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**Interview 15**

**So thank you again for agreeing to be interviewed** (Okay)**. Because I’m doing the interview with both of you as well, I… I know that some questions you might have one perspective on things, and you might have another** *(Yes)****,* and I’m interested in hearing both sides of the story as well, so… sometimes I may repeat the question, but direct it to a different person, so I can hear more about say your point of view** *(Okay)* **and then ask you how do you feel about that. So yeah,** *(okay)* **it might be a little repetitive in that sense. But it’s all… it’s all good information. And the other thing to say is that everything you tell me will be confidential as well, so say you name a doctor or name of a hospital** *(Right)* **or something like that, in the end it’ll all be anonymised, so… yeah.**

*That’s good. Mm-hmm.*

**You can feel free to share. So I know you’ve told me a little bit about how you were diagnosed, and the procedure, and how long it took. But I guess I just want to know about your experience with Motor Neuron Disease, if you want to start from the beginning and give a bit of an overview, that’s fine, if you want to talk about what it’s like now, as well, that’s also okay. So wherever you’d like to start, really.**

**P:** Well… (Mumbles) I did have… three eye operations.

**Okay.**

**P:** So I had two cataracts, I had replacement lenses, and then because the lens was clear, they were able to find some other problems at the back of the eye. So I then had a… an eye operation to remove the epiretinal membrane.

**Okay.**

**P:** Now… none of those operations were in any way painful. They’d… they… they were done just under local anaesthetics, with the head held in a nice comfortable position, for the… ophthalmologist just to go and do his stuff. So… but the last one, the third one, required me to pretty much stay immobile for four to six weeks, because I had gas in the eye…

**Oh.**

**P:** And… and some very, very weird… very, very weird side effects. So things like straight lines could appear as curves, and it really made a mess of my depth perception. So it was, it was a very… took quite a… a bit of time to get over that. And one of the things he did say to me was not to buy any prescription glasses for near vision, because you must allow a full year for it to, your eye to get back to normal.

**Gosh. Okay.**

**P:** And that’s now…

***C:*** *It’s a year, now, isn’t it?*

**P:** ...it’s about now.

***C:*** *May.*

**P:** So my eye should be getting back to what it should be. So about now. So one of the things that happened there was, I started shuffling around quite a lot when I started trying to walk. And so I then, in… a lot of things overlapped here, I started doing some sort of physio and pilates in January of this year.

**Okay. This year.**

**P:** And she told me, “You’re not walking properly, so we’re going to make you walk properly.” So that’s how I’m now walking, because she… it was very, very difficult to coordinate my arms and legs. I’m still having a bit of trouble with that. And my dentist said that... something that was very telling. A child takes years to learn how to walk properly, vertically, and you are trying to unlearn your bad habits as an adult, and you can’t expect it to get completely better immediately.

**Okay.**

**P:** So with that little insight, I keep telling myself it’s got to get better. But it’s very slow in getting better. And so I think some of these things may well be masking some of the Motor Neurone symptoms.

**Symptoms, yeah.**

**P:**Hard for me to distinguish which is which.

**Yeah. Yeah.**

**P:** You know? So it’s a…

***C:*** *I think I, from my perspective, I… I think that since you had your operations, that you, that the Motor Neurone Disease has reared its ugly head.*

**P:** Yes.

***C:*** *And like ‘cause from then…*

**P:** It could be something that… that could be what initiated…

***C:*** *So, then it started…*

**P:** It could be what’s started it (Overtalk)

***C:*** *…worsened. Not started, but it worsened.*

**P:** Worsened, yeah.

***C:*** *Even though he didn’t have a… a general anaesthetic, I think whether it was a shock to your system or what it was… because nobody knows sort of what’s starts Motor Neuron do they. It might have been something that… but markedly, from your operations, your balance was worse, and walking was worse… (Overtalk)*

**P:** Worse, absolutely.

***C:*** *Everything. Even though… even though your eyesight was showing that you weren’t seeing properly, the walking was… your walking was worse after that op.*

**P:** See, I had very good near vision before I had these eye operations. So I… I could see things there very clearly, all the way to my feet without any problem. And then I started off with, I couldn’t really see… (Overtalk) That was going onto firm ground.

**Okay.**

**P:** Because I… because my near vision just wasn’t what it… what it was like before, it had to adjust.

**Yeah.**

**P:** So that’s been something that’s been causing… I think that’s, as [name of wife] says, annexed- it almost sort of worsened it.

**Yeah. Because that… that would link to how you walk as well, in terms** (Yeah, yes) **of what you’re looking at.**

**P:** It’s all masking it, sort of thing.

***C:*** *Yes. Yeah.*

**P:** I… absolutely think that… (Overtalk) they’re all sort of in all this.

***C:*** *Yeah, it’s too… it’s… unfortunately it’s a double whammy with… with [name of patient]* (Yes) *because they eyes were, affected you a lot.*

**P:** They did.

***C:*** *And then after this, your balance and your walking got worse. And that’s when we got concerned, my son and I got concerned that there was something else going on, that needed… needed to have some… some investigations. And here we are. (Overtalk)*

**P:** So I had this… so I had this (stutters) pilates-cum-physio.

**Okay.**

**P:** And I say cum-physio, because the lady that does it is a retired NHS physio… physiotherapist. And she’s… as a, it’s a side line, after being retired she learned how to become a pilates instructor.

