**SMALLBIZ TRANSCRIPTS 01360 311155 and 07801 355 944.**

**Typed by typist A, checked over by typist B.**

**Interview 9**

**Okay, this interview nine. Thank you again for agreeing to be interviewed today. Just a couple of things, also, before we start. If at any point you want to have a sip of something, or use the bathroom, just let me know. We can** (Okay) **just stop and** (Yeah) **take breaks** (that’s fine)**. It’s easy to just turn that thing on and off.**

Okay, that’s… yeah.

**And also, if you feel like any questions are really difficult and you don’t want to answer them, just let me know, we can skip over them. There’s no obligation to answer everything. And also, whatever information you tell me will be confidential. So suppose you say a hospital name or a doctor’s name, all of that will be completely confidential. So you can feel as free (small laugh) as you want to tell me** (So, say what you like, okay, yeah) **things. Okay, so I guess… you did tell me a bit earlier before I started the recording but wherever you want to start, really, to tell me about your experience with MND and how it all started?**

(P): Well I was… (stutters) early ‘17 – 2017 – I was having difficulty breathing at night. And I was struggling with me breathing at night, and I found meself slowly going downhill. I was losing a bit of weight, and when I was at the doctors he kept weighing me and I was losing weight. And I was going downhill, and I thought ‘I’m not going to last very long here.’ When I rang up the… the… the consultant at the [hospital], the secretary gave me a… a… a what’s it? - an appointment, but I said, “that’s not going to be near enough,” I said, “I may not be here by that time.” So she gave me an earlier one. And then I was… she gave me the appointment. And also, I was having difficulty walking, wasn’t I [name of wife], I’d…

[C]: *Yeah.*

[P]: This was before I had the actual, before I went into hospital I weren’t able to, I was… having to use a stick to walk everywhere and things like that, I was finding life quite a struggle. Since I’ve been diagnosed, from the very offset it’s been a lot easier, simply because there’s people been around to help. And I was given a wheelchair. Which made it easier for me to get around. But because I was living in a flat, I was finding it more difficult to get up and down stairs. So I had that, and I also had…

[C]: *Oh, and in the end, he couldn’t get up and down stairs.*

(Overtalk)

[P]:...I could in December, I could get upstairs. [crosstalk] I had this breathing apparatus, the nippy, when I was in hospital, in July 2017…They gave me it for night time only, which was, made it a lot easier. But over the period of time, I’m having to use it all the time. And I don’t, it doesn’t inhibit me at all. Yeah, because I’m breathing normally. So without it I wouldn’t be able to breathe. And I’ve got a smaller mask now, as opposed to it being a facial mask.

**Oh, okay.**

[P]: So I’m able to eat and speak. Whereas with the other mask, you can’t speak, and you can’t eat.

[C]: *But he wears the other one at night.*

**So… okay. So you’ve to take that off and then…**

[P]: Oh yeah, I’ve got another mask that goes over. At night time. And… and I’ve a good night, I have a very good night. This one during the day, I use all the time. And I can eat, and drink through a straw and speak normally. First off, when I first had the mask, because I was only using it part-time, I was finding me breath wasn’t enough to speak, so I had weak speech, I wasn’t eating well enough, because I was having, I was gasping for breath. So they gave me a light writer, they put me on… what do you call it?

[C]: *Fortisip.*

[P]: Fortisips three times a day. Everything to build me up, to make… but since I’ve had this, I’m eating normally and everything’s okay.

[C]:*Goes out for lunch, as well.*

**Oh wow. (Laughs) That’s good.**

[P]: It has got its disadvantages sometimes, because airs comes out the same, I have to have tape around the mask to stop it going sore. But generally speaking…

[C]: *It’s brilliant, isn’t it?*

[P]: It’s very good.

[C]: *Yeah.*

**Okay. That’s good.**

[P]: The equipment is heavy, but we put it on the back of the wheelchair…*(hmm mm)* put it there, and it’s… everything’s okay.

[C]: *When [name of patient] went in for the first time, he- you had the… the what do you call it?... put in, didn’t you?*

[P]: That what, sorry [wife]?

[C]: *Your stomach.*

**Oh.**

[P]: Yeah, they put a tube in me (Overtalk) Because they could see that I wasn’t kind of… they thought I wasn’t going to… I was going to lose the muscles in the neck.

**Oh, okay.**

[P]: That would cause speech and… what’s it called? Eating, I wouldn’t be able to eat, I wouldn’t be able to speak. So within about two or three weeks of being diagnosed they had me back in hospital again, they put a tube in, so that they was expecting me not to be able to eat, and I’d have a… food put through a tube, Fortisip through… put through a tube. But I haven’t had to use it at the moment.

[C]: *I just put water through it, basically.* *Three times a day, and… and it’s just there if we ever really need it.*

**Okay, in case something…**

[P]: But it’s because they… they developed this small mask. A nasal mask. That’s why I’m able to do what I’m doing. If they hadn’t developed this and I’d kept the other one, I’d have had to have been fed through the tube, now. because I wouldn’t be able to take the mask off to eat, it would be too much for me. So through that development, I’m able to communicate, eat normally and put on weight… (Laughter)

**Yeah.**

[C]: *Tell me off. (Laughs)*

[P]: So the only downside now is what I fear, is weakness in the muscles. Yeah, that’s where I can’t do things. I need help because I can’t move my muscles.

