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

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

**Interview 24 part1**

**...for it to be audio recorded today?**

Yeah, that’s fine.

**Okay, okay.**

Could you just hang on a second, please?

**Yeah, sure.**

(Background chatter)

Okay, I’m ready now.

**Okay. So I guess my first question is kind of general, but it’s… if you could tell me your experience with having MND, maybe… wherever you’d like to start, either diagnosis or maybe when you noticed symptoms before.**

Okay. I first noticed problems with mobility, probably around March of last year. I’d had a couple of falls, one on Christmas day, and one in January. But didn’t really think much of them. But then in that March, my walking started to get slower, and less stable. I had a fall in April. When I was on holiday, and I decided that I would use a walking stick. Because I had been struggling a bit, so I thought, well, a walking stick will give me a bit more balance. And then I carried on walking and falling. I fell quite regularly, really. But I had fibromyalgia, and I just thought it was to do with that.

**Okay.**

But then in August I went to see my GP because my partner and I had been to see his neurologist, and the neurologist had said “If your big toe points upwards, it means you’ve got a lesion on the brain.” And I said, “Oh, mine does that.” So I thought, ‘I’d better go and see the doctor,’ thinking that I’d probably had a stroke. So… went to see my GP, and he said “No, it wasn’t a stroke, the other symptoms didn’t match.” So he referred me to the musculoskeletal team at my local hospital. I went to see them in September, and I was seen by an advanced physiotherapist practitioner. And she, after discussing it with her colleagues, said that she thought there was more than one thing going on, and they’d like to refer me for an MRI scan, and an urgent referral to a neurologist. So I said yes, that was fine. I went and had the MRI scan, and when that result came through, she told me that she thought there were a couple of things on there that maybe a neurosurgeon should look at. So she put a referral through for that. And then I heard that my neurology referral had been downgraded from urgent to ordinary.

**Oh, okay.**

I went to see the neurosurgeon, who said there was nothing she could do. But she suggested an MRI brain scan, because the previous one had been on my spine. And that was done. And then I had a letter come through asking me to go for a nerve conduction test. So I had those done a week before…

**Yeah.**

I had those done a week before I went to see the neurologist. By the time I got to him, I could barely put one foot in front of the other. I really was struggling. And he said to me that he would like to admit me that day for more tests. So that was what he did. I had lots of tests during the week, and then at a meeting on the Friday morning – which the hospital consultant had called – completely contrary to my wishes, he said that it might be Motor Neurone Disease, because I’d said I didn’t want any diagnosis mentioned.

**Oh, okay.**

And then in the afternoon I saw an MND consultant… Because at the… (stutters) meeting in the morning, my partner and my son were there, and I didn’t want to hear a diagnosis in front of them. I wanted it to be private.

**Yeah. Yeah.**

Anyway, the… they’d gone, and the MND consultant saw me in the afternoon. He was very pleasant, and he said “I’m going to look at your notes and test results, and then I’ll be back to give you the di- my diagnosis.” And he said “I won’t leave you over the weekend, I’ll come to you this evening” which was brilliant, completely opposite to the horrible man in the morning. So he came back and said it was MND, which was a shock. Because I hadn’t thought it would be anything like that. I’d hoped it would be something that could be cured with tablets. Because my partner has a problem where his foot turns in, which my foot was doing. And he’d been given Pramipexole and we’d both been hoping that it would be something like that. So it was a shock and a disappointment.

**Were you still in the hospital at this time?**

Yeah.

**Okay.**

And I said… I said to the MND consultant that I wanted to be a guinea pig for absolutely anything. Trials, surveys, whatever. I mean, I was already having the student doctors and student nurses coming and doing stuff. And I just wanted that to continue, so that I’d get something… or so that something of benefit would come out of it.

**Yeah. Yeah.**

‘Cause there don’t seem to be many benefits of MND. And I actually was in hospital for a month, and that…

**After diagnosis, or…**

Including that week.

**Okay.**

Yeah. The MND consultant asked me if I wanted to go on the [name of trial] trial, and I said yes. And he wanted me tested and sorted out while I was in hospital. So they kept me in [name of place].

**Oh, okay.**

While all of that was done. And then I was due to go home on a particular Monday, but I lost the ability to walk over that weekend. So they had to delay it for a day. I’d been walking in the hospital, with a zimmer frame, but I just couldn’t… it had been getting more and more difficult over the previous three or four days. And I’d just reached the point where I couldn’t do it.

**Yeah.**

So I had to go home, once they’d got a care package in place. So that was my diagnosis.

