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

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**Interview 28 part 1 (with person with MND)**

**(Non-interview chatter)**

**Thank you again for agreeing to be interviewed.**

That’s all right.

**Just a couple of things before we start, just to make sure… if at any point during the interview you want to take a break or say the doorbell rings or something, that’s absolutely fine.**

Yeah, okay, yeah.

**I can just easily stop and start this.**

Yeah, yeah.

**Also, if there’s any questions that you think are too difficult or you don’t want to answer them, just tell me to skip them, and** (All right) **I can do that. And yes, what you saw on the consent form as well, all the information is confidential, so** (Yeah) **say if you’re mentioning a doctor’s name, or a hospital name or something like that, it will all be** (Yeah, yeah, I understand that, yeah) **confidential, it’ll be… yeah. So I know you did tell me a little bit before I started the recording, about how you noticed the symptoms and your diagnosis and things like that, but if you could just tell me about your experience, whether… from wherever you want to start… (Overtalk)**

Yeah, well, looking back on it… I used to do a lot of road running, as I was saying, and I had a bad knee, which meant I couldn’t really run anymore, but I still used to try, if you know what I mean. And then I finally had to stop running, I’m pretty sure it was at the end of 2014, or the beginning of 2015, because not only did I have this bad knee, which hurts after running. It didn’t hurt, it doesn’t hurt at all normally, but it’s just after, if I went running for an hour or couple of hours, it hurt real bad. Plus I started to get what they now… what they now know, a foot drop.

**Yeah.**

In the, one foot was sort of dragging. It was my right foot was dragging behind me left foot. And anyway, I finally had to give up running, and I think looking back now that that is when… that was the first symptoms of Motor Neurone Disease, and I didn’t know it was that, obviously. And then over the next two or three years I had various tests, and finally in August 2018, I was actually diagnosed with MND.

**Okay.**

So I mean, now I’ve…

**And how was your experience of the diagnosis…? (Overtalk)**

Well I thought… well it was a shock at the time, but it was… yeah, I thought it was done properly, I suppose, in the… the lady said to me that I had Motor Neurone Disease and it could be I only had six months to live, but she felt that – this isn’t her exact words – but she felt that probably in my case I sort of would… two or three years before, you know **(Yeah)**. But I could go on for… I forget the term… the actual term she used, but she did say that she had some patients that she’d being seeing to for seven or eight years, something like… she said something like that.

**Yeah.**

So that, you know, basically she was telling me she didn’t know how long… (Laughs) And she then explained it, which I found useful, that the disease is very… something that, you know, nobody rea-, in the medical profession knows about, and quite frankly, she said, what will happen to you in, is, you know, if you like… she didn’t say this, but it’s just sort of in the hands of God, that they did, they just do not know what forms it will take and whether, you know, it affects your muscles, whether… which muscles in the body it would affect and all that, and how long it would take, she says, unfortunately in some ways, but fortunately – it depends on your view, I suppose – they don’t really know what might happen. So all you can do is hope for the best. (Laughs)

**Yeah. Yeah. Expect…**

But… and I… I just left then, obviously, and it was a bit of a shock.

**Okay. You weren’t expecting… (Overtalk)**

No, no, no, absolutely not, no. No, no, no. I had had a test beforehand. I’d been to a place… [name of hospital] it was. I think twice before. The first time, it was because I had a… I’d had an MRI scan on me back, and that had shown some sort of nerve problem or something, and that’s what they said. So I went and saw this guy, who then said that it, you know, it was a bit more serious than they’d thought, or words to that effect. And I then went back and saw another doctor, whose name I can’t remember, and she did this test on me legs.

**Okay.**

Basically putting electric shocks through like… she was obviously checkinghow me nerves were, I suppose, something like that. Anyway it was as a result of what she must have told this other lady, who is the big white chief there. That she, they decided I had MND, so…That this is what she told me, you know, that…

**Okay. And...**

There we are.