**Okay.**

[P]: You know, so… and I’ve got an electric wheelchair. To be able to move around is…

[C]: *Yeah. I, I use it, and take it in there. (Laughs)*

**You use it?**

[P]: The quality of… The quality of life I have, because of this [points to mask], is very good. I can’t complain. Bit frustrating because I can’t do things, but…

[C]: *We manage, don’t we? (Overtalk)*

[P]: Yeah, we generally… (Overtalk)

[C]: *Yeah, we manage.*

**Okay.**

[P]: Yeah, we get on all right.

**What are the frustrating bits, or the bits you have… find most challenging?**

[P]: Sorry?

**What are the frustrating bits, or the things you find most challenging?**

[P]: These?

[C]: *No, no…*

**No, in general…**

[C]: *Frustrating.*

[P]: Oh yeah, yeah. (Laughter) (Overtalk) Sorry, I’ve got…[points to ears to indicate hearing difficulty]

**No, that’s fine. (Laughter)**

[P]: These are only cosmetic, I can’t hear a thing. (Laughter) No honestly, I can. No, because I can’t move my arms...if I… I can’t reach this, I can’t, you know, pick it up. I’ve got no weight in me… no strength in me arms to pick any weight up. This arm is no good at all, really. Although it moves up and down, but I can’t put any…

[C]: *When he’s trying to get it on the seat, he’s… (Overtalk) it’s sort of like dead weight…*

[P]: Can’t put any weight on it, I can’t lift it. (Overtalk)

[C]: *And I just pick it up and put it on the…*

[P]:Because the shoulder’s weak, see? I mean, my hands… have lost a lot of their strength, I’m finding it very difficult. Especially when the fingers are cold, to put this on. This is only clip on.

[C]: *Magnet.*

[P]: Well a magnet, but I find it difficult sometimes. My writing’s not very good, and generally speaking, the muscle power, and the muscle strength in the… in the upper limbs are very weak. So…

[C]: *And it is sort of like all over, you muscle strength is going all over.*

[P]: Yeah, the legs are… the legs are good, to a degree. I’m able to move the legs. Stand on them.

[C]: *Yeah. You do find it an effort to go to toilet, don’t you?*

[P]: It’s standing up, yeah, because…

[C]: *Yeah.* *And it’s all muscles, isn’t it?*

**Yeah.**

[P]: Everything at the top end. I’m able to get in and out of the car, because we’ve got a… a swivel seat. (Overtalk) But because there’s no strength in me back…

[C]: *...can I just explain, we’ve had a swivel seat put in. We’ve had a swivel seat…*

**Into the car?**

*...put into the car.* *So that I can pull the swivel seat out, he gets out of the wheelchair, with the aid of a handle on there, and then he sits in the seat, and I just push him round.*

**Okay.**

[C]: *But he was finding it difficult to get in and out of the seat.*

[P]:Yeah, and there’s no strength in me back to support me do anything like that, I mean… and I’m holding onto this… and that’s what I’m finding, that perhaps me leg muscles could, are getting weaker, because I can’t put too much pressure on these, now. You know, there’s no strength, if I’m having to get out of a seat, if I’m like in this seat, I find it very difficult to get out of that seat. Too low down. But that’s how it is, but I’m okay. Washing, I could wash meself but it’s a struggle. Cleaning me teeth is all right, but I can’t… can’t get up on the shelf, it’s got to be down in this…

[C]: *I have to put it down for him.* *(Overtalk) And it’s like, he’s finding shaving different now. I do the sides, and he just does this little bit.*

[P]: One little point, if I may say? Is disabled toilets. They have disabled toilets, but the… the dryer is, when you’re in a wheelchair, for me, is too high up. It maybe be okay when I’m standing up and it’s all right.

*[C]: Yeah, when you… (Overtalk)*

[P]: But when you’re in a wheelchair, you can’t lift your hands up. The best disabled toilet I’ve been into… (Laughter) is… is a… a new one, and they got it just by [name of hospital], so yeah, garden centre there. And they’ve got everything within reach when you’re…

[C]: *And you went out and told them… (Laughter)*

**Did you tell them?**

[P]: Well… yeah, when… when you’re in a wheelchair, because you can’t lift your arms out, you want that…What’s the point of having a dryer out there, you can’t dry your hands? So these are… are the little things that you look out for as well. Of course, I suppose, generally, really we… because me arms get weak, I can’t reach up anyhow. Yeah. I’m finding it difficult to read a magazine. To open it, pull it apart. So I’ve mainly got a Kindle and a tablet. (Overtalk) And they’re the ones that I… I use.

[C]: *And one of these.*

**Oh.**

[P]: That’s a Kindle, that’s reading books on it. (Overtalk) The tablet is all right, the doctor said “Split that in four, and put it in water, to dissolve the tablet.” (Laughter) And you can take it easier. (Laughter) But they’re… they’re very useful, these tablets and Kindles. They’re very useful, because books and that are too heavy.

**Yeah. Yeah.**

[P]: That’s the things that frustrate me. And getting in and out of bed. Once I’m in bed, lovely in bed. Because you ain’t got to move anything, see? Just lay on me back, like that…

[C]: *He’s like… he lays like this, because he’s got Berrett’s oesophagus*

[P]: Well it’s, that’s nothing to do with it.

[C]: *No, but… I’m just saying… (Overtalk) You… you did start laying like that…*

[P]: No, I can’t lay breathing down. No I can’t breathe laying down. (Laughter)

**Yeah. I understood what you were trying to say. (Laughter)**

[P]: I can’t lay down. Flat.