**Oh, okay.**

**P:** So she actually uses a combination of her physiotherapy in [name of place], and pilates type exercises.

**Okay.**

**P:** So I got…

**Yeah.**

**P:** ...much… much stronger core muscles now, as a… well as a result of that. And that isn’t particularly visible. You know, but I lost a lot of this stuff.

**Okay. So it helped in some way.**

**P:** Yeah. Yes. But it doesn’t do a great deal in terms of leg stress- strength. But it’s generally okay. tests me, in terms of how… (Overtalk)

***C:*** *It’s very strange, because if you can do that, yet you have to keep lifting your legs when you walk.*

**P:** Yes, yes.

***C:*** *Yeah, but you can do that, you can lift up your…*

**P:** Yes.

**Mm. It’s strange, isn’t it? Yeah.**

***C:*** *And then when you’re walking, you’re scraping the floor.*

**P:** I learned to… lift, actually I think she has started to work on that from me. Some of the exercises she’s been doing with me last couple of times, which is to put a… what they call a brick on the floor, and you have your… have your legs side by side, and you put… kick a leg up, put it up on the brick.

**Yeah. Yeah.**

**P:** That’s… and then you move a little bit away from it, so you… then you… that, put it on the brick, put it on the brick.

**Okay.**

***C:*** *Are you sitting on the… on a chair, then?*

**P:** No, no, that’s what I’m doing.

***C:*** *Standing up, are you?*

**P:** Standing up, and…

***C:*** *Is she holding you?*

**P:** No, you’re putting your… you have your arm on the wall for… to keep balance.

**Okay. And then you push, Yeah.**

**P:** So.

***C:*** *Okay, I’ll ask her. We’ll soon be dancing.*

**P:** It’s all right, I’ve… I substitute… a book from there, at home.

**Yeah. Yeah. Modify it and…**

**P:** Yes.

**And what’s the experience like now, just coping with things and managing on a daily basis? I’ll start with you first.**

**P:** What I… what I really find troubling is that I’m falling more frequently.

**Mm-hmm.**

***C:*** *Yeah.*

**P:** And it’s… it’s… only in the house, at the moment.

**Okay.**

***C:*** *(Laughs) It’s because you don’t go out.*

**P:** That’s probably one of the reasons. (Laughter)

***C:*** *At night, you’ve had a couple of falls, haven’t you?*

**P:** Yes.

***C:*** *Up in the bedroom, when you’ve had... you had a fall, you were… you were showing off the other day, and you fell in the hallway.*

**P:** Yeah.

***C:*** *Yeah. But I think that was because you were walking a bit too fast, you were trying to be clever. And then you… off you went. But the ones at night, so they’re worrying. They are… I… they worry me. Yeah. Gets up to the loo and (Overtalk) either falls going to the loo or falls coming back from the loo.*

**Okay.**

***C:*** *And he goes down like a sack of potatoes, ba-bum. Crash down, right… you don’t hurt yourself, but you’ve had a couple of… (Overtalk)*

**P:** I don’t fall going to the loo at night, fell coming back.

***C:*** *Yes you have fallen going to the loo.*

**P:** That was here.

***C:*** *No, you have fallen going… where you fell in the corner.*

**P:** I wasn’t going to the loo.

***C:*** *Yes you were.*

**P:** I was coming back.

***C:*** *Oh, whatever. You fell anyway.*

**But it’s… it’s the worrying about falling.**

**P:** Yes.

**And when you would have potentially…**

***C:*** *Yes. I… yeah. Can I say something?*

**P:** Of course you can.

**Yes, sure.**

***C:*** *I am, for me, my… my worry is that every step you take, that you’re in… in danger of falling. That’s why when you wake up at night and you… you’re on your way to the loo, I wake up, and I’m watching you go to the loo, walking, hanging onto all the* (Yes)*, all the furniture. And any minute you could fall.*

**P:** Well I’m trying to be as safe as I can be.

***C:*** *I know you are, I know you are. But then you… you go, and then you have to come- you come back, and it’s… and then I’m watching you, and then you get into bed, and then a couple of hours later, you have to get up again to go to the loo, so I wake up then. And I’m watching you, thinking you’re going to fall. It’s very stressful.*

**Yeah. Yeah.**

***C:*** *It’s very stressful. Even in the house, you’re not, I don’t worry so much about you in the house, because there are more things… and it’s light. There’s more things for you to hold onto. But there are times that you do fall down, in downstairs as well as upstairs.*

**P:** Yes. (Overtalk)

***C:*** *And I’m really worried if you go out, you’re going to fall and really hurt yourself. That’s my fears, anyway.*

**Yeah.**

***C:*** *Yeah.*

**Especially if you’re on your own or things like that… (Overtalk)**

***C:*** *Yes. [patient’s] able to get out, he turns himself over, and he manages to get up on furniture or whatever. But when we’ve been outside when he’s fallen, there’s either been somebody there or you’ve managed to get up, haven’t you? So that is the good, that he has managed to get up. But I am… my other fear is that we are here one day, and he’s not going to be able to get up. Getting weaker or whatever it is. Whatever the reason. His muscles are getting weaker, he can’t… nowhere near anywhere to pull himself up, unable to pull himself up in the middle of the night. That’s my biggest fear. Really.*