**And at that point, did you know much about MND?**

No.

**Like did you ask any questions, or…?**

Not really no, because, you know, I was a bit… no. It’s a bit of a blur at the end, to be honest. (Laughs)

**Mm. Yeah. And then what happened once you came home?**

Well on the way home, I couldn’t decide whether I’d tell me wife or not. Because I thought, ‘well...’ You know, since I’d… you know, know very little about it, and you know, it’s a bit of a nasty old diagnosis, how would she react? Anyway, on the way home I was trying to make up me mind whether to tell her or not, to be honest. And anyway, when I got back, and parked up outside, I thought, ‘well, no, I’ve got to tell her, and that’s all there is to it.’ So I came in and told me wife. And she, you know, obviously, we then had to try and cope with it.

**Yeah.**

Yeah. First thing we felt we ought to take the- tell the children, obviously. We’ve got two kids.

**Okay.**

And they… one of them, me daughter was away on holiday in France. So for… it was a bit difficult, because for… I forget how long it was, it might have been two weeks, it might have been three. I think it was two weeks, for a couple of weeks we couldn’t tell anybody, because I felt we… I had to tell our children first.

**Right. Yeah.**

And I… well I’ve got a big family, and I’ve got lots of brothers and sisters, so’s me wife, but we just had to keep it, and it was a bit difficult.

**Yeah**

For a couple of weeks, just not telling anybody. And just acting as though, you know…But anyway, when me daughter came back, we told her, because she lives locally. And then I rang up and told me son, because he lives in [name of place]. And then we left it a day or so, so they could tell whoever they felt they needed to tell, and then we told my brothers and sisters and me wife’s brothers and sisters and… that was it.

**Okay. And once you… once you kind of came home and told your wife and you were both waiting to tell your children** (Yeah) **and things like that, generally what were your thoughts and feelings around that time?**

(Sighs) Em…

**I know it’s a difficult… one to…**

Yeah, it is difficult, in’t it?

**Yeah.**

Em… Well I think… well, I thought that eh (pause) I’m not afraid of death. Because I’m not, because we’ve all got to die. But I was afraid, if that’s the right word, of what might happen to me before I die. Because as soon as I started to think about it, I realised that I got muscles all over my body, and therefore anything could be affected, couldn’t it?

**Yeah.**

Now I might in a sense be lucky, and it’d affect me heart, and I’d be dead just like that. On the other hand, I might be unlucky and, you know, slowly fall apart, if that’s the best way of putting it. So that’s,the sort of thing that was going through my mind, then, yeah. You know, you know, do I want to die quick, or do I want to die slow?

**Mm. Yeah. It… it makes you think about the future and** (Yeah, yeah) **worry about that, too. Yeah.**

Yeah. But yeah, for me personally **(Yeah)** I also was thinking about the future for obviously me wife and me family and that, and… but we’d already… you know, all these sorts of things going through my mind. We’d already made wills, years and years ago. So that’s all taken care of. And I felt, you know, that we’ve… financially, we’re reasonably well off. So I wasn’t… you know, I wasn’t too concerned about the now, if you see what I mean?

**About?**

I feel like… well, I feel that I don’t really need to do anything.

**Okay. Okay.**

Perhaps make my mind up about when I die, how I want to be buried, and that sort of stuff. But do I want to be buried or cremated? And…

**But no sort of concerns about…**

Not really, no, no, but it was just thoughts about all that sort of thing, because…You know, that’s…

**Yeah. I mean, when the doctor tells you something like that, then yeah, it’s about, natural… (Overtalk)**

Well yeah, yeah, exactly. Especially when you can’t… you know, you’re not sure how long it’s going to take, and that sort of thing, it makes you feel that, well, you know, perhaps I won’t wake up tomorrow morning. I mean, I don’t know, it’s difficult, in’t it? Anyway, yeah. So it’s all that sort of stuff.