**Yeah. And that was quite… quite recent, wasn’t it? I remember…**

Yeah. 16th of November.

**Okay. Okay. So not too long since then. And you mentioned that when you did get the diagnosis, it was quite a disappointment as well, and probably a big shock.**

Yeah.

**Do you know what you were thinking and feeling around that time? I know it’s slightly difficult to say it, but…**

The first thing that I thought was that my sister – who died in 2016 – would’ve been heartbroken to hear it.

**Mm-hmm.**

That was my first thought… which was a bit odd.

**I mean, we can’t control these things, do we?**

No. (Laughs) No. But I… I know that I didn’t want to find out anything about it. I really didn’t want to know, because I didn’t want to be sitting worrying about what was coming next. So I decided that I would just deal with things as and when they cropped up. And I… I was like that until the end of March.

**Okay. So when you say not wanting to know about, say symptoms or progression and that sort of thing.**

Yeah.

**Yeah. Okay.**

My… one of my sons looked up MND on the internet, and he said to me that… oh no, did he just send me the link, or did he say? But I saw that survival rates weren’t terribly pleasant. I think that reinforced my thought that I didn’t want to know. But he and I both agreed that we didn’t think it would be a long illness, because of the way it had progressed so far.

**Okay. Okay. And you said something eventually changed in March, or after March. Are your** (Yeah) **thoughts and feelings different now?**

Yeah, I think because it’s progressed more. I just thought I’d look up a couple of things on the [charity organization] website, and I happened across the forum on there. For sufferers and carers.

**Yeah.**

And I read through quite a few bits on there, which I found helpful and informative. And… well I didn’t look through it much to start with, it took a few weeks to really take the time to read it. And then I started to change my view, because I decided I didn’t want any life-sustaining treatments. And then when I started to read about peg feeding, on the forum, and then I looked up more about it on the MND website and what have you, and realised that I could have peg feeding, and I could stop it at any time. So I thought, ‘well that’s okay, I can do that. You know, I can have it or not, however I feel’. So… I told the speech therapist, when she came to see me, and the next day, because I happened to be at the hospital when the MND clinic was on, they had me there and did all the tests and gave the go ahead for the peg feed.

**Oh, okay. Okay.**

So they’ve been very quick in the way they do things. Partly because I’m going there regularly, for the [name of the trial] trial. And that happens to be on a Wednesday as well, when the MND clinic is. So it ties in beautifully.

**Yeah.**

If something’s cropped up.

**Okay. Do you find that sort of helps with like preparing for the future, having a choice to do something?**

Yeah.

**Yeah. Have you decided to go ahead with it?**

Yeah, there are two reasons. One was that I could stop it if I wanted to. But also, the day that I’d been reading about it, in the evening when my partner brought our meal through, he said to me “You’ve got to try and eat it.” And I just thought, ‘I don’t want meal times to be, ‘you’ve got to eat it. I want to just eat what… what I feel like eating.’ And at least, with the peg feed, I can top it up. So I only have to eat what I want to eat.

**Yeah. Okay. So that’s where it started, the idea. Yeah.**

Yeah.

**Okay. And I guess you… you did talk about some of the… the concerns or challenges. But now, on a daily basis, what are the main things that you worry about?**

Oh gosh…

**Okay, lots of things.**

I suppose the main worry is about how unable to do things I will become, and how I will make the decision to stop feeding and that sort of thing. What I forgot to say was that, when I was diagnosed. Each of my two sons asked me if I’d like them to take me to Dignitas in Switzerland.

**Oh, okay.**

So they both understand my feelings about hanging onto life until the grim death. Well I don’t want a grim death.

**Yeah. Yeah.**

And they’ve been very supportive. My partner’s been very supportive, but he wouldn’t agree with Dignitas. But I’m not going there anyway.

**Okay. They… they were there during the diagnosis, and…**

No. One son was there in the morning, before I was given the firm diagnosis.

**Okay.**

The other son found out about it on the phone, because he lives a long way away.

**Okay. And the main thing with the diagnosis, you didn’t mind having it, but you didn’t want… you didn’t want your family, at that point…?**

Em… I didn’t want anyone with me when I was given the diagnosis. Because I didn’t know if I would be really upset and break down crying and what have you. And if that was the case, I didn’t want them to see it. My partner has androgynous depression and has suicide ideation.

**Okay.**

And I was really worried that it might tip him over the edge, which was why I didn’t want a diagnosis until I’d had a chance to learn it on my own and figure out how to talk to him about it. And also my elder son has mental health problems. And I didn’t want them caused all the anxiety of seeing me really upset.