**Okay. Like not knowing how it might get worse in the (Overtalk) future...**

***C:*** *Yes, yes. Yes. But luckily we’re having the physio on here on Friday.*

**P:** Yes.

***C:*** *And I think she is going to be able to give you some walking aids, of some sort. Which you’re… which she will assist you for, which will be good, because you need something to stop you falling. They do what they call the risk assessment of falls, and you’re a very high risk of falling. Is that right?*

**I’m not a physio, but that… I, that sounds like the right procedure. Yeah.**

***C:*** *Yes, they do a… they do a risk assessment. And I’ve done risk assessments as a… as a nurse looking after people. And to me, you’re… you’re very high risk. And they want… they will want to reduce that. Well, I want to reduce it (Laughs), as a help.*

**Yeah. And besides falling as well, are there any other concerns or worries? That you want to talk… (Overtalk)**

***C:*** *Is there are any other concerns, [name of patient]?*

**P:** No, sorry, I’m just wondering what this fella’s doing (Referencing background reversal alarm) (Overtalk) Sorry.

(Non-interview chatter)

**Any other concerns on a daily basis?**

**P:** No. Very healthy. (Overtalk)

***C:*** *The doctor for a year.*

**P:** I’m fairly healthy.

***C:*** *So he’s very healthy.*

**P:** Really healthy.

***C:*** *But also we’ve no risk of colds, sore throats,* (yes) *nothing like that. And we always have a flu jab, don’t we?*

**P:** Mm-hmm.

***C:*** *We’re usually quite… well, mind you, we don’t mix with a lot of people these days, so. But we’ve… we are very healthy.*

**Okay.**

***C:*** *That, you know… my…*

**P:** Including my eyes, I… I’ve steroid drops in my eyes.

***C:*** *Yes.*

**P:** Because I have this… what’s called… it’s kerato… congenital… (Stutters)

**Oh gosh.**

**P:** No, it’s called rosaceation.

**Tricky one.**

***C:*** *Tricky one, yeah. Keratoconjunctivitis, is it?*

**P:** It’s a rosacea keratoconjunctivitis.

***C:*** *It’s like another language, isn’t it?*

**P:** It is. And it’s an inflammation, it’s a, okay, and they don’t know what causes it. But it’s…

***C:*** *It’s chronic.*

**P:** ...it’s not a bacterial infection.

**Ah, okay.**

**P:** But it can… if it worsens, it can cause bacterial infection, which then you… you have (Overtalk) to fight. Yeah.

**Which you’re trying to prevent that. Yeah.**

**P:** But you get this reddening, and I started off getting things… oh, it’s hay fever, and this is January, you know, thinking like that, because the doctors just don’t know what it is.

***C:*** *No, well they’re not experts, are they, in that? They’re just general practitioners.*

**P:** They’re not. So anyway. Yeah. Eventually they got the very best sort of ‘proper’… (stutters, tuts) diagnosis, when I went to [name of place]. And he… he was very, very knowledgeable, and he… he gave me chapter and verse on it.

***C:*** *Yeah. And it got better from then, really, (Stutters)* (it’s, it’s just) *but it is sort of, it’s still chronic, isn’t it?*

**P:** Well it’s just… it’s just… yeah, you just have to keep…

***C:*** *It’s chronic.*

**P:** ..taking FML drops, it’s steroid drops, and it’s very… it’s a very non-invasive…

**Mm. Eye management.**

**P:** ...steroid drop. Because you have to take them, and you… you basically get addicted to them, his body just (stutters) stopped…

***C:*** *Well it’s steroids, isn’t it?*

**Yeah.**

***C:*** *Yeah.*

**P:** You just have to keep on taking drops.

**Mm-hmm. And I know some people also find the whole process of being diagnosed and having MND as well quite emotionally challenging. I was just wondering if you had any similar experiences, or any other** (I…)**, from the emotion side of things.**

**P:** I just… being a sort of scientist-cum-engineer, as I used to be, I just… I know if there’s a particular risk of being one in fifty thousand. This case, I’m the one, if you see what I mean. So once you’ve sort of figured out in sort of those terms, well that’s it, the way it is. And so you’ve just got to come to terms with it.

**Mm-hmm. Just accept…**

**P:** Yeah, accept it.

**...the situation?**

**P:** And just take appropriate measures to… to make yourself more comfortable, which is why we stay in the house, and moved to more appropriate property. Which is…

**Yeah. Yeah.**

**P:** Which is sort of wheelchair friendly, in… it’s a very charming village, and it has a lot of sort of disable facilities.

