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

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**Interview 29 part 1 (with person with MND)**

**Okay, this is interview 28. And thank you again for agreeing to be interviewed. I’ll just put this in the middle**

**(Non-interview chat)**

**And… and you did mention a few things about confidentiality and things like that before I turned on the recording, but just a couple more things. If you want to take a break at any point, if the doorbell rings or something like that, I can really just press stop and start as easily as that. And also, if you do feel any questions are difficult, and you don’t want to answer them, that’s completely fine, just let me know.**

Okay. Yeah.

**And I’ll skip over them. So I guess… because I don’t know much about your story, wherever you would like to start with your experience, it could be when you were diagnosed, ‘cause I know that was fairly recently, or if you want to talk about when you noticed something was wrong as well, wherever you’d really like to start.**

Okay, well I suppose I fell, I tripped, which I thought was at work. I think, I thought. And I thought I tripped over my bag, and I still might have done. But that… that was early November last year. Prior to that, the only possible symptoms I’d had were a slight juddering in my left leg, lower leg, and a really slight tingling in my left arm. Neither of which, in a million years, I would ever have equated to getting this. **(Yeah)** So, you know, I just thought it was some kind of twitch. And I thought about going to a doctor’s, but I never go, I haven’t been for years and I, you know, there was no reason. I was still running, I was a runner, three times, you know like 3/5k, three times a week, until quite recently or relatively recently. And I could still all that, so it didn’t occur to me. Once I’d fallen, my left leg, my left foot, something was definitely amiss very suddenly. It kind of felt a bit detached from my body, but again I thought, again, you would never think of this, why would you, it’s not in the family. Not that I know of. So I couldn’t get a doctor’s appointment for three or four weeks, the usual, so rather than wait, what I thought was a muscular problem, I went back to my physio that I’ve had before from running and things. And I guess I worked with him until about January **(Okay)** trying to get this leg back to **(Yeah)** business and he did some great stuff with it, but it never quite picked up, the… and my running, by the beginning of this year, was getting a bit tougher. So eventually I got on the waiting list for my doctor, and wait, I think, you know, okay, three weeks, but as soon as I saw her, she just said “You need to see a neurologist immediately.”

**Oh, okay.**

And I… yeah. No, she warned me there was a six month wait for Neurology at [name of place]… sorry, [name of another place], wherever, you know, [name of hospital]. So she said “you can’t wait” so I went to [private hospital], within… so I saw **(Okay)** my neurologist, that is now the consultant, within sort of twenty four hours. And within like two weeks, I’d had an MRI scan on my back, not on my brain, I need one of those, but on my back. And, as we were hoping I had jarred my back by falling.

**Okay.**

And I’d also… and I also had a, obviously, EMG tests as well. And then backwards and forwards to get those results, but I got them, I got an appointment anyway, April the 10th. He’d asked me at the [private hospital] what I thought it was, but I wasn’t going to speculate, because I didn’t know whether he thought… I…I don’t like that idea of having to speculate what’s wrong with you, you know? He asked me again, when he had the results in front of him, and again, you know… and then he just told me what it was, which I suppose was always the, you know, worst case scenario, it was at the back of my mind. But you never think it’s going to be. And that was it, I didn’t speak to anybody else then for three weeks about it, just left and this is something that, you know, you might want to be a bit more, other people may have said.

**Yeah. Yeah.**

So yeah, so this was two months ago.

**Okay. So you had no… you didn’t expect that it would be that, or you…?**

Well why would we? Why, you know, I don’t… you would ne- you know, I’m a historian, I’m not a medic, you know, it’s not… it was essential to tell me, you know? (Laughs)

**Right.**

I wasn’t going to second guess. I was petrified, yes, obviously, with the symptoms, but I’m not someone that will spend hours Googling.

**Right. Okay.**

Because I, you know, it’s pointless.

**Okay. No, I’m just asking, because I was just wondering if it came as a shock to you when… when it was…?**

Even if I’d thought it might be, it would’ve been a shock, wouldn’t it? Something like this **(Yeah)**, because you can’t… so I was just numb.

**Mm-hmm.**

Yeah. What can you say, that’s it, your life’s pretty much over. Is, is how it feels.

**And what happened in that time for you, after you were diagnosed, you said three weeks…**

The time… diagnosed, yeah. Out you go into the car park, and you’re just left, then nobody contacted for three weeks.

**Oh, okay. Okay.**

A long time to be left.

**So no health care professional or anything?**

No.

**Okay. Anything after that, or…?**

Oh yes, then it… then it kicked in, after we phoned and said where are, what’s happening…?

**Oh, okay, okay. So you took the initiative** (Yeah) **and… yeah.**

Well, in fact I had an appointment pre-arranged with the physio, that the consultant had arranged for me when he saw me initially, because he could see I was struggling with my left leg. So he arranged for me to go to the [name of hospital], to see a physio. And that was… (Sighs) a catalogue of disasters, as far as the appointments all went there, so it wasn’t straightforward. But anyway, I got the… she then left, so I got another physio appointment, and when I turned up for that, that was only sort of person I saw in that… that kind of time after I was diagnosed **(Mm-hmm, yeah)**, she didn’t have a clue what was wrong with me, so she started off asking how I was doing, was I feeling better, etc. You know, and I turned up saying “Well I’ve just been diagnosed with this,” you know? No, not feeling very good at all. So she then got into action, to give her her due, and she’s been really good, and she was horrified that she didn’t, hadn’t been informed.

**Okay. Okay.**

So it’s not… well, it wasn’t good was it? Because she should know, she should’ve known what was wrong with me.

**Yeah.**

It’s just communications, which had been the… I mean, once I get to see the people, you know, like I’m not complaining about any care I’ve had. But communications with something like this… I think it’s the case of, there’s nothing we can do, so… you know, off you go.

**Yeah. I… at least the communication between the different professionals should…**

Yeah.

**Yeah. But I appreciate this is difficult to say as well, but if I can just get a sense of during those three weeks not receiving support and… what were the kind of thoughts and feelings that were going through your mind?**

I can’t really remember now, I just… it seemed a long time ago. Well just constantly worrying about things that… I just, well ever since I’ve had the diagnosis, all I’ve… you know, life just gets taken over by chasing things and working out what’s going to happen next and, you know, etc. So, you know, it’s just your life stops that you knew, and yeah… I don’t know. It’s hard to… you try just to carry on, I don’t know. I can’t remember. I just kept thinking, ‘well surely, it...’ I was told that it was over Easter, bad luck, I was told, you know, it’s happened over Easter, the people you need are all away.

**Okay.**

But I still don’t really accept that. You know, it’s not really…

**Yeah.**

Anyway. Yeah.

**So and also kind a certain sense of numbness as well, but like…**

Yeah. I mean, how do people feel with… (Mumbles) You know. ‘Cause it’s a terminal illness diagnosis, isn’t it? You’re not going to feel very good, are you?