**Okay. So you were concerned…**

As it turned out, I didn’t get that upset. But I was very angry that that consultant had said it.

**Yeah. Yeah. Yeah, understandably.**

Mm.

**So… yeah. I guess it’s all quite… quite recent, isn’t it, the diagnosis and things like that. But a lot of people I’ve spoken to say that you can get a range of different emotions with MND. So I just wondered if… if it was emotionally challenging as well for you? And what your experience…?**

Yes it was. Yeah, it was… it was very challenging. And for quite a long time, I was certain that at some point I would die by my own hand. Because I didn’t want to reach this position of being stuck in a body that didn’t do anything.

**Mm.**

And then I had someone from the mental health team… and because I’d mentioned it, he then went into a panic that I was about to top myself, and I wasn’t. So I decided not to share anything like that with the mental health team, because it wasn’t worth the hassle.

**Okay. But this wasn’t… it was more a desire for that, but it wasn’t like a depression or that sort of thing?**

No it was an option that I had…

**Okay.**

...thought about logically.

**Yeah.**

I didn’t want my sons to take me to Switzerland, because I don’t want them charged with helping me die. But I didn’t want to, as I say, be suffering all these losses of ability. And I just thought, ‘well, I’ll finish it off myself when I’m ready.’

**Yeah.**

But as I say, he took it as ‘panicsville’. Em… He didn’t seem to understand that it was just a thought, or a decision because I’d thought it through, and it was the logical conclusion. I certainly wasn’t planning to do it any time… Excuse me. I wasn’t planning to do it any time soon.

**Yeah. Rather than being sort of upset then making this decision, yeah.**

Yeah.

**It was more just thinking through.**

Yeah. I mean, now I know I can do it by stopping the feeding. So, you know, same result, different method.

**Yeah. Yeah, were there any… any other emotions that we haven’t spoken about, yet?**

I didn’t feel angry. I was quite accepting of it, really.

**Okay.**

Frustrated at times. But… not angry, because that’s pointless. I didn’t spend time thinking ‘why me?’

**Okay. So it was** (Yeah) **mainly frustration at not being able to do stuff?**

Yeah.

**Okay.**

And sadness that, you know, I… I was probably not going to live all that long. Because I’ve got another grandchild due in July, and my younger son is getting married in November, and he wants me to be around for those. But it didn’t really feel as though I would be, particularly at the beginning of the diagnosis. You know, when I was first given it. So there was sadness as well.

**Okay. Okay.** **And I guess it… it’s probably a number of different things, but how did you… how did you manage to cope with these concerns or emotions?**

Well… just… just lived with them and through them. I do now have a counsellor who comes out.

**Oh, okay.**

I’ve had her for about a month, I think. It might be six weeks. She’s more of a listening ear than anything. She’s not trying to give me therapy, **(yeah)** which is just as well, because I don’t want therapy. So that’s very useful. And she’s also seeing my partner, which I’m pleased about.

**Okay. Okay.**

Yeah, I would… I don’t think they were particularly overwhelming, the emotions.

**Okay. And do you get… do you find this counsellor quite supportive or helpful?**

Very much so.

**Okay.**

She… she really is a very nice lady, I… I like her a lot. I like her demeanour and her attitude, and we get on very well. It’s not a… counsellor/client distant connection. It’s almost like someone that you meet, that you get on with and you chat to. And that suits me.

**Oh nice.**

I mean, I know that she isn’t a friend, that’s… that isn’t what it is. But it’s very easy to talk to her. Yeah. I like the way she works.

**Okay. So it’s that kind of relationship that… that helps.**

Yeah.

**Yeah. Open up and talk about these things. Do you get support from any… any other sources, I guess, you family and things like that? Does that help as well?**

My… it helps me that my partner and my sons are very supportive. And want to do things to help me. And also my daughter-in-law. She and her parents have been absolutely lovely, because she and my elder son were married in March, and one of their main criteria when they were sorting things out was to be sure that I could get there, and I could cope with what was going on. And her parents were doing that as well. They were very helpful. Beforehand, and at the time. So I do feel very lucky. If… if MND has shown me anything, it’s shown me how much love and support I have from those around me. So it’s almost worth having it. Not quite, but almost.

**From the changes of a dif- perspective, or something like that, maybe? Like...**

Yeah. Yeah, I mean, they are very good, em…

**Okay. Is there anything else that kind of helps you cope? Maybe something… it could even be something you tell yourself, or an attitude that you have that has kind of helped you…**

Well I’ve kept my sense of humour.