**Okay.**

**P:** So… but we just decided immediately just to do that.

**Yeah.**

**P:** Whilst I was still walking, if you can call it that.

*(Laughter)*

**Yeah.**

**P:** But I just needed to get… to get sorted on how it is, move off.

**Yeah.**

***C:*** *She’ll teach you the… the… she’ll teach you… she’ll give you strategies.*

**P:** Yes.

***C:*** *What to do, and how to do it. And when to do it, and what to use, what’s… what to use as an aid.*

**P:** Yes.

***C:*** *You know, she will do that for you. It’s in her best interest as well as yours.*

**P:** Sorry?

***C:*** *It’s in her best interest as well.*

**P:** It is, yes.

***C:*** *…as yours. So she’ll do a thorough assessment.*

**And you won’t worry so much about falling… (Overtalk)**

***C:*** *And I won’t worry so much, then. But I… I have been quite emotional, haven’t I? (Laughs)*

**P:** Yes.

**What’s your experience been like?**

***C:*** *It’s been horrible. (Becomes emotional)*

**It’s okay, if you don’t want to…**

***C:*** *Yeah.*

**...say, that’s fine. Particularly with the diagnosis and things like that, or…**

***C:*** *It’s living with it, I think, is the worse thing.*

**Okay.**

***C:*** *Isn’t it?*

**P:** Yes.

***C:*** *To see [patient] like this. (Pauses)*

**P:** Yes. And we don’t exactly know (Overtalk) which… which bit is down to MND, if you see what I mean.

***C:*** *No, but we… we know that it is… it’s… I personally (Overtalk), I don’t think you’ve been misdiagnosed, I think you’ve definitely got all the signs of it.*

**P:** There’s no… (Overtalk) there’s no accurate diagnosis, too.

***C:*** *No.*

**Test, yeah.**

**P:** There’s no test. They’re looking for ‘Biomarkers’. ‘Markers!’

***C:*** *Yeah.*

**P:** Biomarkers. And the… if... they’re trying to find somebody, I actually managed…

***C:*** *Yeah.*

**P:** I was just reading today that asthma… asthma medication may have an affect…

***C:*** *On causing it?*

**On MND?**

**P:** No, to…

***C:*** *Helping it?*

**P:** ...help to… help… yeah.

***C:*** *Oh well.*

**Oh, okay.**

***C:*** *Well take a puff. (Overtalk) Take a puff, that’ll make you feel better.*

**P:** They’ve been doing some trials in China of all places. So...

***C:*** *Yes. Yeah. Well that’s very good news. Very good, yeah.*

**P:** Well, it has to… it has to be sort of go through trials to…

**Yeah.**

***C:*** *Yes, of course. (Overtalk) And you’re waiting to go under one, aren’t you?*

**P:** Yes.

***C:*** *But I… (Overtalk)*

**P:** May or may get used some time.

***C:*** *Yeah. I think for us, I… my… not fears, but… what I’m concerned is, is seeing [name of patient]… worsening. I can see it. And doing less than you have been doing, you know, we love doing the garden and he loves going to play golf. And… going and having golf lessons and going to the gym, he loved all that. To see… for me, to see you like… like you’re not able to do this, it’s very hard.*

**P:** Yes.

***C:*** *And I’m running around like a rabbit…***(Laugh) (Yeah)** *like a demented whatever. And I feel, I don’t feel…*

**P:** Learning a lot, though. Aren’t you?

***C:*** *Eh? Burning?*

**P:** Learning a lot.

***C:*** *Learning a lot of what?*

**P:** Things that are in… things in the garden.

***C:*** *Oh, I know, yes. The gardens. I mean, my garden, now which is fine. But yes, it’s… it’s… (stutters) very, very difficult, I must say. Very, very difficult to live with, to live with… with this disease, for, for obviously worse for [name of patient], but bad for me as well. Very, very bad.*

**Watching him get worse*,*** *(watching [name of patient] getting worse)* **and then the symptoms and things like that? (Overtalk)**

***C:*** *Yes. Because I can… you probably can’t see, but I can see daily that there’s something less that you can do and less, you know, you’ve… things that you… walking and all the rest of it. But you are doing less and less, and it’s getting worse and worse. And that’s my… that’s what I feel. And [name of patient], you may not feel that. But I feel that myself. What I can see. And we’ve been together a long time.*

**P:** Yes.

***C:*** *(Laughs) Been married forty years.*

**Oh wow. (Laughter)**

***C:*** *Forty-one years.*

**P:** Forty-one, come on now.

***C:*** *You’re right, yeah, forty-one years, yeah. So. So…*

**It’s a long time.**

***C:*** *Yeah, it’s… it’s a long time, we’ve done a lot together.*

**Yeah.**

***C:*** *But, you know, it’s just been me and you, really, it was… with our son. So we’ve been very independent of everybody else, haven’t we? We’ve done a lot.*

**P:** Yes.

***C:*** *In our life. And now it’s shrunk, our life has shrunk.*

**It affects both people, doesn’t it, yeah.**

***C:*** *Very much so. Yeah.*

**And… sorry… (Overtalk)**

***C:*** *Oh no, no, no, no.*

**And when you do have these concerns or worries, is there any way you get support or you cope with things?**

***C:*** *Well I’ve got friends, a cup of tea, you know, I just sort of talk to friends. You… you don’t want to depress them, you know? (Laughs) you know, because you, they’ve got their own worries.*

**P:** Yes.

**Yeah.**

***C:*** *You know? Like [name of friend] for example, I wouldn’t… I don’t, I wouldn’t say, because our friends, some of my friends have got their own worries with their own husbands, so…*