**Yeah. No, that’s… (Laughs)**

So that kept me occupied for a couple of weeks. (Laughs)

**Did… did that… did that kind of usually worry you? Or did you… do you sort of have these thoughts and then think of something else, and get about doing stuff…?**

No, I think I’d had the thoughts, and thought something else, it didn’t worry me all the time, but…It’s certainly something that I never thought about before.

**Right. Right. Okay. Okay, and then after… so you’ve told your children and the rest of the family and** (Yeah) **things like that, and now it’s… how long has it been since… a couple of months, at least six months.**

No it’s… I told them, that would’ve been early September.

**Okay.**

Because I was diagnosed the end of August, so it’d be early September when every… then everybody knew

**Okay.**

So that’s… I don’t know, September to now, however long it is. Perhaps it is six months, is it? October, November, December, January, February, March, April, May… it’s about… yeah. Yeah.

**And how have you been feeling now, and coping with things now?**

All right, I think.

**Okay.**

Because my symptoms are very- (stutters) at the moment, anyway, very, very slow.

**Do you think…**

And as long as I can sort of hobble about and all that…

**Yeah.**

...I think I am… but how I’ll cope when I can’t… for instance, sooner or later I’m not going to be able to walk. That’s the first thing that’s going happen to me, well I assume so anyway. And when I can’t walk, and I’m into a wheelchair, say, then things might… I might feel very different. But as long as I can… you know, as long as I can cope as I can now, I feel…I don’t feel too bad. (Laughs)

**Okay. No that’s… that’s fair. And has it changed since like your experience during, just after diagnosis to now, do you see things slightly differently, or…?**

Yeah, I think so. I think I… yeah. I now feel… I feel a lot happier, is the best way of putting it.

**Okay.**

Than I did then. Yeah, for a couple of weeks obviously I was thinking, you know, I… I know that it… nobody can tell me what’s going to happen, but I just felt worse about it then. But now I feel that… as long as I, you know, as long as I can carry on doing what I’m doing, although I’m restricted obviously, I, you know, I think I could cope with it.

**Yeah.**

I could cope with being like I am now. Forever. (Laughter) See what I mean?

**Yeah. I see. It’s… (Overtalk)**

But I am aware in the back of me mind that, you know, that is going to change, or I assume it will.

**Mm-hmm.**

But who knows? Hope springs eternal, doesn’t it?

**No-one really knows, do they?**

No, they don’t.

**Okay. And… okay, so because it hasn’t really changed much, but because there has been a bit of time and you’ve** (Yeah) **just adjusted to things, you’re a lot more positive now, is that…?**

Yeah, I think so, yeah, yeah.

**Okay. Do you think that’s… that’s sort of always been your approach to things, or…?**

Yeah, I think so, yeah.

**How do you… how do you normally cope with difficult news, or…?**

Yeah, I always… no, I… I can cope.

**Okay.**

You know, there’s always a silver lining somewhere, isn’t there, there’s…You cope, you know. No, I… I think I have always coped with life, you know?

**Yeah.**

Yeah.

**That’s just the kind of approach or attitude you… take?**

Yeah, it’s the way I am, you know, very lucky in that respect.

**Mm-hmm. Em (Overtalk)**

Sorry.

**No, no, go ahead.**

We all have, you know, there… in everybody… well not everybody, in my life, anyway, in everybody’s life, I think, is moments when, you know, problems come along, don’t they, that, you know, and either you’ve got to give in, or you’ve got to get over the top, and I’ve always been able to, you know, keep going, if you know what I mean? I mean, I never had any real tragedies, like some people. But I have had experienced trage- tragedies through others, that’s the best way of putting it.

**Okay.**

I mean, my brother, for instance, lost his son, when his son was only four.