**Yeah. And… I guess at those points, was the worry more about the prognosis and those sorts of things, or…?**

I think it was about what… what would happen next. What… what is the, where’s the… I was offered, and I am taking part in a clinical trial, a [name of trial]. But that’s, again, been, you know, and I’ll be seen three months after diagnosis on that. So I’ve held off the Riluzole and it’s all the worries about have I done the right thing, you know? That’s really tough to know.

**Yeah.**

I’ve not been really, you know, my consultant was very anti-taking it. And yet I think, ‘well it’s my life here, maybe I should’ve thought more closely about taking it.’ I know it doesn’t do a whole lot of good. Some of those sort of things you could do, I could do with, you know, there was no… I don’t know where to go. Like there is the [charity organization], of course **(Okay)**, and I have, they’ve been… they got in touch, once the whole thing kicked into action. Once I saw the link person **(Yeah)**, then things started to happen. But I could’ve done with that the following week, or even somebody that day.

**Okay.**

You know, you walk out of that surgery, being given that diagnosis, and the only person that come and talk to us was the nurse who was in with us. And she had a conversation with me about my diagnosis in the waiting room, in front of everyone else. And I just… you know. I don’t think that’s appropriate, we should’ve been, I could’ve done with just being sat down somewhere. Offered a… you know, the proverbial cup of tea, or something, and just been left for a bit, and just offered… but phew, you know. Yeah.

**Gosh. Okay. Okay, so that sense of just being left and… you would’ve wanted help, kind of…? (Overtalk)**

Well (overtalk) I would have thought anybody would. I don’t know, perhaps they wouldn’t. Perhaps they’d rather be left to… how do you take that on board, you know?

**Yeah, no, I’m just asking because different people see things differently about… some people may not be ready to accept any help or information just yet. But in your case it sounds like you wanted to know** (oh I) **what was going on… (Overtalk)**

Yes. I just like to know, you know, suddenly having been in, you know, very… you know, you’ve got… for one, one minute you’ve got a life where you’re in control and you’ve got a future and, you know, and you’ve got a career. And then the next minute it’s all gone. And just to be left… luckily I’m not on my own. But had I been, I don’t know what I’d have done. No wonder people get, you know, people get very desperate, don’t they, at this point.

**Yeah. Yeah. And… what did you do, in terms of how you coped, or where did you find your support from?**

With my partner.

**Okay. Just talking through it, and that… (Overtalk)**

Just crying.

**Yeah.**

I mean, you know, what, how do you deal with it? I don’t think that, you know… very few people you can talk to about this. I’ve got a very good… my sister’s excellent, who’s a nurse, and understands a lot, and she’s great. She doesn’t, there’s no, you know, it’s down, very straightforward, down to earth sort of… my children have been amazing. But, you know… terrible thing to inflict on them.

**Yeah.**

So yeah, it’s very much in house, you know.

**Really. Mm-hmm. And… is… so since… since those few weeks, and the bit after diagnosis as well, and now, have your thoughts and feelings changed about the situation, or…? Have you looked at things differently…? (Overtalk)**

How…How do you mean?

**I’m just wondering if… because sometimes say, if you’re really shocked and, at diagnosis you may feel differently about the situation. And I’m wondering just whether over time that’s… that’s changed, or…?**

No, it doesn’t get any better. Because it can’t, because your body is beginning to crack up. So every day you’re aware that it’s getting worse.

**Okay. Yeah.**

So I don’t see how you can ever feel better about it. Maybe I don’t get so absolutely distraught. But it doesn’t take much for me not to get like that, so I have to be very careful about what I talk, who I talk to about it, you know. Or who I see. If I have any dealings with anyone who pities- who, where there’s any pity… and people will, even family. Not my close family but, you know, they sort of look at me, and look at you like this, and look like, you know, “aw”, like somehow you… you’re not, you think, you’re not you, you know, you’re only defined now by your illness.

**Right.**

And I can’t bear that.

**Yeah.**

Understandably.

**Yeah.**

So luckily, I mean, pretty much all of my friends have been amazing, you know, just treat me as me. And it’s just a nuisance, but it’s not… you know, it hasn’t changed me.

**Yeah.**

But there are people for whom, who can’t cope with it. But I have to keep it at bay. So I suppose I’ve learnt that, you know.

**Oh okay. Okay.**

I don’t want any… you know, there’s that side of it. I mean, I’m starting to look a bit more online about it, I suppose to sort of come to terms a bit more with what’s going to happen. That’s gradually changed, I couldn’t do that to begin with, you know. It’s not like you’re looking up ‘I’ve got a broken leg, how long’s this going take, etc...’ Because there’s a positive end to a broken leg, there’s no positivity here. There’s no good end, is there? There’s no cure. The most positive thing I can do, is do the trial, not for me, but for the future of the disease, you know. I don’t expect miracles, obviously, from the trial. And it’s, you know, as you – I’m sure you know, it’s fifty… it’s placebo drug trials, a clinical trial that… the chances are that, well a 50% chance of not having the trial drug anyway. So… but at least it feels something positive, I have to have that, I have to… I had to do it. I think I will definitely do it, I haven’t… until I see them in July, I’m not 100% certain **(Yeah)** that I can face it, frankly. But **(Yeah)** my aim is to, because at least it makes some sense of this. You know, I need to sort of try and make some sense of it.

**No, that… that makes sense, to me as well. Because a load of other people have said similar things** (Mm) **about, at least not... for you taking part in research and things like that helps** (Mm) **in some way to…**

Yeah. It’s just one, you know, the more I look, the more desperate you get about it, though, don’t you? Well, I mean, if you’ve got it. Because there really doesn’t really seem to be any other understanding of where it’s come from to sort of notice the, you know, just get those biomarkers to sort of know where… where do you start with stopping it, before it starts, you know? And all the things you read about the eating habit, or the antioxidants, you know, I’ve been through the lot, I’ve read everything pretty much out there that there is, in the research field.

**Okay.**

Well, I do all that, you know, am… active, fit, healthy, you know, you know…

**Yeah.**

It has… I don’t know. I mean, I’ve not… I don’t know whether this is the genetic version or not, I’ve not had that test.

**Okay.**

I’m tempted to. But it wasn’t really offered… well, I don’t know whether it was offered, I think if I’d asked they could’ve done. Because I know there’s some quite interesting research going on with the genetic variant, and that sounds quite exciting. So, you know, yeah. And of course that could benefit the non-genetics as well.

**Yeah.**

And all that sort of stuff. (Laughs)

**Yeah. Yeah.**

Which sounds really positive, doesn’t it?

**Yeah.**

I did hear the lady speak about that.

**Oh, okay. Okay.**

Professor. The lady, I’ve forgotten her name. [name of place], isn’t she… she’s Head of the school at [name of place], isn’t she, the medical school, I think.

**I think I know who you’re talking about, yeah. Yeah.**

But yeah, I did go to an MNDA meeting to hear her speak. But of course, mine isn’t… yeah. Yeah. Yeah, you start to think, no wonder people fly off to China or something and have dodgy stem cell research. (Laughs) You can understand it.