**P:** Our (stutters) best friend, male friend, had a seizure.

***C:*** *He’s under the same consultant.*

**Oh, right, okay.**

**P:** So he’s… and the same… same consultant. *(yeah) a*nd so he can’t drive at the moment.

**Oh yeah.**

**P:** Which is… he’s doing his head in, you know?

***C:*** *Yeah.*

**P:** You know?

***C:*** *So she’s… and his mother’s just had a stroke, so…*

**P:** His mother’s just had a stroke.

***C:*** *I feel I can’t talk to her. I’ve got a neighbour who’s very good, but she, all she does is talk about herself.*

**P:** Yes.

***C:*** *Like I’ve got a sister who is… who is very… very nice, but… (Overtalk)*

**P:** Ah, they’re useless.

***C:*** *She’s a… she’s doom and gloom and she’s useless. Because she would never… she doesn’t like anything to do with sickness, she’s like, ‘oh...’’*

**Okay.**

***C:*** *I’ve got a brother who’s a doctor. He’s probably the best of the family to talk to. But he’s very busy, he’s retired, he’s… just does all sorts … but and we’ve got a lovely son, who… who has been fantastic, hasn’t he?*

**P:** Yes. Yeah.

***C:*** *But he needs support as well.*

**Yeah. Yeah.**

***C:*** *So we’re… we’re all trying to support each other, and he’s… he came down yesterday. He’s down here about once a week now, isn’t he? He lives in [name of place]. So it’s very difficult to get support, because you don’t want to bore people, you know? You know, because you… and I think people will actually step away from you if you, if you’re miserable. People don’t want to know.*

**P:** Yes. It’s true

***C:*** *It’s true, isn’t it? And we don’t have very many people coming to see us now. I think it’s probably because people don’t want to see… see you like this. As you… because you’re not like you used to be. (*we don’t*) People can’t cope with that, you know?*

**P:** We don’t… we just don’t go to the sort of places that we used to go to.

***C:*** *Yeah.*

**Okay.**

**P:** Like, even the pub...

***C:*** *We used to go to the pub every now and again.*

**P:** But a lot of that was nothing to do…

***C:*** *It wasn’t actually, it wasn’t, we…*

**P:** It was, we just got fed up.

***C:*** *We just got fed up of going there.*

**P:** Going to the pub.

(Laughter)

**Okay.**

***C:*** *So yeah, so… support, not a lot, really. We’ve got each other. I think that’s… that’s our main support is each other.*

**Would any additional support be helpful, you know, in terms of just someone to talk to, or… is that something you feel you need, or...?**

***C:*** *Yeah, oh it would be. Yes it would be, yes.*

**P:** Well, at the moment, because we’re getting all these people coming round…

***C:*** *Looking at the house.*

**P:** Looking at the house.

**Oh. Yeah.**

**P:** It’s taking up too much time.

**Yeah.**

***C:*** *Maybe when we move.*

**P:** But we’ve got…

***C:*** *When we move to… to our new flat.*

**P:** We’ve just got some of the best support, which has started, which seemed like a very good gardener.

***C:*** *Yes.*

**P:** And also there’s these cleaners.

***C:*** *Yes, that’s right. They… they help me.*

**P:** Which is just fantastic.

***C:*** *Yes, they are… they are very good. So that’s very good. (Overtalk)*

**P:** Spend a lot of time…

***C:*** *But still psychological, support, there’s not much, is there?*

**P:** Yes. I’ve spent a lot of time getting the house ready for inspection.

***C:*** *Yes.*

**Yeah.**

***C:*** *That’s right.*

**P:** Because you’ve got to turn it into a show home.

**Yeah.**

***C:*** *Yeah. That’s right.*

**And nothing from the professional side as well, in terms of seeing the [charity organization] or… (Overtalk)**

***C:*** *Well they’ve just started running… sure, we’ve got, this girl called [name of care coordinator], and she knows about your study.*

**Oh, okay.**

***C:*** *She’s a… she’s a… she’s originally a coordinator.*

**Oh, okay.**

***C:*** *She’s very nice, very good. Very knowledgeable. And she has started the ball rolling. She started the physio. Just had to come and do an assessment with [patient’s] mobility. She’s also got the OT, the Occupational Therapist to come here. And they’re all coming here, which is fantastic, because it’s just myself and [patient] there. And then a speech therapist she wants him to see, because they want him to bank some words.*

**Oh yes. Yeah. I’ve heard of that.**

***C:*** *So you can bank your songs. And is there anybody else? I think that’s it, isn’t it? Oh there’s a nutritionist, she said, as well.*

**P:** Nutrition… what is it?

***C:*** *Nutrition… not... further down. If you do lose any more weight. So that will all happen, and we’ve been to the GP, because he is going to send us a form for a Blue Badge for the car, so that Ian doesn’t have to walk so far.*