**Oh wow.**

Got knocked down. Killed, at a wedding. And it can’t… you know, it can’t be worse than that, can it? For instance, I lost me… me older brother when he was forty-eight. He died of lung cancer, because he was a very heavy drinker and smoker, and **(Okay)** you know. You know, I’ve had sort of tragedies **(Yeah)** like that, if that’s the best way of putting it. And, you know, I lost me parents, like everybody does. And… but some people can’t sort of cope with things like that, can they? But, you know, I’ve always been able to keep going. (Laughs)

**Are there any… any areas you kind of get your support or strength from, or…**

My family.

**Okay.**

My wife.

**Yeah. In what sort of way? Is it more just the fact that they’re there, or also helping out with things?**

Well it’s the fact that they’re there and, I mean, I know that my brothers and sisters… they’d help me without thinking about it. Do you see what I… do you understand what I mean?

**They’d help you… okay. Okay.**

Yeah. We’re all the same, and I’d do the same to them.

**Okay.**

It doesn’t matter. **(Hmm)** You know, that’s what families are for isn’t it, or that’s our attitude anyway, and they’re the same. And the wife’s… well I know she’d always be there.

**Hm. That’s good. (Laughs)**

Well it is, isn’t it, yeah.

**Yeah. Yeah.**

And I know some people that aren’t that lucky, are they?

**Yeah. Yeah. So family is really big in** (Yeah) **keeping** (Yeah) **your spirits up and that kind of thing?**

Well, that’s right, and you know, and having a wife that, you know, you know you love each other. There’s a lot of people who haven’t got that, have they?

**Yeah. Yeah, that’s true.**

But we’ve been together now for, what is it, fifty-five, fifty-six… 1963 we were married, however long ago that is.

**Oh gosh.**

A long time ago.

**Okay. And besides the family as well, like how did you… because I met you at the coffee morning…**

Yeah, yeah, yeah.

**How did you start accessing support from the [charity organization], and…?**

Right, they… well the lady at [hospital] that diagnosed me, [name of doctor], I think her name is. Very nice woman. At the time, they’ve got a good support group or whatever, or an organisation at [name of hospital], as it happens.

**Okay.**

And she gave me information, a leaflet from [hospital], all about MND and the… and what the setup is there, and they’ve got a psychiatrist and another lady, I can’t remember, [name of person] something or other, who is sort of, if you’ve got any problems or you want any information, you can contact her over the phone now, all that sort of stuff. And she then put us onto somebody whose name I can’t remember now, who runs… you know the, there’s a chap called [name of person], who runs this…

**Oh yes, yes, I met him. Yeah.**

...you know him, obviously. And there was another lady who… and she organises the [location] area, I think, can’t remember her name… because [another location] at the time didn’t have any meetings of the M-the MND thing. Because this sort of [name of hospice] was being reorganised.

**Oh, yeah, yeah.**

So this lady from [location], whose name I can’t remember, she rang us upand told us that there was meetings in [location], and all that, so we’ve… well I thought, ‘well, we’d better go,’ and we went to the meetings in [location].

**Okay.**

Two or three of them, I think. And then there was that meeting in [name of another location], that… where I met you. So...

**Oh, okay. So that’s a fairly new group, then, the [name of place] one?**

Well I don’t think it’s a new group, but it’s certainly a new… it’s… they’re reviving having the meetings, because they couldn’t have any, becausethe hospice was being renovated or something, so they didn’t have the… the room, you know? So yeah. And I’ve just… you know, gone to the meetings and they organised… no, you didn’t go to that, did you, they organised a day at Concord, to see the Concord aeroplane.

**Oh nice.**

Go round the museum, which was pretty damn good. I didn’t, I thought all we were going to do was go there and look at the air- the aircraft, you know? But they have got a museum with all sort of stuff in. So that was a good day out.

**That’s good.**

We went to that. Yeah. So yeah, and we’ve sort of… if there’s meetings we can go to, if we’re not on holiday for instance, then obviously we go to the meetings and yeah. But I think they’ve got a good setup.