[C]: *Can’t breathe. No.*

[P]: And so I’m laying like that, upright. Me feet up on this little thing, it’s… I’m comfortable.

[C]: *Odstock Wedge, have you heard of one?*

[P]: The wedge.

**To lift your legs up? Yeah.**

[C]: *Yeah, to lift the legs up like that. Yeah.*

[P]: So I’m comfortable in bed. You know, really nice. So I’ve got no complaints.

[C]: *He doesn’t… what he doesn’t want to do, he doesn’t want to go to bed, and he don’t want to get up, so…*

[P]: No (Laughter), because…

[C]: *Yeah. So he’s okay when he’s in here.*

[P]: Going to bed is… the first thing, is going to have a wash and disturbing yourself, you’ve got to get out of it, it’s all using muscle. Which if you haven’t got, it’s very tiring. By the time you get in bed, you’re exhausted. But once you’re in bed, you just lay there and say “It’s lovely.” But then you know you’ve got to get out of it again, I don’t want to get out of bed. (Laughter) But if you don’t get out of bed, you don’t get to meet people like yourself.

**Yeah. Aw. (Laughter) But it can be quite an effort.**

[P]: It is. It is annoying. It’s very taxing, and you get… sort of like… not lethargic, it’s… you know, it just drains you, it makes you very tired.

**Mm.**

[P]: But other than that, you know, life’s good.

[C]: *Great in the days, he’s fine throughout the day.*

[P]: Life’s good, in’t it? You know, so… can’t complain.

**(Laughs) And [name of wife], how… or what has your experience been like as…**

[C]: *I’m worked off me feet. (Laughs) No.*

**Tell me… no, tell me…**

[P]: Very good… very, very good carer I would say. (Laughter)

[C]: *What it was… you’re actually bombarded with a load of things when you first find out that you’ve got it. It was overwhelming to start off with. But I sort of as time goes on, you sort of like get used to a routine. And it’s just like a routine now, that you get into like when you have children. You’ve got to get them to school and what have you, and… and it’s like that. It’s like a routine. You have to get up in the night for children, I have to get up in the night sometimes for him.* (Patient makes noise in background) *He’s just a big child, really. (Laughter)*

[P]: I *(laughing) ?* that sort of talk, [name of wife]. (Laughter)

**It’s all recorded, too.**

[C]: *Yeah. (Laughter) But yeah, it… some… it must be absolutely horrific for some people that cannot cope with everything that comes into it, all these numbers and everything else, I had to write everything down and… but, you know, as time’s gone on, we get… we’ve got a good routine going, haven’t we?*

[P]: Yeah, and I think that the… the most difficult part, or two difficult bits, for a carer, especially it’s you’re wife, they… we’re both in our seventies. Fortunately [wife’s] a… quite strong, really. But some wives aren’t very good, they’ve got their own problems as well. And the… dealing with the tube.

[C]: *Yeah, because you’ve got to change it, and I’ve changed it today, every Monday I… I change the water and the bubble in the back, you see?* *So you’ve got to do that, and you’ve got to… the first time I read, I had the thing in front of me and I was reading it as I was going along, because I thought, ‘well, I don’t want it to come out...’ Yeah, and so… and yeah. So, yeah, get on with it all right, you know. (Overtalk) Absolutely.*

[P]: Yeah, you do very well with that.

[C]: *And…*

[P]: But also… (Overtalk) Sorry, go on.

[C]: *Oh no, go, go on.*

[P]: I was going to say that [wife’s] able to get me out of bed. She’s not… I don’t, I get meself out of bed, really, but… (Overtalk) What she does, she supports me.

[C]: *I just put my arm low down on his back. And get my arm under there like that, and just pull him up. (Overtalk) I put my knees up against the bed, so I can…*

[P]: I move me legs over. And gets out. But some people – wives especially – aren’t able to do that. So they have to have extra support. But [wife’s] very good, and there’s, she don’t complain about nothing. (Laughter) Absolutely wonderful, really, because no matter what it is… (Overtalk)

[C]: *And sometimes I have to wipe him after he’s been to toilet. (Overtalk) And it’s not a problem for me.*

[P]: She does everything.

[C]: *Some, other people may find it a problem, it’s not a problem.*

[P]: She does everything… (stutters) Whatever it is, you know. Because I just sit here in this chair, reading a Kindle.

[C]: *He’s just like a mess? (Laughter)*

[P]: You know, and I think my life’s good, but… she’s running around doing everything for me, and I’m very fortunate. So she gives me a very good quality of life. So really I can’t complain about too much.

**Good. But not… not that it’s complaining, but there, there must be some bits also that are quite challenging or difficult, in your experience, as well, to do…**

[C]: *Only to start off with. Only to start off with. Pushing the wheelchair was hard, to start off with. Because I, we only had this one. And it did hurt me arms. But yeah, now he’s got the… the electric one, I only push him when we go in the car, because we haven’t got one that can put the… the wheelchair in the car, we haven’t got that, the electric wheelchair, we’ve just got one… I’ve just got one all the time.*

**Yep.**

[C]: *A small one, in the back, in the boot. But when we go out it’s… it’s okay now, because I don’t have to push him everywhere. Before it was pushing him everywhere.* *But no, he’s… he’s motivate- motivated now, aren’t you?*

[P]: Yeah. We don’t go the places that we used to go.