**Okay.**

When I was in the hospital, they would wheel me through to the bathroom. And… because I could only manage to walk one way. And I would have the zimmer frame that I would carry to the bathroom, and I’d hold it out in front of me like a steering wheel. So we’d be zooming round corners and beeping, so that people got out of the way. And so that was a bit of light heartedness. Also if they caught my foot when they were pushing me to or from the bathroom, if they caught it on a particular thing, I’d just say, “Could you not choose one of the nerves that’s been damaged, so that it doesn’t hurt.” (Laughter) So…

**Yeah.**

I have tried to keep my sense of humour about it. What was it… I can’t remember what I was saying the other day, but you know, I do sometimes make jokes… we live very near to the cemetery, and I was telling the ambulance driver the other day, that the benefit was that being so near, we’d get a discount on the funeral. But, you know, it’s the sort of thing that I like to say. And it just helps to get through the day, I suppose.

**Yeah.**

But I also have very good support from the community team. There’s an ad-hoc MND team in my area. They’re part of the palliative care team.

**Oh, okay.**

But there are several of them who have a particular interest in MND, and so they’ve got this informal group with extra knowledge about MND. But I know that they are all available, and willing to help. And that they do help. Because I had an issue that cropped up about six weeks ago, which was very unpleasant. And I happened to have the physio come to see me the following morning, and I was telling her about it. And soon after she’d left, the OT rang me and said that the physio had told her what had happened, and could she come out to see me?

**Oh, that’s very quick, yeah.**

It was. And although I knew that I could ring them, I hadn’t really taken it on board. But that really showed me how closely they work together, how well they communicate, and how they’ve got my back. So I feel very confident and trusting of them.

**Yeah. Oh, that’s…**

So that… that’s a good thing that came out of a grotty situation.

**Yeah, that’s good. So just knowing that support is there in case you need it help…**

Yeah.

**Okay.**

And I know that they work closely with the MND Centre in [name of place]. So…

**Okay, okay.**

...I get very good joint up treatment.

**Oh that’s good. Em okay. Em, because everyone’s situation is so different, I was just wondering if there are any aspects that we haven’t spoken about, or…? Yeah, that we haven’t covered?**

I think the main frustration that I have with MND is not being able to get out very much. I’ve got a motorised wheelchair, but taxis where I live, there’s a twelve pound minimum charge, because they have to come from the main town, not from the smaller town where I live. So even if I want to go to the dentist half a mile away, it’s going to be twelve pounds plus that. And they’re not very reliable, they don’t turn up on time. And also, they might send what they say is a wheelchair accessible vehicle, but isn’t.

**Oh, okay.**

So I’ve found that very difficult, because I… I’ve tried several times to go to things, and not been able to get there. So that’s very disappointing.

**Yeah. So…**

So I don’t like what that… what the MND has done for me in that direction.

**Yeah. Losing your independence, a bit, isn’t that…**

Yeah.

**Okay.**

I mean, I changed my car in September, because the car I had couldn’t be adapted to hand controls. So I bought a different car, had it adapted. And I could only drive it until I went into hospital. And then when I came out, I couldn’t get in the car. So that had to go. And, as you say, independence.

**Yeah. And the changes all happen quite quickly, don’t they?**

Yeah.

**To adjust and then readjust and…**

Yeah, that’s been very difficult, because my partner and I… if something’s difficult, we find a way round it. And by the time we’ve found a way round it, things have moved on again, and it doesn’t work. So that’s very frustrating. And a bit… not depressing… soul destroying, I think. Because we’re always playing catch up.

**Okay. Okay. Okay, so you don’t feel like you are in control of…**

No.

**Yeah. Okay.**

And there are so many medical appointments and people that come out. Most weeks, I’ve got at least four people coming out. So it’s difficult to fit in time to go out. Even locally. Because my carers don’t finish until nearly eleven. So I’ve really only got the afternoon, and then if four afternoons are taken up, that doesn’t leave much for me. And the awful fatigue. That’s frustrating.

**Yeah. It’s a lot to deal with, deal with all at one…**

I sound like a real moaner, don’t I?

**No, actually, this is a good opportunity, even if there is more to moan about. Because we’re trying to just record what the different problems are. So…**

Yeah.

**I’m happy with what you’re telling me, because it’s all useful (small laugh).**

Yeah. Yeah, I think transport is a… is a real problem and, as I say, all those medical appointments.

**Yeah. Yeah. I think… so in the beginning, also, just following up on something you mentioned, you didn’t want to look for information online and things like that** (Yeah)**, or you said your son looked first and then kind of** (Yeah) **pointed you towards things… so I guess at what point did… did you decide that you wanted to look up things online, or…?**

It was about the end of March.

