it keeps him out of a wheelchair for three months, it’s all worth it.

**Interviewer:** Yeah, yeah.

**Respondent (C):** And all of this week and and so, you know, he’s just like okay, we just gotta report back so we’ve done blood tests all the time, I sent him to [name of country], what [name of country] says is completely opposite. Every time here they say he’s fine, he’s fine. He’s not fine, he’s not fine and I keep telling he’s not. The people in [name of country] say holy Hannah, you know, he is he’s he’s borderline anaemic, he’s, you know, his B12 is so low and they tell us things to take and things to do to change it.

**Interviewer:** Okay

**Respondent (C):** And so, and so that’s what were those are the things that we’re trying to do. But there’s such a contrast.

**Interviewer:** And did you, did you sort of know what uh MND would look like or how it would play out, or were you not prepared for, um, all these symptoms and things like that?

**Respondent (C):** So, now I, some might, you know his brothers suffered from it, so he saw both his brothers and his sister, he, you know, he was with his brothers when they died. But it was a long time ago, first of all. His first brother had it for quite a while, a year probably, and he was only with him at the end, only saw the worst. And his other brother, he was only with him at the end and he only saw the worst. If you, and you can do all the research you want, and there’s a million things and everybody says just that. You do realise how this progresses. And we just say yes now because everybody is different.

**Interviewer:** Yeah

**Respondent (C):** It is, it is so individual and you can, there’s some people, I mean my husband’s 70, he’s no spring chicken, right, and his brother, his sister got it at 40, his other their brother at 50, his other brother at 60 and he’s 70.

**Interviewer:** Yeah

**Respondent (C):** He’s going to have different symptoms than anybody else. He can progress, we have, our doctor he’ll tell you right now our GP has said we have slowed down, it should be progressing rapidly and with what all the stuff we’re doing and all the, you know, we don’t stop, he takes vitamins, we, you know, we get a B12 shot, we’re seeing other doctors, we are doing tons of things w- ‘cause we didn’t give up, you know. Some people they say oh I’m sick and you know I’m they and they sit on their couch and die. Well the less you do, the less you do, right?

**Interviewer:** Yeah, yeah that’s right.

**Respondent (C):** So, we uh oh we’re completely we’re active, I’m making him walk. You know we’re out going all the time, even though it hurts and even though he doesn’t feel good. You know you get his mind off of it, you keep it active, we do, you know, things. We play scrabble, you know, we play scrabble, we walk. And so, we are we’re constantly stimulating him to keep things better and our GP will tell you. He’ll say he i- i- it’s unbelievable what he’s doing still.

**Interviewer:** Wow. That’s really good, yeah.

**Respondent (C):** So, there are thi- we just haven’t given up, I don’t give up and everybody says, you know, you’re pushing him, he wouldn’t be doing that without you. No, he wouldn’t, he wouldn’t. But, you know, I talked to here and everybody, everybody here is ‘he’s gonna die, oh he’s terminal, he’s gonna die’. I just hate ‘em. And you talk to people in [name of country] and they’re like ‘you can do this, you can do this, you can’t make him better, but you can make him longer, you can do this, you can do this’. You don’t do that here, everybody’s just like ‘oh you’re gonna die’ [Laugh]. It’s just so, it’s just so maddening. Even, he went to a, I don’t know what it’s called, a breathing, he breathed in something and in November when I was gone, he had a score. Then, you know, I’m back home doing all this other stuff, he has a better score. She goes I can’t believe it, he’s improved. She goes I never see that. We’re like yeah [Laugh] we know it. So, I don’t know. I’m I’m not a big advocate of the UK, I’m so sorry.

**Interviewer:** No, that it’s um, and as you say as well, everyone it happens differently with everyone so you can’t say this is how the future is going to look like, ‘cause it’ll be so different.

**Respondent (C):** [Crosstalk]Yep

**Interviewer:** Um, yeah. I was just wondering as well uh for from your personal point of view, um, were there any, how did this impact your life, did you have any worries or concerns and stuff?

**Respondent (C):** Well, we’re all going to die [Laugh], right? We’re all gonna die. Um, you know, I I I worry, you know, I I’ve left [name of country], came here with him, you know, like my family’s at home and, so things like that make it hard.