[C]: *Not so much, no.*

[P]: No, because I don’t find it very comfortable in a car, really, now. Because you… once you’re sat there and you can’t move around. You know, you… you’re sort of sat there, because I think I need strength, really, to move meself around. And… and then also the battery. That lasts about six to eight hours, but you’re… so therefore you don’t go long, too long a distance (Overtalk) nowadays.

[C]: *We go to garden centres and…*

[P]: Have… have meals and things like that (overtalk).

[C]: *Yeah, go out for meals. Yeah.*

[P]: We do a lot of things that we have always done. But some things you have to sort of curtail, really, you can’t do everything. Eating is easy, but it’s tiring, because [wife] has to cut it up, and I eat with a fork and a spoon so… (Overtalk)

[C]: *Fork or a spoon.*

[P]: So I don’t eat with this hand, either got a fork or a spoon in this hand, I eat like that. And sometimes it can be quite tiring. But I’ll eat everything on the plate, and I’ll think, ‘oh, good, fantastic.’

**It’s all gone, yeah.**

[P]: And but I do eat what’s in front of me. But I’m not able to sort of cut it up or anything.

[C]: *He can’t cut it, not now.*

[P]: But I’m virtually right down on the plate…

[C]: *This is what I’m saying, it… a lot of it sort of like comes on gradually.*

**Yeah.**

[C]: *Because first of all, he could cut his meals up. He was able to use that left and his right arm.* *And so it comes on gradually, so you think, ‘oh well, I’m going to have to do that now for him.’ And it’s just one thing at a time. You know, because as, first of all he was able to go to the toilet on his own and everything. But it’s just, gradually sort of like he can’t do these things, so I do it.*

**Yeah. It just keeps changing almost…**

[C]: *Yeah. Yeah.*

[P]: Yeah, that… that’s about right, it does…

[C]: *Changes sort of like…*

[P]: Yeah, you wake up and you think, ‘I wonder what I can’t do today.’ (Laughter) No, but it’s little things like, you know, like I say… this finger, for instance, putting on a glove, wants to keep out the way.

[C]: *It keeps on going… (Laughing) up in the glove like that.*

[P]: You know, it… and they… they all… (stutters) I can’t hold these fingers up, they shake all over the place… (Overtalk)

[C]: *But his fingers keep hanging like… he said, “Oh, it’s all right,” and…But it’s only like a child. Child does that. I said “Spread your fingers out, if you can.” (Laughs)*

[P]: You know, so it’s… it’s those little things that go. But… we’ve seen other people at, with MND at… we go to a coffee morning at [name of hospice] And some of them have got… well a couple there, one’s got very bad fingers, he can’t do anything with his fingers.

[C]: *Yeah, it’s just like that.*

[P]: And he’s got, similar to me, he doesn’t need a mask all the time. But he needs it a lot of the time. And yet the other guy, he can’t move his legs and he… so… but he can breathe.

**Okay. It’s different.**

[P]: So he’s got different areas that he’s struggling with. You know, so he’s able to breathe without any worries at all.

[C]: *And he can’t eat on his own, [name of patient]. He can’t eat on his own.*

[P]: No, he can’t eat…

[C]: *[wife] was feeding him, I noticed that.*

[P]: No, so me personally, between the three of us is, I’m the only one who can eat normally. You know, because I can… I don’t struggle too much, so I… I eat quite big meals, whereas the others eat…

[C]: *And drink through the straw.*

[P]: They struggle a little bit. But there you are, that’s the way it is. They… the respiratory people have said they don’t like the idea of me eating and breathing with one of these in. I said, “well, if I should choke,” I said, “I won’t come back to you and say that you told me not to.” (Laughter) I said “I’ll leave you alone, you out of it.” But it’s easy to do, because you don’t… you don’t choke. You don’t, when I’m drinking now, you don’t have to wait for the right time, you just eat and just breathe normally.

**Like normally.**

[P]: Yeah. So at the moment I haven’t been choking, although I do cough… and that’s the annoying part, not… you know, you get a little bit of a tickle down there if you’re eating sort of like sweeties stuff. And… or any cough, any sort of cough. Once I start coughing, I want to blow me nose. So you’ve got to take off all this stuff [breathing apparatus] Blow your nose. And I have a good blow, and me fingers aren’t very good at blowing it. So it’s, that’s the annoying part, you know, you… or the machine may make you sneeze. Going through, back and forth, all of a sudden you’ve got to sneeze.

**[C]:** *(Mimics him sneezing) That’s all it is. (Overtalk) He doesn’t sneeze properly, it’s just a… (Mimics)*

**Oh. (Laughter)**

[P]: I can’t sneeze. I can’t sneeze. Course that makes you…

**Does all this bother you?**

[P[: Pardon?

**Does all of these little things, do they like bother you, how you feel about things, or…?**

[P]: Anything bothering me?

[C]: *(Overtalk) Yeah, does it bother you?*

**Does it bother you?**

[C]: *Does it bother you to not be able to sneeze properly, and…?*

[P]: It doesn’t bother me. What bothers me is sneezing, because I have to blow me nose. (Laughter) You either take off me glasses, take off the mask, or I just lifts it up, blows me nose, puts it back on again, puts me glasses back on again…

[C]: *I can’t say that anything…*

[P]: Then I’ll find that me nose is starting to run again. (Laughter)

[C]: *I can’t say that anything fazes you, really.*

[P]: Pardon?