**Yeah.**

***C:*** *A disabled badge. And also for some additional…*

**P:** It’s to kick off all the…

***C:*** *The payments for Mobility Allowance… It’s the allowances, isn’t it?*

**P:** All the…Yeah, all these support that the State provides.

***C:*** *Yes.*

**Yeah.**

**P:** That all kicks in. (Overtalk)

***C:*** *So that’s all… so that’s very much in the beginning. What happened, the reason why we didn’t… we’ve only just had this from [name of care coordinator] is because she was supposed to have been sent an email from [name of doctor], just to come and see us. And she didn’t get the email. So I waited for a month.*

**Oh, okay.**

***C:*** *Before I thought, ‘well I’ll just ring her, just in case she didn’t get the email.’ And she hadn’t got the email. She was here in two days, so we wasted… we wasted a month of getting these people here, because the secretary of [name of doctor] didn’t send a… she’s got it, now, but she didn’t have it. Didn’t get the email for the referral. So, So that was a bit of a waste of time. So then we, and time really… with [name of patient], it’s of an essence.*

**Yeah.**

***C:*** *We need things done straight away. Because if [name of patient] is, you know, his condition isn’t… it… well I’m just going to say it is, it’s deteriorating, then you want things… you want things now.*

**Quickly, yeah.**

***C:*** *You know?*

**P:** Well the DS1500 form is…

***C:*** *That should, that would…*

**P:** ...it’s through to fast track it.

***C:*** *Yes, I mean, I’ve had to check all that, they won’t fast track the physios or anything, we’ve done that ourselves, I…I’ve rang them up.*

**P:** Yes.

***C:*** *And it’s okay, I can do it. But a lot of people don’t know.*

**Yeah.**

***C:*** *A lot of people don’t know what’s there.*

**Yeah.**

***C:*** *And they will sit at home for months and months, waiting. You know, it’s just not good enough, really.*

**Have you found that a struggle as well, or… because of your background** *(Yes)* **did you sort of know…?**

***C:*** *I do… I’ve worked… (Small laugh) I’ve worked with disabled people for many, many years. I worked with the [name of foundation]. And they have people with MS, Motor Neurone Disease, any type of neurological disease. And I did… I did that for many… oh, over seventeen years. And… and before that I worked looking after people with MS for five years. Like I know how… how the system works.*

**Yeah.**

***C:*** *Which is good, because I know what’s available.*

**Exactly.**

***C:*** *It may not still be, it may not be current… current. But I know now that what [name of patient] needs.*

**Yeah. And it’s easier to, now to get that?**

***C:*** *Yes. Although I don’t… I don’t mind ringing up the hospitals complaining, and kicking their whatsits, because sometimes they need it. (laugh).*

**Yeah.**

***C:*** *They do. They do. Yes. Otherwise you’re just sitting there like a… (Overtalk)*

**P:** They keep on losing paper. There’s so much **(yeah)** paper.

***C:*** *They’ve lost… they lost [patient’s]… all of [patient’s] records at [name of hospital]. Lost them. How do you lose them? God. It just makes you wonder, really. So yes.*

**P:** It’s because they’re in a different sort of…

***C:*** *World.*

**P:** No, it was the… that GP… group of GPs that set up… oh, what the [name of place]?

***C:*** *Oh, yes, the [name of place].*

**P:** [name of place], yes.

***C:*** *It’s a different Trust.*

**Oh, okay. So the...**

**C:** *We’ve… we… what we’ve done, we’ve gone into this loop where [patient] sees his consultant at [name of place]. Which means that he’s not seeing him at [name of hospital], which is the on-the-go hospital. So in that case, we are… we won’t see this doctor at our local hospital. So because we aren’t seeing him at the local hospital, his secretary is unhappy, or whatever the word is, to send any emails to us, because we’re in another Trust.*

**Yeah, the systems aren’t joined up… (Overtalk)**

***C:*** *Yes, they’re not joining up. So… but that’s been very frustrating. (Overtalk) I’ve had phone calls after phone calls trying to ring this secretary of [name of doctor], and she will… she speaks to you as if she’s… she’s on the train. (Mimics) Doesn’t she?*

**P:** She does. She does.

***C:*** *And then she won’t listen to you. She won’t listen to what you’re trying to say. And then she’s, “Right, bye...” And I’m going, “Oh, excuse me...” And she’s… she’s gone.*

**Okay.**

***C:*** *Nightmare. (Laughs) But anyway. That’s my experience. (Laughs)*

**And in terms of more like a personal attitude to how you cope with things, I’m sure there must be differences in how you both deal with it. I’ll ask you both separately. Is there anything you kind of tell yourself, or use for inspiration, or something like that?**

**P:** I’ve got my little motto. (Laughter) which is tone your muscles, tune your neurons.

**(Laughs) Tune your neurons?**

**P:** Yes.

**Okay.**

***C:*** *And you’ve got your song as well.*

**P:** (Sings) ‘Always look on the bright side of life...’ Monty Python.

***C:*** *He’s very… you’re very…*

**Oh yes, I’ve heard that.**

***C:*** *I admire you, because you are very, very positive. You are very, very positive.*

**P:** Yes.

***C:*** *And you don’t let anything get you down. And you say to [patient], “How are you?” And he goes “I’m fine.” You’re not fine… (Laughs)*

