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

**Interview 23 (with person with MND)**

Yeah, absolutely fine.

**Okay, brilliant. So I guess I’d like to start wherever you’d like to, really, about your experience with MND. Maybe around diagnosis, or if, you know, the symptoms before that. Wherever you’d like to start.**

Well, I don’t mind, you can start when I first noticed the symptoms, if you like?

**Okay. And…**

Which was in 2016.

**Okay. And what did you notice, what was your experience around that time?**

Just some shoulder pain and some loss of dexterity in the left hand.

**Okay. Okay. And how did you go about getting a diagnosis and things…**

Well… well first of all, I thought it was a sporting injury, so I saw a chiropractor.

**Okay. Okay. And then did he point you out to other professionals?**

Well when… when the sort of standard treatments didn’t work, he suggested electrical nerve conduction tests.

**Okay. Okay. Okay. And then what was your experience of the whole diagnosis process?**

Well it took a long time, because first of all they treated it as if I had a different condition, I think.

**Oh, okay.**

MNA. (*multi nutritional assessment?*)

**Oh, okay.**

So and now I had treatment of Immunorel, three courses of ‘immuglobulin’ *[immunoglobulin]* infusions over 2017.

**Mm-hmm.**

And they didn’t really benefit me that much, but I didn’t get much worse either, in that time.

**Okay. Okay.**

And… and then in 2000-March 2018, I had the diagnosis.

**Okay. So you were diagnosed fairly recently, then, but it took…**

Yeah. Yes.

**Okay. Okay. And what was your experience of the diagnosis?**

Well I sort of half expected it could be one of the outcomes.

**Okay.**

From what the neurologist said. But again, I wasn’t so badly affected by the condition back then.

**Okay. Okay. And what were your thoughts and feelings around that time, when you got the diagnosis?**

My… I was still very positive. And then it was a slower progressing form, PLS. Or that’s what the neurologist said. Or thought.

**Okay. Okay. And since then until now, what has your experience been like?**

Well up until December 2018, I still could do quite a bit, though I’d got weaker. But in the last six months, I’ve become significantly weaker all over.

**Okay.**

And it’s now having much more major effect on daily life.

**Okay. Could you tell me a bit more about how it affects your daily life?**

I can’t… have difficulty getting dressed, putting on shoes, socks. Not much energy. Get tired easily. Can’t… can’t do what I used to do.

**Okay.**

And sometimes when I’m tired my speech is slightly slurred.

**Okay. Okay, so it affects everything, then?**

Yeah.

**Okay. And have… have your thoughts and feelings changed, now that these symptoms have got worse? Or…?**

Well yes, they… they have, a bit more, yes.

**Mm-hmm.**

Not… sort of not quite so positive about the outcome.

**Okay. Okay. And… so if you could tell me some of your main concerns or challenges that you go through… now, when just having to cope with MND?**

Well just… I have to, I suppose the biggest factor is that I have to rely on other people doing… getting me dressed, so I can’t do things when I want to do them. So it’s relying on other people, and not having the ability to do things when I want them.

**Okay. And how… how do you feel about that?**

Well it’s just frustrating.

**Okay. (Small laugh) Because the reason I’m asking that is, where a lot of people say that MND can be quite emotionally challenging as well. Like it’s not just the physical things that… so I was just wondering if you had any other concerns from the emotional side?**

Yes, I mean, yes, it is challenging on that side as well.

**Okay. Could you… I know it’s a little difficult, but could you tell me a bit more about that?**

I… I suppose it’s just realisation that you’re not able to do things that you could in the past.

**Okay. So just… yeah, kind of comparing what you could…**

Yeah. You’re… you’re… things have changed, and they’re… I suppose the other factor is they’ll… they’ll never get better.

**Mm-hmm. Having to process that fact as well. Yeah. And… so these… you do get, occasionally, these difficult thoughts and emotions and things like that, and what’s your… do you have any strategy for coping with that? Or…?**

(Laughs) That’s a good question. I go and do something, I… I focus on the things I can do. I can still walk a bit. I can still sort of… enjoy family life, do things like that. So yeah, I just focus on the things I can do, and not think about the things I can’t.

**Okay. Okay. Just try and look at the positives, or things like that?**

Yeah, all the time, yeah. See friends and things like that.

**Okay. And are there any other particular things that help, like say, you just mentioned seeing friends…**

I enjoy going out just for coffees. I bought an exercise bicycle, which I can do a little bit on.

**Mm-hmm.**

I can still do some light exercises, stretching. Spending time with the children.

**Yeah, that’s nice. For those sorts of things.**

Yeah.

**Okay. And also in terms of… this is more like in doing activities and things like that. Are there any things you kind of tell yourself, or like certain attitudes or approaches that are more helpful?**

Well again, it’s to focus on what you can do. Don’t try to do something difficult.

**Mm-hmm.**

So I sort of… or find new ways of doing things. I’m good at doing that. I found a new of doing things, think about things in a different approach.

**In what way did you mean? Like a physical activity or something…?**

Yeah, a physical activity, and things like that.