[C]: *You’re not really… even when you bump into the wall, you’re not bothered. (Laughs) Nothing fazes him, really.*

[P]: Well… it is just a bit frustrating. You get frustrated. I don’t get depressed, but I get frustrated. Because you want to do it, but you can’t do it, it’s a lot of effort to do it. Like I say, I’ve got to take… it’s nothing to take this mask off. But then you know that you can’t breathe very well. You know, so that’s another problem, so… it’s frustrating more than depressing. I’m fortunate that I’ve got a… a… a what do you call it? Oh, what’s that word… a… a cheerful disposition.

**Yeah.**

[P]: I’ve always had that, and I’ve been fortunate. So when I see people or I’m speaking, we’re speaking together, generally happy. When I speak to people at other places anywhere, I don’t complain about meself, because I want to know what they’re doing. So I like people, I like to hear people, and I (mumble)?? cheerful. Some people aren’t perhaps as cheerful as that. My brother goes, because he’s a person who’s got a stroke, or has had a stroke, and he’s a little bit of a complainer. He’s one of those sort of people. And that’s depressing for the person who’s going to visit, and they don’t want to visit too much. So… but generally (stutters) I’ve got a cheerful disposition, I’m fortunate.

**Yeah.**

[P]: So really I ain’t got any complaints about it. And there’s a lot of people who have got, who’s got a problem and they’ve got pain. Got no pain. And nothing’s worse than pain. Got it day and night, and you can’t get rid of it, now that must be awful. But I ain’t got that. So...

[C]: *I’ve got pain. (Laughter)*

[P]: No. So. If I was going, you know, if I… and people say, “Well what… what disease would you like me to catch,” I say “Well try to get one of these, because you don’t get any pain with it.” (Laughter) Don’t get one with pain in it.

**Okay. (Laughter)**

[P]: If you’ve got to move around and you’ve got to take one.

[C]: *Yeah. (Laughs)*

[P]: You know.

**So that’s how you cope with things?**

[C]: *Yeah.*

[P]: Yeah, so and you know, it’s… it’s just not… it’s a… it’s a bit of a nuisance one. But they’ve, over the years, they haven’t got a cure but they… they make things easier. Develop things. And like this little nippy I mean it’s a brilliant little thing, really is.

[C]: *You wouldn’t be here if it weren’t for that.*

[P]: Oh yeah, I wouldn’t. I wouldn’t. You’d take it off and I’d hardly get anywhere. Brilliant. And with that, you see, I’m all right. It’s a fuss to put on and all but it’s not painful. I can’t put me coat on or anything like that… well [wife] puts me coat on. So there you are, you see.

**Thank you. Yeah, that’s… that’s a good… (Overtalk)**

[P]: I think some people do find a bit of pain with theirs.

**Yeah.**

[C]: *I don’t know if they do, no-one’s said so, have they? (Overtalk)*

[P]: Well I think that [name of another patient] got a bit of pain with… with some of his, and certainly [name of still another patient] got some in his feet.

[C]: *Oh has he?*

[P]: So I’m fortunate, I ain’t got any pain. So you know, I can put up with the rest of it, it’s… you know, a friend of my friend’s been, has been diagnosed with (*asbest-*) asbestosis.

**Oh, okay.**

[P]: You know, so he’s only got a year to go, he said. Well…I don’t know, he gets on without hair, he’ll get through that. But… but that’s just the way life is, in’t it? You know, you never know what’s around the corner, so…

**Yeah.**

[P]: But…

*[C]: You see [name of patient] in that photograph over there, he thought at the time of this photograph, they even gave him my… my daughter, give him a party, right? Because they didn’t think he was going to reach his 70th birthday.*

[P]: I didn’t think I was going to make 70.

*[C]: He was… he felt so…And losing so much weight and everything.*

[P]: You know, but that’s when I didn’t need the mask all the time. But then I didn’t think I’d make the… the Christmas. Then we ca- we’ve been here a year now, we came here in January last year, and I thought ‘I’ll never make… I’ll never make the end of the year.’ Well I’ll never make the 71st. The 71st. Then I made the year, get into another year. You know, I think, well, if I have to end up in Christmas time, I probably won’t be able to move much.

*[C]: Yeah. (Laughs) Yeah.*

[P]: I’ll still be breathing, they think that I won’t be able to move much. But there you are. And so, you know, it’s… you just take it as it comes along, don’t you? You know, so…

**And I’ll give you a little break if you want to take a sip of something, I can ask [name of wife] questions.**

[C]: *No, no, he’s fine.*

[P]: Yeah, go on.

**But some people also say for being a family member when you’re looking after someone, it can be quite emotionally challenging as well. I wonder if… (Overtalk)**

*[C]: Only at the very beginning, when… at the very beginning, yeah, I did break down and I actually cried with a friend. But it was because you’ve got so much to take in. You’ve got so much to think about. But after that, no, I… I don’t get emotional. Got over it. And yet I am quite an emotional person. But I don’t get emotional over that. We’ve done our funerals and everything. So no, I mean, I know he’s got to go but we are religious people.And we believe that… that he’s going somewhere better. And… and I shall just get on with it. I’ve got a load of friends, within the church and that.* *Family. Just get on with it.*

**And when you say it was a lot… a lot of things to take in, what… what was the difficult bit? Was it more to see how much time he’s got left, or…?**

[C]: *No. No. Not that. It was having to sort everything out for him. He’s not able to do this, he’s not able to do that*