**Yeah. Yeah.**

You know, life, you just want to prolong it, and you don’t want to… and there is a feeling, and this must be common, I imagine that at some point – I haven’t looked yet at the paperwork that the [charity organization] sent about, you know, passive euthanasia, or whatever it is, you know, I’m going to have to look at that soon, I realise that. But, you know, there’s a point at which I would not want to be, you know, sort of kept alive. So… I mean, I’m getting nearer to be able to work that one out.

**Right.**

So that’s taken a bit of time, but… maybe not, it’s only two months, isn’t it? I’m not there yet. (Laughs) I still feel… I still feel all right. Yeah.

**Yeah.**

But, you know, I can still walk and my arms are still okay, I still swim, you know, I’m still pretty active. But it’s getting slower, no doubts.

**And what are the… the main bits that are challenging for you, now, with the symptoms…**

Oh you mean… well, I mean, my walking… it’s my balance.

**Mm-hmm.**

Fundamentally it’s my balance isn’t it, it’s the core that kind of goes a bit, you know, something’s really wrong there, and I… I do take a lot of note of the physio, and I’m getting, I’m having some private physio, just to keep that, you know, well, it’s just something positive, **(Yeah)** otherwise I… so, yeah, there was something I was going to say about, needing to do something to help it, I can come back to that, because that’s quite important for me. And I’m sure loads of people… So it’s the walking, I think. Yeah, it’s not being able to go out independently, I suppose. I haven’t driven for a long time, I stopped myself driving, nobody told me to stop driving, it was me that thought, ‘well, you know, this leg isn’t good enough,’ and **(Yeah)** I spoke to my doctor about that, actually, and she said “Yeah, I’d stop if I was you.” And I thought, ‘well, it is quite dangerous, I think perhaps I should.’

**Yeah.**

So I’ve still, I must sell my car, I’ve still got it. But I don’t want to drive using hand things, because actually it won’t be long before probably I can’t use my hands… there’s no point, I don’t, you know, that’s not me being defeatist, I just don’t see… it’s not that important, I’ve got, you know, an amazing person who is always there for me, and I can always use taxis. Although taxis independently aren’t a lot of good, because I can’t get in and out on my own terribly well. I need someone with me, I think that’s the tough bit. I’ve kind of lost, I can’t just… but I mee- you know, I meet friends, I still go out and about, [name of husband] just, you know drops me off, and I’m with friends. But it’s the nervousness around people. Because of my lack of balance, if they bump into me, and I’m not, you know…

**Oh…**

I just, I don’t mean… people don’t make me nervous, it’s just they’re, you know, I can walk on my own with a stick, as long as I’m not worried that someone’s going to rush across, you know, kids are around or whatever.

**Right.**

Because if they bump into me, I… I just go. And I haven’t fallen much, thankfully. But that’s because I’m mega-careful. Because I know if I fall and break something, I’m really messed up. So, no, I’m really, really careful about that. I suppose I’m just worried about my arms, they just feel stiffer, you know? I know that they’re not right now, but I can still swim so, you know, I keep that up. I just think exercise as much as possible.

**Mm-hmm?**

Yeah.

**Yeah, you mentioned something about the need for positivity I thought I’d just**

Yeah, it’s just doing something… yes. I mean, in all… you have to keep going, you know, seriously to keep having some means of going, keeping going, basically. I think if I can do something, as I say, like going swimming and… so we try and fit in some things like, I don’t know, just making sure we walk somewhere, like we’ve been to town this morning and I will… you know, just walking around **(Yeah)** and we do a lot of (mumbles) (Laughs) Like that, you know, things that we would normally do and, you know, I still go to [name of place]. We’re going this weekend. Oh no, to my son’s in [name of place], (Stutters) next week, the following weekend we’re going up to [name of place] for the weekend, we go on trains, I’m still doing that.

**Yeah.**

I’ve given up on the tubes, they… they really terrify me, now.

**Oh, yeah.**

Because I can’t use the escalators anymore.

**Yeah, that’s…**

They just move too quick. And I get off, I nearly fell… I forget how long ago, maybe a month ago. And I just thought, oh, I felt so scared, and just sort of shaking, in bits, and [name of husband] was shaking… it was just awful. So I thought, ‘what am I doing?’ You know, so I just get taxis everywhere now. It’s easy, isn’t it? Easier. But I’m determined to keep doing that, I’ve got a son up there, so… yeah. So we do that. So, you know, in many ways I’m still doing as much as I did. I was going to retire anyway from teaching, this May. That was my… and I’m doing an MA in something else, you know, fun one. I’ve done all my academic stuff, now it’s fun. Although I’ve still got the dissertation to do, whether I’ll get it done, I don’t know, but I’m determined to do it. So, you know, I’m still, you know, still involved in other things. So…

**Yeah.**

Yeah. And the idea was that I could sort of retire. I was… I didn’t do last year, I could kick myself now. Hindsight’s wonderful, isn’t it? I had, I just took it on, so I thought, I don’t know, I thought, ‘oh well…’ but I could’ve had another year of just… I could’ve had, that would’ve been a year where we wouldn’t have had any work to… anyway. Can’t look back, can you?

**So is this… I didn’t catch that, is it…**

As I say, I took another year, I wasn’t going to, I’d already retired last year, but I did another year.

**Oh, okay. Okay. Oh…**

I only missed two months, actually, of sick leave, so…

**Yeah.**

Yeah, I missed the last one… I… well, I fell again at work, actually, after I’d been to see the consultant. I fell the following week. For no reason, this time, you know, I couldn’t blame a bag this time. I just literally keeled over, and I thought, then, ‘mm’. Yeah. I was beginning to think… I knew then it was on a spectrum of things. But I didn’t know where I was on that spectrum, but… I suppose I thought MS or Parkinson’s.

**Yeah, you never…**

They were the better options, of course. But I know they’re not… don’t think I think that that’s a picnic, either, I didn’t mean that whatsoever. But it hasn’t got quite the… when you look it up, the sort of… no. No, I wouldn’t have wanted either of those, I didn’t mean that. At all. Yeah.

**That’s all right. It’s quite normal to just compare it to other…**

Well I know. I try not to, you, but you find yourself thinking that.

**Yeah.**

I know. I mean, I… my… I lost a, yeah, one of my parents really young from cancer, just dreadful. I mean, really awful way to go. And it… this is dreadful coming out, but I remember thinking to myself, ‘well it’s not that, I’m not...’ ‘Cause I’ve always worried about that. …still time to get that. But, yeah, I don’t mean to compare at all, there’s no… yeah. (Laughs) Neither of them are very good, are they?

**(Laughter) No. I was just thinking, in terms of… we spoke a bit about getting information and...** (Mm) **Because I guess you sort of hinted at certain information you wanted to know about, and you actively went looking for** (Mm)**. But some information is probably** (Mm) **too much too soon** (Mm)**, that kind of thing.**

Yeah.