**P:** Well.

***C:*** *“I’m fine.”*

**P:** In… on a lot of respects I do feel fine, you know? That’s…

***C:*** *Yes, I know you do. I know, it’s just your mobility, isn’t it?*

**P:** Yes.

***C:*** *It’s the mobility is the biggest thing.*

**P:** It’s the biggest thing.

***C:*** *You’ve got… you’ve not get headaches, you haven’t got pain… and that’s good, not to have pain, you know?* *And it’s, falling is the worst thing at the moment, I think.*

**P:** I didn’t get any kind of pain with these eye operations, they said “Take a few paracetamol, and if...” (Overtalk)

***C:*** *Maybe you don’t… maybe you’ve got a very low pain threshold or high pain threshold. High, isn’t it?*

**High, yeah.**

***C:*** *High, yeah. (Laughs) Maybe you do.*

**P:** And all those needles being stuck in me for the bloody…

***C:*** *Test.*

**P:** EMG.

***C:*** *Yes.* *That was amazing, and he was telling everybody.*

**Oh.**

***C:*** *But you are very positive, you tell everybody, don’t you, that you’re going to get better. You’re always saying you’re going to get better, aren’t you?*

**P:** Yes.

***C:*** *And you’re always looking at research.*

**P:** Yes.

***C:*** *To see what you can maybe… something will help. Is that somebody coming here?*

(Non-interview chatter)

**So it’s kind of focussing on like all the things you still can do and stuff like that? Keeps you positive...?**

**P:** Yes.

**Okay.**

**P:** Well... can’t actually do very much…If you see what I mean. Because...

**Yeah.**

***C:*** *You… you’re on the computer, you can do the computer, can’t you? You’ve got…*

**P:** Yes.

***C:*** *...that keeps you occupied, doesn’t it?*

**P:** Yes.

***C:*** *You do all the finances, don’t you?*

**P:** Because… which I’ve always done, so I’m…

***C:*** *Which you’ve always done, so that’s… at least you can do that, which is good. Because I can’t do that. I must learn. (Laughs)*

**P:** Yeah. And it’s coming up to tax year, tax form. (Overtalk) Got to do that, when I get one more bit of paper.

**Okay, so less about what you can or can’t do, and it’s more… at least I don’t have pain, or at least I don’t have** (No) **all these other things. (Overtalk)**

***C:*** *Because if you… if you had something else as well as this, it would be awful, wouldn’t it, if you had* (Yes), *if you had arthritis or something, very bad arthritis, or…*

**P:** Yes, exactly.

***C:*** *Very bad pain in your back or something that people have. Or if you were very overweight, you know, some people have, you know, problems with their knees and stuff like that. But you haven’t got any of that. You’re fit.*

**P:** I’m getting less fit if I’m not doing all these… (Overtalk) things.

***C:*** *I know.*

**So you try and stay active, wherever possible.**

**P:** Yes.

**Okay.**

***C:*** *Yeah. This is one of [patient’s] biggest fears of, about having a wheelchair, and…*

**P:** The problem is, if you… if you can’t… you can’t be sure about you’re not going to topple over, then you can’t really be particularly active.

***C:*** *No.*

**Yeah.**

**P:** That’s the thing.

***C:*** *Yeah. And you’re, it’s just… well it’s just saying, now, that when you… if you, when you get your, you are going to get a wheelchair, there’s no question about that.* *When you get your wheelchair, it’s that you are worried that it’s going to stop you walking. Well it’ll help you, it’ll help you walk. Because you’ll be able to hold onto it, and get up and sit down when you’re tired. I’ll use it. (Laughter) It is a good idea, to get across to the pub, I’ll sit in it. (Laughs) Yeah.*

**Yeah. Do you… do you have a similar stay positive kind of motto, or do you use… (Overtalk)**

***C:*** *I… no, I don’t have a motto, I listen to [patient’s] mottos. I… I’m a very practical person, because I’ve always been a hands-on (Overtalk)…*

**P:** I do make you laugh quite a lot.

***C:*** *Pardon?*

**P:** I do make her laugh quite a lot.

**Yeah. Okay.**

***C:*** *We do, we make each other laugh. Which is great, we… we have… you know, we still sit and talk and we do try and… try and cheer each other up. And but I do, I find… I am finding it very hard.*

**P:** Saw a very good… on the… monthly newsletter, about stage three… initially a stage three trial of a very promising drug in the US. But only in the US.

**Yeah.**

***C:*** *(Sniffs, sounding upset) Yeah.*

**P:** And then they might be… this is akin to…

***C:*** *It does take so long, doesn’t it? To come over here.*

**Yeah.**

**P:** ...this is to arrest the progress of MND.

***C:*** *Yes. God.*

**At least there is research happening. It’s… amazing.**

**P:** There’s so much happening, and it’s amazing.

**Yeah.**

***C:*** *Yeah. Yeah.*

**P:** That’s why you’ve got to try and take part in these trials. Because if… if it is something good…

**Yeah.**

**P:** Then… and you’re in it…

***C:*** *Yeah.*

**Yeah.**

**P:** Then of course you’ll probably stay in it. Which is really good.

**So you keep an eye out for research… (Overtalk) surveys and things like that.**

**P:** I generally don’t react very much to anything. So. I don’t have any allergies, other than bright sunlight, that’s not an allergy. (Laughter) But I will sneeze a couple of times if I go into bright sunlight. There’s the big crane again.