**Interviewer:** Yeah

**Respondent (C):** But, I I I just haven’t, that was what we were looking for, you have a name, you have a [Pause] illness [Laugh]. You know, I can live with that. It’s the unknown that makes it hard. My hu- my first husband died; he had a high-grade brain tumour in the fourth stage. You know, he was going to die and they had said when he was first diagnosed they said he had weeks, if that. And, you know, we and I I’ll I’ll be honest I checked him out of the hospital, I said well I don’t like what you think and I went to another hospital and, you know, they were great people. They said ‘what do you want?’ and I says well I says ‘he has this, he’s going to die, but I don’t want him to die now’. I want him I want, we had Halloween, thanksgiving, Christmas, and I said ‘I want those with my kids’. I don’t want it to be Christmas he died, thanksgiving he dies, I want it to I want [gets emotional] and they said we can do that, and they kept him alive until the end of January.

**Interviewer:** Mmm

**Respondent (C):** And, you know, that was four months, compared to, you know, days or weeks that that other hospital had given us. So, I know there’s a difference.

**Interviewer:** Yeah, yeah.

**Respondent (C):** So, I don’t give up. [Laugh]

**Interviewer:** Is that, is that your strategy also to help you cope to keep doing something and not giving up as well?

**Respondent (C):** Right. [Pause] And they and they tease me, I mean everybody knows I I write letters, I make phone calls. I’m I’m all, I work on every day, every day. I my friend says ‘oh you working on coming back to [name of country]?’, I says I don’t I don’t have time I’m working on [name of patient] every day.

**Interviewer:** Yeah, yeah.

**Respondent (C):** You know? People who say stuff, you know, the helping people ‘cause they the wheelchair lady help called the helping people, they called the next day. They’re gonna give a letter, we’re gonna put you on the list. So, two weeks later there’s still no letter. I called, we we didn’t we’re we’re not on the list, you know. Okay, add me, change me, you know. You just [Pause] y-you just y-y- have you just keep calling. And yo- and I’m kind and I give him plenty of time but [Pause] there’s just so many people here.

**Interviewer:** Yeah. And are you, do you currently feel like you have some support in place, or is it still not that [Crosstalk]?

**Respondent (C):** Not in the UK, no. Now that, I mean my supports from [name of place], I’ll be honest, from [name of country]. I mean, like I said my my doctor in the, he call, he calls us, he emails us, I can talk to him day, evening and night.

**Interviewer:** Okay

**Respondent (C):** Any time I want. It’s just [Exhale] unbelievable. And they always have a positive, you know, do this, do that. You know, [name of patient] constipated, do this, it works immediately, you know. We we’re working with this, do this and so my supports in [name of place]. Here, I, I mean my doctor doesn’t, I mean he doesn’t care that it’s been 8 months since I’ve seen him, you know. They don’t care it was 4 months since [name of patient] lost his voice. You know, they, they all want to get you off their list. You know, the pain guy, you’re not oh you’re not in enough pain you’re off the list. Oh, you can’t, you know, the wheelchair won’t work in your home, you’re off my list. You know, they’re all we’re always, they just want to get you off the list [Laugh]. And that’s not a support.

**Interviewer:** Yeah, it’s more a battle fighting to get.

**Respondent (C):** Yeah

**Interviewer:** Yeah

**Respondent (C):** I I will say that [name of nurse] um [patient] sees, she is extremely good, I’ll I’ll admit that. But, you know, she was out 2 weeks still, sick, and when she was out two weeks nothing happened. You know, and a lot of times when I’ll I can email her and I’ll say you know this, here’s the problem, and she, you know, if she can help she will can if she, you know, referred or whatever. But, you know, I think is she a support? I don’t know. She’s just, she she’s a resource. I think that’s a difference than the support, does that make sense?

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

**Respondent (C):** A resource, she’s one she’s very quick to give out information but uh

**Interviewer:** Yeah

**Respondent (C):** She’s not a support.

**Interviewer:** Yeah. And, um, for you as well do you, um, just to help keep you going as well do you, do you have, say, a family back home you chat to, or?