**Ah okay, okay.**

[C]: *He’s… you know, you’ve got to put the water in so many times a day, you’ve got to change the tube, and…And… but the rest of the stuff, like having to wear a… a mask and that, I will keep it clean and that, you know. It’s gradually come on. But… (Stutters) you’re given a whole list of numbers and everything, when you’ve… I’ve got a… a box in there, that I keep with all the MND stuff in.* *And you’ve to give him so many, you know, I’ve had people phoning me up, “Oh have you got an OT?” I didn’t even know what an OT was.*

**Yeah, it’s a lot, isn’t it?**

[C]: *Didn’t know that.* *And I said, “I think I’ve got OTs coming out of me ears,” that’s exactly what I said to her.* *And but I didn’t even know what it was. And they are very helpful. Very helpful. We have quite a few people coming down to see us from different places, don’t we [name of patient]? And they’re all very… like [name of trust] and [hospice] and [charity organization], and… we just have people come in.*

[P]: And the lady from… a nurse from [hospice], and she…

[C]: *Yeah, I said [hospice], yeah. Yeah.*

[P]: Yeah, sorry.

[C]: *And then we go to the coffee morning, MND coffee morning, like [patient] said. So we are seeing people with the same thing, which in a way helps, because you can help them as well.*

**Yeah.**

[C]: *And we see like people in the church and that. They’ve got their own problems. There’s quite a few people in the church at the moment that’s got their own problems.* *And so you can help with… with that as well. And when they see [patient], they think ‘golly… mine’s not as bad as that.’ And so it’s a boost, isn’t it? They see, well he’s always cheerful. Yeah.*

[P]: It helps you, not too much information, [wife]. (Laughter)

[C]: *Yeah.*

**So it was just the initial bit that… that was… (Overtalk)**

*[C]: It’s the initial… yeah.* *It was really frustrating when we couldn’t get out of the flat.*

**Couldn’t get out of the flat, okay.**

*[C]: Mm. And waiting for this bungalow.*

**Oh, okay, okay.**

[C]: *We… we had a look at, what, about three… three bungalows? And of course the OT said “They’re no good, you can’t get a wheelchair in there.” So… when were we ever going to get one.*

[P]: Which is very useful, because we… we go down the little chapel down the bottom here.

[C]: *The little chapel then, bottom of… you’ll pass it, when you go down the road.*

**Okay.**

[P]: Did you see it, when you…(overtalk)?

[C]: *No, she didn’t, she wouldn’t have noticed it, no.*

[P]: You may not have noticed it. I mean, we park our car there, no parking facilities up here see. And then we’ll take care… electric wheelchair, stay there, leave it in the chapel, get in the car, go away, come back, pick up the… it’s so convenient.

[C]: *Yeah.*

[P]: Everything’s good, in’t it, [name of wife]?

[C]: *Because I’ve got a key, as well, you know, it’s so easy just to put the… put it in there.* *Oh we’re down there quite a few other times as well, I mean, we’re down there on a Wednesday morning. [patient’s] down there on a Thursday morning. I take him down and pick him up. Because he meets the other guys.* *Yeah, yeah. He goes to Saturday morning breakfast sometimes.*

[P]: Friday. Friday, [wife].

[C]: *Oh Friday, we’re in Friday afternoon, we’re down there, we do a… a coffee, cake, and.. afternoon.*

**Oh nice.**

[C]: *Been doing that for about twelve years, I think we have.*

[P]: How many?

[C]: *Twelve.*

[P]: Yeah, got to be that.

[C]: *It’s got to be that, if not more. And so we do get out. We go down for Sunday lunch, after church.*

**Oh nice.**

[C]: *Sunday lunch down at the pub. (Laughs) And so, you know, we’ve got a lot of friends in there, haven’t we [patient]?*

[P]: Yeah. It’s a lot easier here than what it is at [name of place].

[C]: *I just feel sorry for those people that haven’t got church that they can rely on people in it.*

**Mm. So community is quite strong…?**

[C]: *Oh absolutely. Yeah. And we’ve got good neighbours either side. Yeah.*

[P]: Yeah, from the wheelchair point of view, it’s not hilly, it’s all flat.

[C]: *No it’s not, it’s all flat around here.*

**Is it, here?**

[P]: Yeah. (Overtalk) Whereas at [name of place], where we were, could be hilly, and it’d be busy and the pavements weren’t very good. Here it’s okay, it’s quieter.

[C]: *Yeah.*

**Okay.**

[P]: So, you know, generally speaking it’s good, in’t it?

[C]: *Yeah. Yeah. And you can’t hear the traffic, whereas we could before.*

[P]: And I’m able to use the wheelchair around the… around the rooms. One of the friends that we see at MND, he’s in his own… this is council property.

**Oh, okay.**

[P]: He’s got his own bungalow, and he’s finding he can’t get his electric wheelchair in the hallway, to go round the rooms, because it’s too small. Which is what we found with some of the bungalows…

[C]: *That we were shown.*

[P]: Because they’re too narrow.

**Ah, okay.**

[P]: So he has go round on a four wheeler push along. He’s got to the stage, now, that his wife wheels him along, because he can’t use the legs to push himself along. So he’s got a bit more of… whereas I’m happy and I’ve got me wheelchair, I can come in here, sit in it. Go out... go out to the bathroom, go anywhere. So, you know, everything’s good.

**Yeah.**

[C]: *But we’re gradually getting little things, like we got that table for him, because that’s much easier to eat off of.*

**Oh okay, yeah.**

[C]: *Yeah?*

**Yeah.**

[C]: *Much handy- much handier for you, in’t it [patient]?*

[P]: Yeah.