**Do you think there was any… any point in time where you were more receptive, I guess, to reading about things, or… like even in terms of what we present, should we pay attention to when it’s a bit too sensitive, and how…?**

I think, when I couldn’t… and I still can’t really look at all the information yet about, you know, the latter stages of this, I guess. I mean, one of the issues with this disease, isn’t it, it is sort of… I think there is more about it in the media, interestingly, I think one is seeing more. Sadly the… I read about the footballer, you know, her husband, and there’s obviously I know about the rugby players. But once that happens, you start seeing, you know, it… you know, I’m desperately sorry for these people but, you know, it… somehow it’s out there a little bit more, isn’t it? And it’s because it isn’t, and it’s always, you know, I think it’s a disease that is so feared and so surrounded by hyp- you know, hyperbole, if you like, you know, it’s the… when you just have to type it in, and all you get, you, the first thing you get is ‘the worst disease you...’ you know, when, if you look on Google, that’s what I mean, **(Yeah)** if you like type in some, you know, to have a look at it, the searches are… you just look at it, you can’t even look at them, so I just think, you know, fatal, fa- you know, all the words that are highlighted.

**Yeah. Yeah.**

I mean, who wants to see that? So there needs to be some kind of way into it, that kind of bypasses all this extreme stuff. Which, you know, is true of course, a lot of it. But it sits… so… so… I don’t want to look at that, I guess, because it’s still shrouded in horror, I suppose. You know. And… you know, you just read that it’s… oh, I don’t know. I don’t know when I ever will. I mean, I filter it through [name of husband], through my husband, you know. He gets it, he’s read it.

**Okay.**

And again… oh, and I know a lot of people probably, you know… I’m in touch with the [charity organization] via the assoc… visitors, the association of visitors, and I gather that’s not uncommon.

**Oh, okay. Yeah.**

That people **(Yeah)**, you know, poor him… but you have to, you know, he just said “you don’t need to see that, yet.”

**Right.**

So he is doing that for me.

**And then he’ll present that to you? (Overtalk)**

I mean, I just can’t… if it… if it… I could do it for someone else. But to do it for yourself, to have to look at it yourself, that’s just not in my character. But there must be people who can do that, I guess.

**Yeah.**

I’m not putting my head in the sand, I know what I’ve got wrong with me, and I know what my life expectancy is. I’m under no illusions about it. But at the moment, I need to carry, you know, to… in order to survive, to stay ali- you know, to not, you know finish it all, frankly, I need to be positive, in the best I can. And knowing what’s coming round the corner is, you know… why would you look? My doctor gave me a good analogy. She said, she spoke to… she said it’s like, you know, “you stay up on the top of the cliff on the meadow, occasionally you peer over and you see down the abyss, and you… yeah, you peer over the cliff, but you don’t do that unless you have to”. You know, I’ve got the analogy she meant, you know, stay back in the meadows, you know, stay back as long as you, as much as you can. There will be times when… you know, I read about this… this… footballer and everything, you just start looking a bit more and you think, ‘yeah, I was thinking, you know, what’s this...’ Sometimes it, you know, I’m only slightly nearer to thinking, ‘is there something at a similar stage, you know, what’s their feelings of, you know, how are they coping with it?’ So… so it’s the sort of disease, isn’t it, where I don’t want to go to the [charity organization] coffee mornings, I don’t want to see people further down the line than I am.

**Yeah.**

And I, you know… that’s not out of hard- hardness on my part.

**Yeah.**

I just have to survive, you know. I’ll support anything, and do anything I can otherwise, but you know… and as a volunteer, I could work there.

**Yeah.**

That’s different.

**Yeah.**

Without the disease. But when you’re in that situation, you don’t really want to see what’s down the line.

**Mm-hmm.**

Well I don’t.

**No, I… I completely understand that. You’re… you are being realistic about it, but you also need to have some… some kind of hope to keep you going to… (Overtalk)**

You have to, you have to put up those mechanisms that help you get through the day.

**Mm.**

You know. Otherwise I’d never sleep. Luckily I can sleep and, you know, and that’s because I have most of the days are on… on the meadow, you know, the top looking out, I’m not looking over. And…

**That’s a really good analogy, I’m going to remember that. (Overtalk)**

It’s a good analogy, isn’t it?

**Yeah. Yeah.**

She said she’d been speaking – she’s lovely, that doctor of mine – and she’d spoke to a colleague of hers, who worked in, you know, in hospices I think and what have you and, you know, I think she was asking, “How do you...” You know, ‘cause my doctor had never seen a case like this, she’d never come across… and it’s so rare, isn’t it?

**Yeah. Yeah.**

So she was… a similar age- you know, a bit younger than me, but it makes, it must make you think, ‘my goodness,’ one minute, you know, February I was running.

**Yeah.**

And now, you know, I shan’t be doing that again. But… yeah. Yeah.

**Yeah. Is… I know we have covered a lot about what the emotional experience is like and how you cope with all of it.**

Mm.

**But I was just wondering if there’s anything you’ve missed out, or haven’t covered?**

Like how I cope, you mean?

**Yeah.**

Yeah.

**Because we spoke about support, and…**

Yes. I mean, I’ve got a sort of link, I’ve got someone now I can contact if I think I’ve had a problem seeing a consultant again. I just… I can’t deal with the ringing up any more, I just get… but he, this person will… I just email them, and they’ll take it on board.

**Okay. Okay.**

And deal with it for me. So that’s… you know, I’ve… now I’ve got, now it’s kicked in, the support, you know, I know there’s people there. I’ve got this very… person via the [charity organization] website, there’s a voice banking person I’m in touch with.

**Yes.**

And we’re… I’m supposed to get back in touch with them, actually, because… I know what happened last time, it was ‘echo’ was wrong, but I will do that. I definitely will do that. And at the moment, it doesn’t feel like I’ve got to do it soon, because it doesn’t feel like I’m doing it for… for the reason I’m doing it.

**Yeah.**

If that makes sense? **(Yeah)** At the moment it’s a bit of an experiment, and I’m quite happy to be doing it. So as long as I can deal with it like that. I mean, yeah, I just… I just have to be very protective of what I look at about it, and I’ve come to a point… most, you know, I can detach a bit, when I’m looking now. A bit better.

**Okay.**

I’m not quite, you know, I’m looking at it… yeah. I think the trial bit will make me think again, I don’t know. We’ll see. I’ll face that when I go. I’ll see how I get on with that.

**And let you know like if it keeps changing how you feel about… (Overtalk)**

Yeah. Yeah. I keep thinking perhaps you, how do you live with it when you are so incapable? And I… you know, that really scares me.

**Mm.**

You know. I… I suppose I haven’t mentioned feeling of being scared. I don’t know whether I’m scared for me, but really scared for those around me. You know, and how they cope with it.

**Okay. Okay.**

I think probably more than me. Because I’m absolutely… I can’t do anything about it, but for them, you know, it must be so tough. And I think that’s probably the hardest thing.

**That’s a big worry, isn’t it? Yeah.**

I don’t know about worry, I suppose it is a worry, isn’t it? There’s nothing I can do about it, but I… I’m just really sad. I suppose sadness is the most dominant emotion.

**Yeah. Yeah. It would be, wouldn’t it. Yeah.**

Yeah.

**Yeah, and I guess other stuff you mentioned as well about positivity and continuing to do the things…**

Yeah, as long as I’ve got an aim, a goal, you know, something to focus on.