**Did you go sort of as… I can’t remember when you met the lady at [name of hospital], but was this quite soon after your diagnosis, or…?**

Yeah, she… I didn’t meet her, I actually just to her on the phone, because when I had the diagnosis from [name of doctor], she gave me all the information and a leaflet all about the setup. But the lady that – [name of person] something or other – this sort of liaison person at [hospital] for MND, she wasn’t there at the time, she was away for a couple of weeks. So… but I then spoke to her on the phone, and she put me in touch with this lady in [location] and, you know, it all came from there.

**Yeah.**

Yeah.

**Okay. And… you were happy to go to these meetings and things? Yeah.**

Oh yeah, yeah. Yeah.

**It didn’t sort of… because I know some people are a bit worried about seeing…**

Yeah, no, I can understand that. Yeah. Yeah.

**That was not the case for you?**

No, no, I felt that… well, you’ve got to face your demons, haven’t you? Well you have, you know, I didn’t see any point in… because, yeah, me and wife talked about it, because, I mean, I realised that if I went to these meetings, I might meet people who… who were in a much worse state than I am. And indeed we did. But I feel that, well, no, you’ve gotta… as I say, you’ve got to look your demons in the eye, so…

**Okay.**

And you never know what you will learn, you know, and I found it very interesting. I mean, at one for instance, they were talking about… I think this might have been at [location], I can’t remember now, or it might… it was, might have been in [location]. They were talking about the fact that you can bank your voice.

**Oh yes.**

Something I’d never ever have thought about it, but we… I decided not to do it, to be honest, because I mean, you can get a… you can still get your voice… it won’t be your voice, but you can still get a machine that you can tap things into and it speaks for you, you see what I mean?

**Right. Right.**

But if I did a banking your voice, I can see the appeal of it, is I could actually spend time, you know, putting my voice in a bank, as it were, so thatif… if and when I can’t speak anymore, I could with a machine, actually have my voice, so that people that know me, you know, would actually…

**Yeah. Yeah.**

...think it was me talking, if you see what I mean? Yeah, I find that very interesting.

**Okay.**

Yeah.

**So sort of learning about how different people cope and** (Yeah, yeah, yeah) **what’s available.**

So when you meet, you know, if you meet people at these meetings… there’s never many there, because as you said, well like **(Yeah)** for one thing there aren’t many of us about. And I mean, I can quite understand why people don’t want to go, but… no, it’s, yeah, you can talk to people that **(Yeah)** are suffering like you, but yeah… yeah, no, I find it… I find it useful, yeah.

**Okay.**

Yeah.

**Okay. And besides this group – either [name of two locations] - have you accessed any other support from any other organisations or…?**

No. Well… no, we didn’t… funny enough, we didn’t access it, but I also got our… well I got a heart… well I’ve got a heart condition is the wrong way of putting it. I had to have a new valve, a valve repaired in my heart, **(Okay)** back in 2011, I think it was. So they classed me as having… not having heart disease, but having a heart condition. (Clears throat) And because I’ve got a heart condition, and also I was then diagnosed with MND, the doctor’s surgery, because I’ve got two conditions or something, they put me automatically through… in the… they told the, what are they called, Age Concern about me.

**Oh, okay.**

So they rang me up, and sent me a letter one day, and this guy… turned up, and it’s been very useful, because he filled out some forms for me, so I can get a blue badge for driving.

**Oh, okay. Okay.**

Which is very useful, because although I can walk, I can’t walk very far, you know? There’s that. And he also filled out forms so that I can get financial support from the government. I forget what they call it, now.

**Some sort of allowance?**

Yeah, that’s right, yeah **(Yeah)**, so that you can get a… pay to have a cleaner to come in and that sort of stuff.

**Oh, okay. Okay.**

If you know what I mean? So yeah, so we’re… they’re sort of helping us, if that’s the right way of putting it.