**It’s little things like that that help.**

[C]: *Just little things, yeah. Just little things.*

[P]: Yeah, it’s good, in’t it. This was… given me by the… well… well, it was loaned at one time by the MND, I only had it… I only had MND, I was only diagnosed for about four weeks, but they came out with one of these chairs.

[C]: *One of those, yeah.*

[P]: It’s me climbing chair, it helps me get up. But this is second hand and that, and it was… I should have had to return it. Because I no longer need it. But now they don’t do it, it’s mine to keep.

[C]: *Yeah.*

**Oh. Nice.**

[C]: *So I told him, you’d better look after it. (Overtalk)*

[P]: To have it. *(Laughter)*

**And…**

[P]: So there you go, so that’s… that… which is, these are very useful. So I, you know, I can’t complain about that.

**And besides like all these people and things that help you, are there… because you mentioned like you’re… you have a cheery disposition, and that kind of thing. How… how does that help? Or how did you also… (Overtalk)**

[P]: Oh, it helps a lot. It helps a lot. There are times when I… if I’m on me own and I think, ‘oh goodness me.’ Not depressed, but frustrated. (Overtalk)

[C]: *But not on your own, if I’m maybe out in the kitchen. Is that what you mean?*

[P]: Yeah, that’s it, I… If I’m trying to get something, ‘oh, dear, oh dear, oh dear...’

[C]: *Yeah, he tries on his own, without shouting me. (Overtalk)*

[P]: Oh dear, trying to reach something, trying to do something.

[C]: *(Overtalk) If I’m there, he doesn’t usually…*

[P]: Can’t do anything. But I’m fortunate that I don’t take… when I see people, they cheer me up, or they… I like people. And so therefore I, I can be… (Stutters) well in fact, ourselves, we… we use a lot of… we’re cheerful with one another. But it can be frustrating, and if you ever… if you’re easily depressed, it can bring you down. Because you think, ‘oh, I can’t do this. Woe is me, woe is me...’ (Laughter) You can complain about everything. Because that’s how it is, you can’t do nothing. But fortunately, I’m not like that, so…

[C]: *Only when he thinks he’s on his own. And he goes, ‘oh dearie, dearie, dearie...’ (Laughs)*

[P]: I do feel cheerful. So people, family and friends like to visit. And so that’s okay. And family especially, have become closer, haven’t they Jackie?

[C]: *Yeah, they are, yeah.*

**Yeah.**

[P]: They’re more closer now than what they ever been. Because you know, it… it’s just like that, people seem to muster around. So, you know, I’ve got nothing to complain about. In my life, sometimes… I get tired. You know, when there’s people here they want to do a lot of talking, and I’m thinking to myself, ‘I don’t want to talk to them.’ (Laughter)

[C]: *Oh no, I don’t think he’s including you. (Laughter)*

[P]: I can get tired of people coming to visit, asking me a load of questions. (Laughter)

[C]: *No.. (Overtalk) ...parties and that. We’ve been to parties, haven’t we, [name of patient]?*

[P]: Pardon?

[C]: *We’ve been to parties, haven’t we?*

[P]: Parties? Yeah. Parties.

[C]: *Yeah. Parties. If the chair can get in the place, it’s fine. If we can’t get in there, it’s rubbish.*

[P]: You know, so.

[C]: *But yeah, he’s… was it, the last party, he had a young twenty two year old sat next to him talking to him, so I’m sure he was happy.*

[P]: What party was that?

[C]: *That was what’s her name? Oh… [name of person’s] grandchildren. [name of person’s] grandchildren. What’s her name? [name] and…? [name].*

[P]: Oh, [name] and [name].

[C]: *[name] was talking to him.*

[P]: Oh yeah, well they’re family.

[C]: *Yeah. (Laughs)*

[P]: You know, and they’re very… everybody’s very nice, because…If you’re cheerful, they don’t mind speaking to you.

**Yeah.**

[C]: *If you’re grumpy, they don’t want to.*

[P]: If you’re grumpy, sharp, miserable, cantankerous, if you’ve got any friends, so you’ve got to be very careful. Fortunately I’m not lot like that. Hopefully. So people like to have a chat.

**And you like chatting to people, too.**

[P]: Yeah, and I like to talk to people, and I don’t talk about meself, I ask them what’s, about how they feel and things like that. So…See, everything seems to be okay with that.

**That’s good.**

[P]: But if you’re a cantankerous person who’s always shouting, grumpy, and then nobody wants to visit really. Because it’s not good for [name of wife], because we’d have no visitors here.

[C]: *(Laughs) Yeah.*

[P]: ‘I’m not going round there and being, for him to keep moaning all the time.’

**And [name of wife], do you use a similar way to cope with your own issues and things?** (oh yeah, yeah) **Yeah?**

[C]: *Absolutely. I mean, sometimes we’re laughing and joking and, and he’s sort of like coming back at me, and I say “If you’re not...” This is when people are around as well, “If you’re not, don’t behave yourself, I’ll cut your air supply off.” (Laughs)*

[P]: Yeah, no, I… this is one of the things is, see the controls there? [name of wife] goes out, leaves the control. Sometimes, it’s all right, because I don’t worry too much about it. TV’s on, and it’ll stop, because you’ve got it on it… we tape a lot of our programmes.

**Mm-hmm.**

[P]: It’s stopped, and the what’s it’s? - on, the… the mute’s on. So I thought, ‘oh goodness, this is...’ So she left them on the side, there, so I try to get over and get them, and I slipped and I fell against there…eventually got myself sat up, got into the chairs, and I said “You’ve got a verbal warning for that.”