**Right.**

Like, you know, we’re pretty packed out on the old calendar, you know, to keep putting things in, you know, for weekends. I… I’m learning to pace myself a bit better, I do get tired-er.

**Okay.**

Which is a pain. But I, you know, if I sleep in a bit, I don’t care anymore, you know, I’d never have done that. And that was… you know, it’s so… I kind of… it’s like hitting a brick wall, this. I’m sure it is for so many people. You know, everything was, you know, I don’t know, you… one just had a future planned, you know, I might be sixty but, it was just a new phase beginning, you know. I’ve got a grandchild due next month. And, you know, I just think that’s, again, it’s wonderful, but it’s just tinged now with… you know, my son is just distraught, obviously. Both of them are, for me, you know, they never show it when they’re with me. But I… well sometimes they do. And they need to, don’t they? But they’re very close to their dad as well, so… they’ll be all right. But, you know, I lost a mother young, so… young, you know, young actually, I was younger than they are. But you never get over it. So, you know, obviously.

**Yeah, so you’re concerned for them…**

Well, I’m concerned that it… it changes their lives.

**Yeah.**

And I’d have died at some point, wouldn’t I? You know so obviously. But a different feeling. My father’s eighty-nine, and you know, a couple of times recently we’ve thought ‘this is it’, you know? And obviously I’ll be heartbroken and it’ll bring up all sorts of… I don’t know, all sorts of emotions, of course it would. And I don’t mean to sound heartless at all, but he’s had a really long and fruitful life, and achieved loads and… you know, not just in terms of material stuff but, you know, and I think, ‘okay, it’s… you know, I can celebrate his life’, let’s put it that way. But for losing my other parent, I was so much younger, that was just devastating.

**Yeah.**

And wrong.

**Yeah, I see what you mean. Yeah.**

So for them it’s not, you know. It just seems early, doesn’t it? It’s never going to be the right time, I’m sure if I was ninety, I would still be feeling cheated, yeah.

**Yeah.**

(Laughs) (Overtalk) You want more, you want to be greedy, yeah, you are, because you still think… yeah, we’d just both retired, you know. But there you go. I think you have to make the most of what you’ve got, and I mean, I do think that, my sister said that to me, she said “It’s not the life you planned, but it’s another life, you’ve just got to live it the best you can.” You know, the best life you can live. And that’s, I guess, I – that’s most of the time.

**Yeah.**

I can hold onto that.

**That’s good.**

Yeah.

**Yeah. No, thank you, that’s been really… I think I can get a sort of good picture of both the problems and concerns, but also how you manage to deal with it, and** (Yeah) **it’s been really… (Overtalk)**

I mean, deal with it… you know, days… are they different? Some days can be. You know. I just… and I just, well, I watch ‘Sixty Three Up,’ I don’t know if you know that programme that’s on, because it’s a similar age to me, and I’ve seen it since the start, but they take a child… so they started sixty three years ago… oh, well, anyway, they took a child who was born sixty three- and then they, seven, you know, take, I’ll give you a child of seven, I’ll give you the man, you know that… and they’ve done it every seven years, it’s fascinating. But this, I shouldn’t have watched it, and I was… it finished me off for days, because one of them, one’s died, and another one’s terminally ill, and I… what I… how I sat there and… why was I watching it? I had no, I thought I was stronger, I thought I might be able to cope with it. But that… that night was terrible. And it took me a while to sort of, you know, get my equilibrium back after that. Because that really **(Yeah)** bring it home, brought it home. Yeah. Things like that, that’s, you know, my fault, I should never have watched it. But that, you know, I’ve got to sort of watch, you know, carefully, if anything like it comes on again, I will just think, ‘no, I can’t.’ I don’t want that brought home to me. So diff- (Stutters), everything, you know, it’s different.

**Yeah. Some things just trigger…**

Some things trigger it, yes.

**...those emotions, yeah.**

But it can be, that was an obvious one, wasn’t it? I might have known that wouldn’t have been terribly helpful for my state of mind. But there are other things as well, sometimes, which just, you know, you just find yourself coming in floods of tears, and you just think, I mean, where did that come from? You know, then I’m… I can back, because I’ve got somebody with me who’s very calm. You know, I’m really lucky.

**Mm-hmm. That’s good. (Laughs) Yeah. If there’s… there’s anything else you kind of skipped, we can come back to…**

Yeah, I just think… I mean, I… I don’t know, you know, it’s a difficult one, isn’t it, because it is a very emotional topic, isn’t it?

**Yeah. I guess the other question I wanted to ask you as well, because I’m developing an online resource for people to help** (Yes) **them cope as well, I guess you did mention certain bits when we were talking about how you look for information online and things like that…**

Oh yes, yes. Yes.

**Do you think there’s anything we need to pay attention to, or keep in mind when… anything that’s…**

**(Non-interview chatter)**

I don’t know. Perhaps… is there, it probably is question and answer type… you know, they’re quite good on websites, I sort of go for question and answer type… you know the ones that have a Q&A on a website, and you think ‘oh, has anybody asked that question that I want to know?’ You know, and then it all get… you know, it sort of… oh, I don’t know.

**Oh like a… like a frequently asked questions…? Yeah.**

Yes, that sort of thing. There probably is one on there, I don’t know.

**Okay. Thank you.**

I mean, I haven’t looked at other websites for people with any illnesses, you know, so I don’t know what, what is on them. But it… but this would be for people… so would it, would it sit **(Yeah)** within the [charity organization] website?

**Well, I’m not sure where exactly it would sit at the moment, but I guess it’s hard for me to ask for your feedback without actually showing you what it looks like, but I guess what I’m trying to gather is, do you think you might look for help for emotional concerns and issues** (Yes, probably) **online? Is that an okay… (Overtalk)**

Yes, yes, I think it is. I think it is, yes. Yes. It’s sort of detached, but not, you know, there’s a sort of… I don’t, can’t explain it, but I think… yes. It’s… I think I would. **(You would, yeah, okay)** I would. Yes. Yes. I’m trying to think of the sort of things I would look up, really. Is it, you know… because I have been offered… I don’t know whether I sort of look like I’m about to collapse every time I go to one of my physios, or they… I don’t… but sort of help with, you know, speaking to somebody. I suppose they offer it to everyone, I can understand that. Who would I see… phys- psychologist…

**Psychology? Yeah.**

Yeah, psychology. And I haven’t taken that up, because I don’t know what I would get out of it.

**Okay. Okay.**

So perhaps something just slightly removed from a psychologist on… well it’s actually your field of course **(Yeah, yeah)** isn’t it, I beg your pardon, yes. So that’s… I haven’t found that I want to do that, yet. I’m not sure I will. And I’ve talked to [husband] about it. I’ve never… you know, it’s just something that’s completely not in my realm to talk about with people, **(yeah)** and I just know I couldn’t hold it together, probably. And maybe psych- they would be used to that, they must be if they’re talking about this sort of thing. But if I could do it on a platform, you know, on a, on a website, might, you know… it might be different.