**Okay. Did you just sort of feel ready, or…?**

I think it was probably something that was happening to my body, but I can’t remember what it was.

**Okay.**

And I just thought that maybe I’d have a look about it. It may have been because I wanted to do an advanced decision, and an advanced care plan. So I was reading up about that, and then it sort of led me through to other things.

**Okay. Okay. No, the reason I’m asking is, because we also plan to develop something… some sort of resource online. But mainly to help with how people cope with MND. So just sort of simple techniques and things like that, or things you can** (Yeah) **read about that’ll help you get through it when things are difficult. And I guess it’s… it’s different for everyone, but it’s trying to understand when people are likely to… to want to read things like this, or how they interact with this kind of material, because the… initially with the diagnosis, there’s probably too much going on.**

Yeah.

**Yeah.**

I can’t… I don’t know, because everyone’s different, aren’t they? And their MND is different. Some people like to know the ins and out, but I don’t know, I like to bury my head in the sand. Because I know that I would sit and worry about it all the time. And I don’t want to.

**Yeah. I mean, it’s some people’s ways of coping, really.**

Yeah. (Background noise)

**But… sorry, I’ll let you speak first.**

No, I… I mean, I don’t know… I don’t know how you’d measure when is a good time.

**I guess that sort of maybe just having it available for whenever someone felt ready** (Yeah) **or are most like how you found information on the [charity organization] website, when you thought you were ready for it.**

Yeah. I mean, it was… it was good that I was given the information about the MND website. Or the [charity organization]. And I hung onto that. And I decided to join, some time this year. So that was handy, because I’d got the stuff there and I could look at it when I wanted to.

**Did you get it from your neurologist, or…?**

I got it from someone in the hospital, but I don’t know what… who. The MND consultant actually told me about the [charity organization], the day that he gave me the diagnosis.

**Okay.**

I think I may have looked on the website, but decided I didn’t really want to. And then came out of it again. But I certainly got paperwork while I was in the hospital.

**Okay. Okay. And do you think… I know you… you probably have a counsellor at the moment, and you find that helpful. But do you think you might access something online, even if it offers you support from the emotional side of things?**

Well the MND forum I find is quite a good support.

**Okay.**

Because there are people on there who have had MND for a long time. And so they’re quite knowledgeable. And they are friendly and welcoming when you join the forum. And that’s really good. I don’t think people feel awkward about asking questions on there. So yeah, I do find that supportive.

**Okay. No, that’s good to know, that’s a good resource. And to link people to it, as well, isn’t it?**

Yeah.

**Okay. I think I’ve asked you most of my questions. I don’t know if there’s anything else we’ve left out, or…**

I don’t think so.

**That’s okay.**

Yeah, I mean, I’m very fortunate because of where I live, and how good the services are. You know, the community services and the hospital and what have you. I… I think I’m in the right place to have MND. I get the feeling that other places are not as fortunate.

**Yeah.**

In the speed with which things happen. Or the equipment that’s provided, or whatever. So sometimes I feel a little embarrassed on the forum, because I think it’s not like that for me, I get better service than that. So I don’t like to say it, because… it’s not going to help other people, if they don’t get that level of service.

**Yeah. It’s… as you say, it depends on the kind of care you receive as well. And** (Yeah) **there are different… which it shouldn’t be, but it is.**

Yeah.

**Okay, are you happy for me to stop the recording? I can continue talking to you, but if… from an interview point of view, can I… can I stop the device?**

Yeah, that’s fine.

**Interview 24 part2**

...meeting. Because I’ll see people in a real state.

**Yeah.**

So to actually suggest meeting someone who’s got it, is quite a departure for me.

**Yeah, yeah. Well that’s… that’s really nice that’s worked out. But you didn’t attend any of the like [charity organization] groups or anything like that?**

No. I think they’re quite a distance.

**Okay.**

And although I can afford to pay for the taxi, I don’t think I want the hassle. And I don’t… as I say, I don’t want to be surrounded by people who are further along than me.

**Mm.**

Because it’ll be difficult to keep my head in the sand.

**Yeah. Yeah. Everyone has different preferences in this respect, isn’t it?**

Yeah. And it does annoy me when people tell me I’m brave, because I’m not. Bravery is a choice, you know, this is not a choice, I’ve just got to get through it. And with my head firmly buried in the sand, that’s not brave. So yeah, I get a bit annoyed when they call me brave. (Laughter)

(END OF RECORDING)