**Mm-hmm.**

Age… I think they’re called Age Concern. And yeah, so yeah, that’s the other thing I’ve had, apart from support from the actual MND people.

**Okay. Any… I guess from the hospital or something, any say physiotherapists or…?**

Well no, I don’t think I need them, but yeah, they got that- all that sort of thing.

**Okay. You’ve not accessed anything for psychological help or things like that either?**

No, but I didn’t… but they got a psychiatrist, or is it a psychologist, can’t remember which now. They… there’s a guy there, and **(Okay)** when I was there, not in August, but when I went… when was it? Later in the autumn last year, I went in, you know, for a routine… I think they’re going to see me twice a year, by the look of it. And I went in for the next visit, and did arrange to see this chap. I can’t remember his name. Anyway, I saw him, and we had a chat about, you know, what he could offer or whatever, but I don’t think I need it to be honest, but the understanding is that if I feel l need any psychological support or whatever, I’ve just got to ring them up.

**Okay.**

And this guy will see me… I mean, not immediately but, you know, pretty damn quick, if you see what I mean, so. Which I think is useful.

**Did he sort of say when… when to phone him, or...?**

When what, sorry?

**When to phone him, when you feel… (Overtalk)**

No, he just said if I feel… he just says that, you know, if you think you need any sort of help or whatever, just give him a ring and go in and see the guy. But…

**Okay. And…**

But I don’t… I don’t think I do, so…At the moment.

**Yeah. (Laughs) So you feel you’re coping and managing alright, yeah?**

Yeah, I think so, yeah.

**Okay.**

Yeah, yeah. (Overtalk) I have bad days sometimes, but that’s life, isn’t it?

**Yeah. And how do you usually cope with those bad days, or…?**

Well I don’t know, I just do. (Laughs) I can’t… it’s difficult…

**To say, yeah.**

Yeah. But not very often, but just occasionally I think, well, you know, start thinking ‘I am dying, or whatever, I can’t deny...’ I can’t even explain what it is, but just sometimes I feel a bit down. And some… some days, I notice I’m not walking as well as I was, you know. Even my wife notices sometimes that, you know, I’m just dragging the foot a bit more so, you know, that makes me feel a bit low, should we say? But fortunately, I usually get, you know, a few days later or the next day, I’m walking a bit better again, so.

**Okay.**

But I do realise it progressively is getting worse. But it appears to be very, very slow.

**Okay. It’s good that it’s slow (laugh).**

Yeah, well, you know.

**Yeah. Okay, so you just sort of wait… wait and get on with it, and wait** (Yeah, yeah) **until the next good day** (Yeah, and…) **comes up.**

Yeah.

**Okay. I guess, are there any other sort of difficulties or challenges that you face every day? Or have we pretty much covered most of… (Overtalk)**

No, I don’t think there is, to be hones-… I’m not very interesting, am I? (Laughter) From your point of view.

**No, that’s…**

No, I don’t think so, I…

**(Laughs)**

You know, I just face each day as it comes. No, I don’t think I’ve got any...real problems.

**And do you feel well supported, is there any area you feel you might have done with better support or something like that?**

No, not really, to be honest.

**That’s good.**

Yeah, yeah. But again, I only realise this because, relatively speaking, you know, I’m still in good shape.

**Right. Okay.**

But… but one thing is it, now, I notice… well, yesterday we went out with [wife’s] brother, it was his birthday, for lunch. And… it was… I went into this restaurant place, and there was a guy there, in a wheelchair, sat at a table, and he was being fed. I think he could talk just a little bit. But things like that… before I wouldn’t, probably wouldn’t have even noticed him, do you know what I mean? But now I feel… and I feel, what I would like to have done was to have got up and had a word with him, to be honest. To see, you know, what was it he had wrong with him. Anyway, but that makes you feel, well, you knowthat could be me in, I don’t know when.