**I see what you mean.**

I don’t know whether that’s too detached though for psychological help. I don’t know.

**If… I just think it… it just really varies on how you want to receive help, in a way.**

Yes.

**Some people feel comfortable and want to talk to a person.**

Yeah. Yes, yes, I can understand that. I mean, I…

**Other people just don’t…**

Yeah.

**...want to as well, and that… that’s equally fine, there’s no right or wrong** (No, no) **way of coping with it, so…**

But it, I must say, the emotional side of it has been… it just… you know, like a tonne of bricks hit you. Hard to know because you’re dealing with that and deterioration of physical things. **(Hmm mm).** So the two together, it’s a… you know, it, you know, terrible… I mean, do other… I don’t know, I presume, you know, if you’ve got sort of other terminal conditions, this isn’t, you know, I haven’t got a monopoly on terminal illnesses here, have I? There are things above us, and I don’t know what there is there for that. Whether there’s anything similar, I don’t know. But...

**Yeah. There’s something like that.**

Yeah. Because it just seems this is… this is… you know, this, [charity organization] is, I suppose it’s quite young, is it, forty odd years old, isn’t it? As an association.

**I actually don’t know how old they are.**

I think it is, actually, I think it’s forty years. Is that old for a charity, I don’t know. They do amazing things, yeah, forty years. It’s it… fortieth anniversary?

**Okay.**

Yeah. Didn’t really know anything about it at all… wouldn’t have known a thing, would you? Well you’d know about… what’s his name, Stephen Hawking’s.

**Yes.**

Just what the person told me when I’d been diagnosed, she said “well you must think about being positive, think about Stephen Hawking’s,” that’s what I was told. And I thought, you know, standing there in front of all these people in the waiting room thinking, ‘sorry?’

**Yeah.**

How am I meant to feel positive?

**Yeah.**

You know. And he’s a one-off, totally, isn’t he, in terms of how his disease manifested. Not something that was a very appropriate thing, I didn’t think, to say.

**Yeah.**

But… you know. And I was lucky, apparently, she told me as well, that it started in my limbs. I don’t feel very lucky. You know, there’s that sort of… (Overtalk)

**Yeah. So it’s communicated, isn’t it?**

So I… I suppose, would I have gone straight to a website then? I certainly didn’t go straight to the [charity organization], I couldn’t… didn’t want to go anywhere near it. Perhaps I was in denial for a bit. There must be stages that we go through. It’s like it is with anything, isn’t it?

**Yeah.**

I don’t know what stage I’m at, but I’m not sure I’ve ever really denied it. But I may have denied that it’s going to affect me, does that sound strange? No, I…I still occasionally think it’s a terrible mistake. You know, I’m going to suddenly wake up **(yeah)** and, you know, I can just leap out of bed.

**Yeah.**

I do think that.

**Okay.**

But…

**No, that… that is helpful. It’s not denial, but I see what you mean. Sometimes just not… it may be too soon to look up how things…**

Yeah. I don’t think I need to really know, in a way. **(Hmm)** Actually. It’s going to happen. Do I want to be reading about it? I’m not the sort of person that probably does.

**Yeah.**

You know, I’m sure there are other people that are on Goggle the whole time, probably. I don’t know. But I’m not… no. Goodness. I mean, there’s far too many other things, nice things to be doing in what time I’ve got. (Overtalk) Yeah, I mean, I’m very aware that, how precious time is. And there have been some very positive things, actually, in… I’ve seen my children way more than I would have done.

**Okay.**

You know, not that we weren’t close, just that very lives, we’ve got busy lives, but we’ve made such an effort, now, and they have. And I think, actually, that’s really, really positive. So there’s, you know, I… if one has to look for… **(Yeah)** if one wants to look at… silver … I don’t think it’s a silver lining, do you, but… you know, it’s… you know.

**Yeah, I know what you mean.**

I’ve said that to [husband] quite a lot, and we spend all our times with going out and doing things, which is just lovely. You know. So… maybe that’s a real positive?

**Yeah. Making the most…**

I think, you know, it makes you realise the people who, you know, value. Yeah. So that, I think **(Okay)**, you know, that sort of from an emotional side, I suppose, is a positive. Yeah. Yeah. It has its downside, though. (Laughter) But yes I would, I would… I would look something up.

**Okay. That’s good for me to know…**

Yes. Yeah.

**Yeah. Yeah.**

Because that’s a side I could probably have done more with, help with.

**Right.**

Earlier.

**Right. Yeah. Yeah.**

Actually. The physical stuff, well, you know, because… (Stutters) They’re interrelated, aren’t they, of course they are, one impacts the other. But… yeah. I mean… (sigh) I don’t know. Yeah. Yeah, I think that side of things could be a, probably… you know, the visit, the sort of link visit is very cli- clinical, really. It’s going through a set of questions, this is a visit I had, you know, after three weeks- when it… and, excuse me, and it was all very, very clinical. And he was talking then about things like breathing problems and feeding problems and speech problems, and this was three weeks after I’d been diagnosed, when actually I felt fairly okay, apart from a slightly bad left leg. And I was like, “Whoa, you know, first I’ve heard of this, do you expect me to have looked this up in the three weeks since diagnosis, or what? How do I know?” And it was really, you know, and… I was…

(Phone interruption) (Non-interview chat).

That was… and then, you know, I’ve got a very… we got a copy… we’re sent copies, now, obviously of all our medical… of everything, aren’t we, this freedom of information thing.

**Oh, okay.**

So the copy that went to my doctor was, ‘I have seen [name of patient]...’ And it went through all the things that he, how he was kind of rating me. And one was cognitive abilities, and I thought, ‘I didn’t even know I was being assessed for my cognitive abilities,’ I didn’t know they were going to go. I didn’t know that. So to read that, and I was still doing my MA final assignment at this point, and I thought, ‘my God, I haven’t got any...’ Thankfully I mean, passed it with flying colours, So I thought, ‘there’s my bloody cognitive ability.’ You know. Anyway, I didn’t mean to say bloody but, you know, I just meant **(Yeah)**, you know, I’m all right. But it was just, right, that, I couldn’t look at that letter. I went about three paragraphs down and I said “I don’t want to read this.” So it’s all very bald for it, there’s no emotion in any of it, there’s no understanding about how that is impacting on people. You know, if I… again, I say, I keep saying, if I was opening it on my own… we got to a point where I didn’t open any letters until [name of husband] was with me. Because…

**Yeah, I see what you mean. Just to…**

I just could not deal with what was in them. It was all so bald. And… I know it’s going to go, you know, ‘Dearest [name of patient]’ you know, it’s not going to be all sort of flowery. But it’s pretty stark stuff to deal with.

**Okay.**

That’s communication again, isn’t it? But, you know. Yeah. And people maybe deal with it differently. But so the emotional aspect of that isn’t, I don’t think…

**Well, yeah, yeah, well the communication angle can also trigger the emotions.**

Yes, it certainly does.