[C]: *(Laughs) Yeah.*

[P]: She said…

[C]: *He’s told everybody about it…*

[P]: Next time, it’s going to be a written warning, and if it happens a third time, she’ll cut the life support to me. Wouldn’t really, but some people…

**No, but yeah.**

[C]: *Makes them laugh.*

[P]: It’s my fault, I can understand.

[C]: *I told him off. I told him off, I did tell him off. Because he shouldn’t have done it.*

[P]: Because… yeah. She does care for me. And I… I’m not caring for meself when I go over there, (Overtalk) to end up on the floor.

**Yeah.**

[C]: *I mean he could’ve… could’ve shouted me.*

[P]: I thought, ‘I’m going to get told off for this, oh yeah.’ (Laughter) You know, so.

[C]: *He’s struggling away.*

**Em… I think I’ve finished most of my questions, but because everyone’s experience is quite different, is there anything I’ve missed out that you want to talk about or share? Anything’s… just about your… what was difficult, or how you coped, or… things like that? (Overtalk)**

[P]: No, not really, because it’s very… it’s very hard to say how people cope. How they don’t cope. They just… adapt theirselves to whatever… daily thing. And then you just… you’d still do things, but in a different way. You can’t do it so quick. Can’t do it so easy. And those things that you can’t do at all, that you have to ask help for. And that’s the thing that I, perhaps I found it a bit difficult at first.

[C]: *Most frustrating for you, wasn’t it, yeah? Yeah.*

[P]: Yeah, because I’m an independent person who likes to do it meself. You don’t like to ask people to help me. But when you have got to have help, then you just… people will rally round and help. Surprising, I’m really amazed at how good [wife’s] been, really. Really is. Because without her, I wouldn’t be able to do anything. And she don’t complain, and that makes a big difference. Because she’s cheerful, and therefore you don’t mind asking. She’s not one of these people who sits out in the… in the kitchen, out the way, I’m ringing the bell, no-one’s answering it. (Laughter) But whatever I ask for, she comes in straight away and does.

**Yeah.**

[P]: So I try to do some things myself, rather than keep on burdening her. Because…

[C]: *And he makes a mess of it. (Laughs)*

[P]: Thing is... she’s got her own things, and it can be very wearing if you’re looking out for somebody else and trying to do your work as well. So I try to do some things meself, best I can. And I can be, I have got a bit of a… a habit… not a habit, no… it’s not, I don’t know what to call it, when [wife] comes in and she sits herself down, I said “Before you sit down, can you get this now.”

[C]: *I said “I’ve already sat down.”*

[P]: I should’ve asked her… I should’ve asked her before. (Laughter) Because I don’t really want to ask her now, because she’s sat down, but I want it.

**She’s sat down, yeah.**

[P]: And I forget to ask for it. It’s one of those things that you forget, don’t you, when you…

**Yeah. You do.**

[P]: When a person comes in, I must ask [wife] to get so and so.

[C]: *He says, “I’m not… well don’t worry now, don’t worry now.”*

[P]: Yeah. Don’t worry about it now, it’s all right.

[C]: *Yeah, don’t worry about it, now. So I get up and do it.*

**(Laughs) Yeah.**

[P]: But I, you know, I’m trying to help her out by doing as much as I can meself. But I am limited. But she’s an excellent carer, and that makes a big difference. If you’ve got a very good carer (Laughter) You can feel better. You’ve got a good quality of life, and you feel good yourself. That makes a difference, if you’ve got… I have a carer, so who’s complaining? Their life can be quite difficult. And you feel a bit low, perhaps, but I don’t. So the pair of us, quite happy together.

[C]: *Yeah.*

(Sings) We’re happy together… (Laughter)

**You’ve broken into song, now.**

[C]: *Yeah. I’m always singing. So’s he. But it’s usually (Sings) ‘Oh...’ Oh what is it, what’s it? Do you…*

[P]: Oh, it’s…

[C]: *‘Oh golly gosh, my golly. Mistletoe and holly.’ (Laughs)*

[P]: I remember when I went round to have this tube put in, they put a wire up your nose. And it goes down into your stomach, they take you along to the… to the x-ray place. They find this wire, and they know where the stomach is. Put the hole in. When they put this wire in, I was struggling with it up in the ward. And I don’t, thy never did get the wire down in me stomach, because it ended up in me lungs (Mumbles) But I was in a distressed state. I couldn’t breathe very well and I, and I started singing ‘oh my gosh, my golly, mistletoe...’ She said “What are you doing?” I said “I’m singing.” (Laughter)

[C]: *The nurse says “What are you doing?”*

[P]: I was singing ‘oh my gosh, my golly, mistletoe and blinking holly.’ (Laughter) I make a song and dance out of anything. Yeah.

[C]: *That was a bit worrying, when it went into the lung. (Overtalk)*

**Yeah*.***

[P]: They must’ve thought… they must’ve thought there’s something wrong with him

[C]: *Yeah.*

**I’m sure they enjoyed it. (Laughter)**

[P]: Yeah. Yeah.

**Yeah, so if there’s anything more to add, or we can stop the recording.**

[P]: No, I think you can… (Overtalk)

**Yeah? We’ve covered everything?**

[P]: Been quite comprehensive in our answers about everything.

**Okay, I’ll stop…**

(Non-interview chatter)

(END OF RECORDING)