**Yeah.**

So that… you know, that gets into your brain a little bit. But…

**But when you see things or…**

Yeah, that’s right.

**...something reminds you of…**

Yeah, yeah. Yeah. And, you know, whenever I see anybody in a wheelchair, because that’s going to be the next thing, isn’t it? But, you know, when you see people that can’t speak, and that sort of thing, all makes… makes you feel a bit… low, down, whatever the word is. But… but, you know, generally speaking, I’m…

**You’re okay.**

...not very interesting, from your point of view. (Laughter)

**No, all of this what you’ve told me is really interesting, because it’s… I’ve not met a lot of people close so, to when they were diagnosed actually, so, your experience is** (Yeah, right, yeah, yeah, yeah)**, is really useful.**

Yeah.

**If there’s nothing more about your experience that we’ve missed, or do you feel you haven’t…**

No, I don’t think so, no. No, I’m… no, I don’t think so.

**Okay. Can I just… (Overtalk) sorry…**

It’s just a question of when it started and how I sort of manage up to now.

**Okay.**

But I manage, I think, for two reason- One I manage anyway, because I’ve always been that sort of person. But secondly, you know, I’m relatively in good shape, and I realise thatand, you know, when it gets worse, well I’ll have to see how I can’t cope then.

**Yeah.**

I think I’ll cope all right, but you know, nobody knows anything until it happens, do they?

**And… yeah. That’s fair enough.**

Mm. Well. (Laughs)

**Can I just ask, did you ever go online looking for support or information about what MND is and things like that?**

We did right at the beginning. (Clears throat) Went on the dreaded internet. My wife did it, because I don’t use the damn thing, to be honest. But… Google, or whatever it was, I don’t know, but we didn’t find it very… it is what you’d expect, you know, **(Yeah)** I didn’t find it very inter- well, interesting perhaps but, you know, you can’t… you can’t believe things on the internet, generally speaking, can you? But we have had… well, we joined the [charity organization].

**Right.**

So they… they… and they sent me stuff on there. They sent me something the other day about somebody… somebody… some sort of research they’re doing, to do with people’s gut. The… the…

**Oh, uh-huh.**

...things that live in your stomach, in your guts, what are they… what do you call it?

**Some bacteria, something like that…? (Overtalk)**

Yeah, that’s right, yeah, the good bacteria, you know, and the fact that if you… they’re doing research about the effect of not treating your good bacteria properly, and how it might affect not just MND but your whole nervous system, all that… so I’ve… very, very interesting, anyway, pages of it. So I read it all and all that. But yeah,they do us send us stuffand we’ve filled out a survey for them…

**Okay.**

...you know, back along, I forget when it was now but, you know, several months ago. So yeah, we get that from the [charity organization]. And they send through all the booklet thing, every so often.

**Yes, I think I’ve seen that, yeah.**

Yeah.

**Okay.**

So that’s, yeah, that’s useful, I mean, I think it’s useful, yeah.

**So you usually don’t trust a lot of other sites, but say the [charity organization] is fine and… (Overtalk)**

Yeah, yeah, no, because, you know…

**Okay. Yeah. (Overtalk)**

I don’t trust the internet anyway, because… well people have got an axe to grind, it’s like reading newspapers, isn’t it? I mean, I read the Telegraph, but I understand they, a lot of what’s in there is the view of the editor, not, you know, necessarily…

**Yeah. No, the… the only reason I’m asking is, because we’re also thinking of putting up some… I guess you could call it like a resource, or information on how to cope with MND and things like that…**

Yeah, yeah, yeah.

**...and it’s a good thing we’re working with the [charity organization], so we can** (Yeah) **use their…**

Yeah, no, it’s a good idea that, yeah. Yeah.

**Yeah.**

Oh yeah, I think it’s an excellent idea, because…

**Yeah.**

...people, you… we all need help with that sort of thing, it’s… yeah. Yeah.