**It’s not just what’s happening, it’s how it’s communicated to… (Overtalk)**

Well it’s how it’s communicated. I would say that’s the thing that’s been the most difficult for me **(Okay)**, how… you know, totally. You know, I got a letter for the MND clinic before I had an appointment to tell me what it was. Because of the mess up of whatevers. You know, so I’d… luckily I didn’t know it was this clinic, but anyway, it doesn’t matter, going into it now I knew it, anyway I found out it was. But, you know, had I known that was the clinic, that was before I was told what it was.

**My goodness.**

So things like that have been… but it’s one thing coming after another, you know, and chase, chase, chase, you know. Hmm. But I always say you’ve got to be pretty on it, to be ill. You really have. You’ve got to be, you know, pretty on it. And you’ve got to be pretty determined, you know, I mean, I have fought hard to get that appointment very, very swiftly at the [private hospital] even though I was paying for it, I was still given an appointment three weeks down the line, and so “I’m just not having it, you know, no, I want them now,” you know, you have to… you have to sort of be able to do that, don’t you?

**Yeah. Yeah.**

You know?

**And know how everything works and…**

Yeah.

**Yeah.**

Yeah, and I don’t care that I jump, you know and goodness me, I’d still be waiting for an appointment if I hadn’t done that, I’d still be… well, I wouldn’t, I’m sure. You know, six months.

**Yeah.**

I probably, you know, and maybe I’ll be seen in July, I thought, no wonder people… it’s… that’s nothing to do with the people I see, they’ve been very, very good. That’s not what I’m saying, it’s the system, isn’t it, that’s…

**Yeah, that you’d be worrying about.**

I mean, neurology is under-resourced, hugely, isn’t it?

**Mm-hmm.**

Across the… across the country. And we have got this on the doorstep, so no complaints there. But, you know, I don’t see much of that, I’ve had an appointment through the six-month gap between appointments with the consultant, and that makes you, emotionally that’s a hit, because you think, clearly this is, you know, that’s too long… I mean, I queried it because I was told four months, and then the letter comes this week that it’s six months, and I thought, ‘six months?’ You know, that’s just… so that’s emotionally, that impacts me. That can knock me for six.

**Yeah.**

Because I have to then go into action to chase it. You know. Luckily someone’s doing it for me.

**And this is just with the neurologist, as like a check-up, or…?**

Well it’s a re- (Stutters) his clinic’s reassessment that, the fact it’s only six months, a six-month gap, tells me all I need to know about what can be done, you know… it’s not very hopeful, is it?

**Oh, I… yeah, yeah.**

Do you see what I mean? You just think, ‘oh, okay.’

**Yeah.**

But actually, I have a letter to say that he… he said “in four months...” So I don’t know what’s happened there. But, you know, it’s just another sort of… you know, I just think, ‘oh, goodness...’

**I see what you mean.**

Goodness. Anyway. Yeah, no, that’s… but it’s all emotionally draining.

**Yeah. Yeah.**

When you’ve got enough to deal with.

**Yeah. You could be getting on with….**

I mean, those sort of question and answer things, I didn’t know, you know, this is all kind of new, and… if there’s some, you know… I’ve looked up blogs, they’re very useful. I think a blog… and I don’t, one of my friends said… because I’ve been typing, I speak to her about it. And she went “put it in a blog, put it in a blog...” And I think, oft… am I ready for that? Do people want to read it? But actually, I am looking at other people’s blogs **(Okay)**, very, very useful.

**Okay. May I ask you for some of them, later?**

Well I… if I… I just went, I just literally typed in MND blog.

**Okay. Okay.**

And I’ve… I just… there was a poor child of nineteen, you know. So I forget, but I was, you know, reading just how they coped on a day-to-day basis, that was useful.

**Really? Okay.**

So that’s an interesting thing, isn’t it? **(Yeah).**  I do think that’s… because I mean, people blog all the time with cancer, don’t they? You can’t… there’s always somebody in the news, whatever, you know.

**Yeah.**

That’s why I think one of these more high profile people would be really useful if they… they were up to doing a blog (laughs). I think, you know, let us see what this is like.

**Okay. And… how does it help, if it…?**

I don’t know. I think you feel you’re not alone. I think you think, ‘okay...’ Because I don’t know anybody else with it.

**Mm-hmm.**

I mean, with cancer, I know loads of people, sadly, with one… (Stutters) Now, I’ve had friends, you know… I would know who to turn to if I had that.

**Right.**

And say, “how are you coping? How did you get through this?” I have ‘spoke’ to a friend about waiting lists and times, he has had a terrible time with a cancer diagnosis, on that respect. So that was pretty useful as well. **(Mm-hmm).** Even just hearing somebody else’s **(Yeah)** experience. So that’s that… so I think it’s just thinking… and actually it was quite uplifting, because you could see the swings in the mood. There was a teacher actually, one of them was a teacher. I was astonished that she managed to carry on teaching while she had it, and then… the students were helping her. I mean, you can only believe what, what’s on the page, it may not be what’s real, you get an idea that it might be totally false. But… I think there’s something about other people’s experiences, maybe. I don’t know, it’s hard to find that in the [charity organization] stuff.

**Yeah. It’s very… this is the information.**

It’s just… it’s just, this is what you’re going to get, this is what’s going to… and it is, you know, hard-hitting stuff. The stuff on the research is fascinating, on their site, I like that very much. And just interested in that. I find that interesting. Actually, research, I do… I have been, looked at that a lot. But yeah, so that’s something. So I’m not going to look at that. I expect that rugby player, he did loads didn’t he, one of the… one, there was two of the high profile rugby players, wasn’t there? I don’t know whether one is still alive. I’ve heard quite a lot out there already from him, I think.

**Okay.**

You know, yeah.

**In terms of blogs?**

Well I… I don’t, no, I haven’t found it, if I’m honest. But it’s just… just ordinary people, it’s just coping with it, I suppose.

**Yeah. Yeah.**

That’s what you want to find out, I think. Well I would find that quite useful.

**Just the personal experience of these… (Overtalk)**

I mean, you’ll collate quite a bit, won’t you?

**Yeah. I will. (Laughs) Yeah, so I’m hoping to use some of these quotes as well in the intervention. I don’t know much will be of a story, but** (Yes) **at least it’s, it’s hearing directly from people, rather than** (Yes) **a health care professional, or something.**

Oh yes. Absolutely. I mean, you know, we are different in front of people, who… depending, I mean to talk you, I can talk to you much more freely, I think.

**Yeah.**

I’m sorry if it does see emotive at times, it’s just the nature of the, you know, the thing.

**Yeah, exactly.**

And… but if I’m in my physio, I’m all very positive, you know. ‘Yes, I’m doing this, I’m doing...’ (Laughs) Because I think, ‘oh, I’ve got to (whispering) show my doctor how well I’m doing.’ Please, no offence, I’m not trying to…

**Yeah.**

But… yeah. Yeah. Yes, it’s just… no prep for it, is there? No-one teaches you how to… there’s no… yeah.