(Non-interview chatter)

**Yeah. I think I have asked you most of my questions. Was there anything about your experience that I haven’t covered, or that you’d like to talk about?**

***C:*** *I don’t know, it’s… it’s… I think the biggest thing about this is that it’s such an unknown. Because everybody is different and, who knows how much, you know, how long this… this, you know, this disease is going to affect you. We don’t know. Because everybody’s different, and that’s, that’s the uncertainty, for me, is very… it’s very hard to cope with, because you can’t make plans. You can’t plan. You can’t plan to go away. Because we don’t know how [patient’s] going to be. But if somebody had another… if you suddenly had Parkinson’s or something, as I said, yeah, oh, we’ll… it’ll be all right. We’ll go on holiday and whatever. But we can’t plan anything, and it just makes us feel very isolated a bit, doesn’t it?* *But we’ve… we’ve done a lot of travelling in our life, thank goodness.*

**P:** Yes.

**I think… (Overtalk)**

***C:*** *Yes, we’ve done… we’ve done a lot of…* (a bucket list). *Yeah, we have. And… and it’s been good. But that’s… that’s gone now from our life. It’s the sense of loss, isn’t it?*

**Yeah.**

***C:*** *This loss, what you’ve… what you’ve had, you haven’t got anymore.*

**Mm-hmm.**

***C:*** *That’s what I find. And it’s unexpected.*

**Yeah.**

***C:*** *Because we didn’t… oh, nobody expects the Spanish...*

**P:** Nobody expects the Spanish Inquisition.

***C:*** *...Spanish Inquisition, yeah. And nobody expects this to happen to them.*

**P:** Yeah.

***C:*** *It’s the last thing I would have thought of.*

**Yeah. And even once you have it, how it plays out is different for everyone, isn’t it?**

***C:*** *Yeah. And I think… I think [name of son] is quite angry, our son, he’s quite cross that this has happened to you. He’s a bit better now than he was, but he… he was very angry that this has happened to his dad. But he’s… he’s better now, he’s actually coming down and he’s helping us, isn’t he? He’s good, he’s a good kid.*

**P:** Yes.

***C:*** *Yeah. So there you are.*

**Okay. Do you… do you use the websites and online platforms to look for help, or…?**

**P:** Not for any help, I just… I just, I’m just very curious about the research that’s going on.

***C:*** *But the [charity organization]… you’ve been…*

**P:** I’ve joined them and these…

***C:*** *You’ve joined that.*

**P:** Yeah. And I’m trying not… trying to get register..

**Oh, yeah. Yeah.**

***C:*** *So that’s… that’s how, that’s what you… but no other platforms, is there no Facebook or anything like that? Is that what was it.. is that what you mean?*

**No, more like say if you’re having any concerns, say if you’re worried about falls or if you needed support, even as a family member, would you go online to search for this kind help or information?**

**P:** No.

***C:*** *No, I don’t think so. I don’t think so, no.*

**Okay. Okay.**

***C:*** *Yeah.*

**P:** I guess the wee- weekly newsletter pops up on my screen every day. And another thing comes in an email.

**Okay, it’s more for meeting people than…**

**P:** Yes, no, yes.

**...healthcare professionals that you get your information.**

**P:** See, I like to just be able to walk out, just to… just to be able to get up and walk normally. But, I’m walking like I’m robot, when I do walk. Because that’s how… I had to get some sort of coordination back.

**Yeah.**

**P:** Pain in the whatsit. Other than that, can’t… I’m just completely fit and healthy. So I… I don’t want **(yeah)** that to change. I also… I also thought, doing pilates would be very, very good anyway. Because I think if you build your strength in your muscles, there’s… there’s more that has to waste away, if you see what I mean?

**Yeah. Yeah.**

**P:** You’re giving your… (Stutters) a better chance.

**Yeah. Yes, from a prevention point of view. Yeah.**

**P:** Yeah.

**Okay. That’s… that’s your strategy as well.**

**P:** Yeah, exactly. So I think it’s a very good form of sort of exercise.

**Pilates.**

**P:** To… to fight this off. In fact there’s been a few sessions with my dear lady that I go to, where she’s said, “Oh look, that’s just another nerve kicked in.” You know, because I’ve been able to… suddenly I could somehow move where I wasn’t able to move a foot in a particular… because it’s just a particular movement, where you can do it one leg, you couldn’t do it in the other.

**Okay.**

**P:** And then… yeah, after several goes, yes. Able to do it. Because it’s just pinged in.

**So that’s the…**

**P:** So another pathway’s come in, sort of thing. That’s happened a couple of times.

**Oh, okay. Okay. Okay.**

**P:** So we’ll keep… have to keep…Having that happen.

**Okay.**

(Non-interview chatter)

**If… is there anything else you wanted to talk about, because I have finished my questions, but I’m happy to have a chat with you.**

***C:*** *No. I’ve… I’ve got nothing else, really. Have you got anything else to say?*

**P:** No. No, no.

**No? Should I stop the recording?**

***C:*** *Yes. (Laughs) Then we can talk normally.*

(END OF RECORDING)