**Respondent (C):** Yes [Crosstalk] A lot of family [Laugh]

**Interviewer:** [Laugh] A lot of support.

**Respondent (C):** So that’s a, so I have I swim every day. I have I swim across the street and I have some great friends at the pool who listen to me day and night. They’re just great. So, I have a friend I have a group of friends, um, at the pool, there’s no one here at our flat, they’re all, they all got they’re all sicker than [name of patient], me talking about sickness here in trouble [laughs]. But I have I have a good group of 10 friends here and, you know, and I have I have, you know, friends back in [name of country], there’s I have a lot of family back in [name of country] and friends who are just constantly asking, talking and looking for looking for things, you know. Sending articles and, you know, I saw this, you know, did you know this, and did you see this and so, you know? But my my biggest is the doctor in [name of country] who has, who gets paid nothing, who you know has, he’s more invested in this than anybody I know and and h-he’s just a friend, you know.

**Interviewer:** Yeah, yeah. I’m glad you have at least that to lean on.

**Respondent (C):** Mmm

**Interviewer:** Um, and how do you do you um look online as well for lots of support?

**Respondent (C):** I’ve, yes, everything [Laugh]. Yeah, but it, um, the online, you know they say there’s things you just don’t look online, right? [Laugh]

**Interviewer:** Yeah, yeah.

**Respondent (C):** It’s it’s, you know, you can look and you can say, do you know you can go to Germany and get free care. People with motor neurone can go to Germany and get free care, they just give you free care for science.

**Interviewer:** Oh, okay.

**Respondent (C):** And you think oh my gosh, should I be doing that? We can go to China and they do stem cell replacements. They completely, completely reversed motor neurone in China, and you think ah do I go to China and do mo-mo- um stem cell? Do I go to Germany and get free care and try that? You know, do I go here? You know, we we want, we do want to go to [name of country], we’re waiting for a visa. We want to go to [name of country] and get some treatment.

**Interviewer:** Okay

**Respondent (C):** So, the stuff online is, it only makes you realise what terrible care you’re getting here.

**Interviewer:** Yeah

**Respondent (C):** It’s just frustrating, you know. Everybody is more advanced, everybody is doing more than England is. E-everybody, a-almost everybody is [Laugh]. You can go to Mexico, Mexico, and get better care in Mexico than you can in the UK, and I think that’s sad. So, the internet is a great resource you know. There’s so many, you can spend hours on it, you know, looking. I look online and there’s just so much information and you see so many testimonies and what people are doing and how they’re doing it and you think I I hope, yeah, w-we want, you know, shall we go to China? I don’t know. Should we go to should we go to Germany, you know? Yeah, we can, okay, we can go to Germany. We can go to Germany, you know, and and do it. And and that’s what my doctor just said, you know, if these IVs don’t work, if we’re unhappy with it, then he’ll, my doctor in [name of country], will work out a place for us to go in Germany and set it up.

**Interviewer:** Yeah

**Respondent (C):** [Laugh] But you try to talk to somebody in the UK about that. Hah. [Laugh]

**Interviewer:** [Laughs] Doesn’t work

**Respondent (C):** Basically, if you, yeah, it it it won’t happen. I mean, if we went to [name of doctor] and says oh we’re going to Germany, you know he’d he would just like huh, huh. And, you know, continue with his agenda for the day and and get you out of his office.

**Interviewer:** Yeah

**Respondent (C):** I I mean he has has [Pause] had ohh I can’t even go there. [Laugh] So sad, it’s just it’s so sad. He’s had a, we actually asked to be removed from him, we actually said okay, this isn’t working we’re unhappy. You don’t trust him, you don’t like him, you don’t trust him. You can’t get good medical care and, um, and sadly we we we’d have to go all the way to London to get into another. Yeah because he’s head of neurology here in [name of place]. But, oh like over, over like [name of other place] and, I mean he’s everywhere. He’s… and so you can’t you can’t get away from him ‘cause we’ve tried.

**Interviewer:** Yeah

**Respondent (C):** And [name of other doctor] who is so great, I mean I just really liked him, we really felt comfortable with him, you know, he’s retiring. And so, you can’t [Pause] we signed once and we’ll probably never see him again. But you know what, I don’t think we’ll see, I do- I don’t see us seeing [name of neurologist] again so what the hay.