**Guide… (Overtalk)**

Guide… there’s no guide to it is there? But maybe, you know, I’m sure there is, I’m sure there is something out there, isn’t there? I’ve just read a Ted- I’ve just come across a Ted talk, actually. From a woman in… I don’t know, it’s from a Tweet. Who’s just been talking about… I must listen to it, actually, who’s got cancer, terminal cancer, and she’s talked about, you know, living with a terminal diagnosis. That sounds… I mean, that, I will listen to that. So that sounds… hard listen, but, you know, I just want to see how do you cope with it, you know? As well as you can, don’t you? You know **(Yeah)**, you just do the best you can, don’t you? Make the… but yeah. Mm.

**Yeah, there’s lots of real life stories (Overtalk) helpful…**

Yes.

**I see…**

Yes, you find people who are prepared to sort of… I mean, I would do that. I would, you know…

**Write, or…?**

I… well I mean, I… I have a… because I’m doing writing as my other MA. Oh, well, for children, I don’t think this is children’s stuff, do you? But actually, it must affect children. You know, it must… mine are grown up, but they’re still children. But there still must be young children, and I just think there should be something. And I’ve really felt this, that someone can go to and think, has it, you know, this is somebody else’s experience. Yes it’s like mine and, okay, I’m doing all right, actually, that is okay to be like that.

**Yeah.**

Because I haven’t, you know there isn’t that out there.

**Yeah.**

You know, is it all right to be screaming blue murder when, you know, you’ve been given an appointment two months later than expected, you know, something like that, you know, just things like that and…

**Yeah.**

A bit like a Mumsnet. (Laughs)

**Okay.**

You know, do you see what I mean? And sort of…

**Yeah. Just like reassuring you that… it’s okay… (Overtalk)**

Yeah, an online chat thing.

**Yeah.**

I don’t know, hmm mm. I don’t know what the profile is… they profile of people with this of course, I don’t know. There’s not that many people with it, are there? I don’t know. But it seems pretty rare.

**Okay. But yeah, we can do bits like that, just give that support.**

Mm. Mm. And there’s lots of questions about why you get it as well, in my mind. I know they’re pointless because I’ve got it now. But there is… I do sometimes just go over and over, and think… then like, it’s the more research I do **(Yeah)**, the more I’m thinking, ‘I’m all right, so was that,’ you know, like pollution now is the latest big thing, isn’t it? That was all over the papers, wasn’t it, at the weekend, about brain and pollution, and the connection and… you know, it’s interesting. And you do think, ‘well, you know’. But obviously you’ve got to either say, right genetic kind of make up for pollution to affect you in that way, I get that. It hasn’t affected anyone else I live with, and we’ve had the same experience, so… but what is it about… you know, those sort of things.

**Yeah.**

And that just… it doesn’t get you anywhere, of course, but… it isn’t bound to, you’re bound to ask it, aren’t you? If you’ve got something, you know, what’s caused it? I never think ‘what have I done,’ thankfully. I don’t go down that route, because I haven’t done anything. You know. Not really. But… yeah.

**Yeah.**

Just… I know it’s just a genetic thing that’s gone haywire, isn’t it? Just one of those things… yeah, it’s just one of the, I guess, you know?

**Yeah.**

Bad luck. (Laughter) To put it mildly. However… yeah. And the other thing one can say is that I sometimes try and get in my mind, is that I have a chance to… to leave things as I want to leave them, for the future, you know. I mean, if I was run over by a bus tomorrow, my affairs would be in a dreadful state. And does that make some sense, you know, **(Yes)** I don’t, haven’t quite got as far as thinking about a funeral… although my sister was asking about that. I can’t quite get my head around that one. But I can make sure that certain things are all… kind of a, planned.

**Yeah.**

I mean, that’s a bit bleak, isn’t it? But on the other hand, you know, one could look at that quite positively and think, you know, I can… you know, I don’t leave a mess, I’ve inherited stuff from an aunt, who had left… who had eighty-five years of accumulation… I’m still dealing with it. Yeah.

**Okay.**

Nightmare. A serious nightmare. And like, I won’t be doing that… well, my husband will, but I don’t… you know, I’m not going to leave him with that.

**Mm. Okay.**

And so everything will be, you know, how I want it to be. I hope, anyway.

**Yeah, some people say that as well, like thinking about planning for the future can help, because you know** (Yeah) **you put stuff in a place.**

Yes. I mean, I can get everything in place financially, that, you know, all that sort of thing. Of, you know, just so that nobody’s inconvenienced, or anything like that. So make, it just make you think, it really does, about getting your affairs in order. Cliché, but you know what I mean. I say I’m going to do all this, I’ll probably think ‘sod it… you can sort that. You can sort the lot.’ (Laughter) But you see, yeah. Yeah. Something in that. I don’t know. Yes.

**Yeah.**

But I think it sounds a really, really good idea. What you’ve got in mind.

**Oh thank you. Thank you.**

And I would certainly use it.

**Thank you.**

Yeah.

**Are you… are you happy for us to stop the recording… (Overtalk)**

Yes, absolutely, I talked and talked and…

**No, that’s exactly what I wanted.**

Is it? Yes. Yes.

**I’ll stop it anyway.**

(END OF RECORDING)

**Interview 29 part 2**

**Okay, so just… just recapping on another… another issue.**

Yeah, just… we were just chatting, weren’t we? I think one of the things that’s really hard to come to terms with, or to deal with, is not knowing the… the prognosis. Well, you, one knows the eventual prognosis, but not knowing how long it will take. And not knowing, you know, you get given an average of life expectancy, but no-one’s average. So, no, how long is, could this be? And I know no one can answer it, I understand that totally. But it doesn’t make it any easier to sort of take on board. And every different twinge you feel, every different ache, every different bit of stiffness, you know, is that the start of the decl- you know, the next bit of your decline, and your body? And, you know, you know, should you book a holiday sort of three months’ time type thing? It’s that kind of thing **(Yeah)** you know.

**Just the uncertainty?**

Total uncertainty. And it’s not like anyone can say you’ve got horrendously, when they do tell you with any other, some other terminal disease, that you’ve got six months out, you know… or something like that. It… I don’t know, it must be dreadful, you know… but, you know, similarly, this is open-ended. And it might be a year, it might be two. But at what… you know, I don’t know. But yeah, I think in terms of emotional distress, I think that’s quite a… and no-one can answer it, can they? So it’s not like there’s any… **(Yeah)** any answer to that one. And… I suppose it is quite interesting to see, or hear… I don’t know. Yeah, I mean, people… no I don’t know if I’d want to know too much, though. (Laughter) I do and… I do and I don’t, you know? It’s a tough one.

**It’s a… it is.**

It’s the uncertainty, isn’t it?

**Yeah.**

It’s the uncertainty.You’ve been given this sort of horrible kind of sentence, really. Op- you know, you know, it’s not open-ended, but it’s… and even talking about it now, I still don’t… I, still part of me in brain is thinking, ‘this is somebody else, you’re talking about somebody else, this isn’t… never going to be you, this can’t be.’ You know.

**Yeah. Yeah.**

But that must be very natural, so… I would’ve thought. You don’t… you know. Anyway, that was what I was going to say.

**Thank you.**

I hope that makes some sense.

**Yeah.**

(END OF RECORDING)