**Yeah. Do you think, looking back on your experience, there were some… some points when you just didn’t want to look for any help or support? I don’t know, maybe around diagnosis, but if it was too much or something like that?** (No) **Were you always quite…**

No. Quite the opposite.

**Okay.**

Yeah.

**Okay.**

I mean, that’s why I went to the meetings originally, and…

**Okay.**

No, I think you… you know the point, I don’t see any point burying your head in the sand or turning your back, I… yeah. But, you’ve got to realise that some people might have an axe to grind, but no, I think you… it’s what it’s all about, isn’t it?

**Yeah.**

Yeah. Yeah. Because after all, somebody’s been through it all. You must, you know, you must know and grasp something. No, I think you’re… it’s…

**Okay.**

But I did, I also appreciate that some people… that’s what they want to do, isn’t it? They… they just want...don’t want to be involved, because they can’t cope with it, I guess. But anyway.

**Yeah. I mean, it’s… it’s always different with different people, that’s** (Yeah, yeah, true, yeah) **that’s why I thought I’d ask you how, how you approached it.** (Yeah) **But…**

No, I can quite understand why some people don’t want to. But that’s not me, because…

**Yeah. You’re very active and…**

Well yeah, and you need, you know, without information and knowledge you’re not – in my opinion anyway – you’re not going to get anywhere, are you, so… yeah.

**Uh-huh. Okay. I think I’ve asked most of my questions. Let me just check. Yeah. I think I have.** (Yeah) **Unless we’ve missed anything…?**

No, I haven’t, no, I mean, I’m trying… yeah, yeah.

**Okay. I’ll stop…**

I just hope you find it of use.

**It is definitely. It’s…**

Well, I hope so.

**I’ll stop the recording…**

And certainly, if you produce reports or whatever it is, through...

(END OF RECORDING)

**Interview 28 part 2**

**Yeah, so we were talking about em… oh, I forget now, what did you say before? At least knowing people are looking for the answers,** (Yeah) **even though there isn’t an answer** (that’s right)**… available.**

At least it makes you feel that something is being done. And you’re not alone. And no, no, I… no I find it useful, yeah, yeah. It makes me, cheers me up. (Laughs)

**And you said about other people as well.**

Yeah. Yeah.

**What was that?**

Well that…that, you see, if you see other people that are worse than you… I can’t remember what I said, now, to be honest. (Laughter) That they’re… it might be, you know, they’re in a worst state than you, but… I mean, that’s where you’re going to be going, I guess, but at least you feel you’re not alone. You know, I, I think, I think it’s a selfish thing to think, but if you’re not on your own, it’s a bit like having a family, isn’t it, it’s… there are others around you that are in the same condition, or a worse or a better condition than you and, you know, it’s, it’s not just you that’s suffering.And I think that is a selfish thing, but I mean… but it does, for me anyway, it does make me feel better.

**Yeah.**

Yeah, I’m not the only person in the world that’s dying of this nasty disease. I don’t wish it on anybody (Laughs) but… you know.

**Yeah, but at least…**

And a- yeah. And the fact that other people are out there trying to get an answer, you know, I find it very… yeah, it’s helpful, it’s uplifting almost, if, you know, at least there’s people out there struggling… and people moreover that haven’t got the disease, that’s the real… but it’s the sort of same with any medical research, isn’t it?People are out there strivingto help people like me. I mean, probably because they’re getting paid for it, if you want to be a, you know, a fatalist about it. But they don’t have to do it, and it’s, you know, if they were dying of the disease I can understand why they’re striving to find an answer. But they’re not.

**Yeah. I see. Yeah.**

They’re just people that are out there doing a job and, you know…You know, and I find that also helpful. I don’t quite know why, but if you understand what I mean?

**That, I completely understand, yeah.**

No, and it’s good.

**Okay, sorry about that.**

(END OF RECORDING)