**Interviewer:** Yeah

**Respondent (C):** I mean do you need to go see a doctor to know you have MND.

**Interviewer:** [Crosstalk] Nothing will be learned. Yeah.

**Respondent (C):** Well, yeah. Or that your symptoms are worse. I don’t. [Laugh]

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

**Respondent (C):** I, I just don’t need it.

**Interviewer:** Yeah, yeah. It doesn’t help at all, does it?

**Respondent (C):** No, it doesn’t. Ah ah, no I, unless you want to see me for to help us get better th- then don’t see me.

**Interviewer:** Yeah, yeah. Well the reason I was asking about, um, online support as well is because, um, I’m not from a medical background, uh, I’m more from like the psychology background.

**Respondent (C):** Mhm

**Interviewer:** Dealing with, um, emotions as well and even when you do have a terminal illness there are still things you can do to feel better as you were saying. Um

**Respondent (C):** Yeah

**Interviewer:** Even from a psychological point of view. So, we’re trying to develop something at least online which people can access from wherever they are, so it doesn’t

**Respondent (C):** Mhm

**Interviewer:** depend on do I get an appointment or things like that.

**Respondent (C):** Mhm

**Interviewer:** So, yeah. At least that there’s some support handy [Pause] till you get the right support, or something like that.

**Respondent (C):** [Inhale] Yeah. Though websites and stuff that have gone with the MD and stuff, they’re just so depressing.

**Interviewer:** Yeah

**Respondent (C):** You know, there’s nobody upbeat, there’s nobody doing something different, but, you know, in the UK. There’s nobody that says ‘try this, it’s been working great’ or whatever. They’re all like ‘oh I’m dying, oh this is worse, the pain’ and I don’t need that.

**Interviewer:** Yeah

**Respondent (C):** So, if you were going to do something it would just have to be, I don’t know, monitored. You know monitored for people so that it it it’s bringing hope rather than desperation.

**Interviewer:** Yep. No, that’s that’s really useful to hear that perspective as well, because how we frame things, like if if it’s not, um, if if you’re not gonna if people are not gonna like it, or not engage with it then what’s the point in creating it, isn’t it?

**Respondent (C):** [Crosstalk] Right. Yep. And I just, you know, I I’ll be honest I don’t, I I realise a lot of people have other problems and some people just live for that, you know. Problems and problems and they want to, me too and all that stuff. I I don’t want that. I want, I, there’s nothing out there right now that is just a positive platform of, you know, let’s, let’s cheer motor neurone or let’s beat it or, you know, I I I’m uh I’m living better. [Laugh]

**Interviewer:** Yeah

**Respondent (C):** You know, ther- I’m telling you, you can do stuff to make yourself better. You know, you don’t have to, like I said you don’t sit on a couch and slowly die, you, you know, we’re we’re getting on a plane Sunday and we’re going to [name of place], you know.

**Interviewer:** Okay. Oh, nice.

**Respondent (C):** Yeah. And people are, people over here are just ‘oh, how can you do that?’ and I says ‘how can I not?’. [Laugh] ‘What do you mean how can I do that?’ ‘Well, you know, you’re taking him’ I says ‘yeah, well I’m not going by myself’, you know. ‘Well he’s sick’ huh ‘we all are’ I says, you know this the elderly flat, ‘you’re all gonna die, before him, so I don’t know what you’re worried about’ [Laugh]. You know, these ladies are 84, 89, you’re gonna, you know, he’s gonna, you know what he’s sick uh no, the world doesn’t stop. It just doesn’t.

**Interviewer:** Yeah

**Respondent (C):** And so, if if we’re not, you know, if if to find support on a platform like that, it’s got to be positive.

**Interviewer:** Okay. No that that’s really useful to know as well. Um, I think I’ve kind of covered my questions. I was wondering if there’s any aspect of your experience that we haven’t spoken about, or?

**Respondent (C):** No, I I think I’ve told you more than you probably wanted to hear. [Laugh]

**Interviewer:** No, it it’s really really useful. I’m gonna turn the recording off then if you’re happy and then I can still talk to you.

**Respondent (C):** Oh, okay, yeah.

**Interviewer:** Is that okay?

**Respondent (C):** Yeah, that’s fine.

[END OF recording]