**Okay. So a new way, you mean by like having equipment or…**

Yeah, having equipment or just approaching it in a different way. Trying to think of a… good example. I…(pause). Well, a good example is I used to do a lot of sit ups, and I can’t do those anymore. So I use em a…a fitness ball.

**Okay.**

And sit on that and do it with that.

**Okay.**

So I try and adapt.

**Okay, I see what you mean. Yeah, the same kind of activity but slightly…**

Yeah, but adapt the way I do them, and being very careful in how much I do, never to overdo it.

**Mm-hmm.**

And just do little bits.

**Yeah. So also pacing yourself.**

Yeah, that’s really important, yeah.

**Yeah. And I know you mentioned something about not doing things that are difficult. So, just so that I understand you clearly, that means say if you used to find something difficult, trying to not force yourself to do that, because it will upset you or…?**

Yeah. Well in… in the past I’ve never had a problem doing difficult things, because I could always do them. Now I realise if you get something difficult, you won’t be able to do it, because of the limitations of the condition. So I just move on and do something that I can do.

**Okay. Okay. And mainly, I mean, say physically difficult to do?**

Yeah, mainly physical. Also… you know, sort… I’ve become slow at doing things, even thinking things through.

**Okay. Okay.**

So I ask for help.

**Okay. In what sort of situations? Just so that I have an idea.**

Em, (pause) eh…ooh, good question. Like losing the ability to write, so I get somebody to write for me, rather than trying to continue with some writing, which is difficult to read.

**Okay. Okay.**

So… so I’ve sort of, you know… I’ve accepted I can’t write, and somebody’s going to do it for me, rather than struggle.

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

And I used to do a lot of running, and I can’t, so I’ve adapted and have a sit-down exercise bike.

**Okay. So you can get a bit of cycling done as well.**

Yeah, inside the house, yeah.

**Okay. So… sort of doing the things you still like to do, but just modifying it…**

In a different way, yeah. Yeah.

**Yeah. Yeah. Okay. I see what you mean. Okay. And… I’m just going to look through my questions. Do you also get any support with managing MND on a daily basis?**

Only from my family.

**Okay. Okay. Do you also get any support from like managing something that may be difficult emotionally as well, or…?**

Not really, no. But I haven’t asked for any, either yet.

**Okay. Okay. Would you… do you feel you would need something like that or not, at this point?**

Em… Possibly, but I’d probably go to a friend.

**Yeah. Yeah. So they have usually been your sources of support in the past, if you had any issues like this? Is family or friends or…?**

Yeah, I normally use family and friends.

**Okay. Okay. And just kind of talking it through with them?**

Yeah.

**Okay. I’m just trying to see, do you have any professional support from any other organisations?**

Only from the [charity organization], but that’s fairly infrequent.

**Mm-hmm.**

So I just sort of… if I think I need some guidance, I contact them. And they come out to see me maybe once a year. Or every six months.

**Oh, okay, so that’s like a… a visitor, rather than you going somewhere. Yeah.**

Yeah, yeah, yeah, yeah.

**Okay. And any of the other groups, or any other activities…?**

No. No.

**Okay. And do you feel you need any other support, or are you quite happy?**

No I’m happy with… at the moment.

**Okay. Okay. Just – sorry – just quickly going back on something you mentioned before, it just suddenly struck me as well. Because you mentioned having to adapt your activities or say with the writing instance, having to ask for help and things like that. Did… did you find that change easy or difficult, or how did you kind of adjust to that…?**

Well I found it quite easy.

**Okay. Okay. You just get on with…?**

Yeah, just changing, really.

**Okay. Okay.**

And I’m going to do some voice banking and some software for writing.

**Oh, right, I didn’t realise you could do that.**

Yeah.

**Okay. So this is for the future…**

Yeah.

**...preparing yourself for…**

Just preparing. Yeah.

**Okay. Okay. I was just wondering if there are any aspects of your experience that we haven’t covered? Anything that you’re maybe concerned about, or you find difficult?**

Not… not really, no. I mean, one of the biggest factors for most people I think is to make sure… yeah… sort of financial affairs and family affairs are all in order.

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

Yes.

**Okay. Has that been for you, as well?**

Oh, it’s been a concern. To make sure it’s all properly sorted out.

**Okay. Okay. Any other concerns? I’m just trying to make sure we’ve covered most of the things.**

I don’t think so, not at the moment.

**Okay. Okay. Is there anything else about how you usually cope with things, if anything has been helpful in the past, or you’ve tried something and it’s not been helpful? I know we’ve covered a lot of things, but just making sure, you know, we’ve spoken about everything.**

Oh it… it’s just about adapting, really, and focussing on the things you can do. And not try to continue doing things you can’t do.

**Right. Great.**

So sort of move on as the condition progresses. You’ve to move with the condition, really. And trying to keep ahead of it by preparation and planning.

**Okay. Okay. So very active approach of…**

Yeah. Very, very. Yeah.

**Right. And have you found that that change happens quite quickly? Or…**

Yes, it can do, it can… Well it can happen quickly.

**Okay. Because I remember you said, in the beginning yours was… it said initially it was a slower progression, wasn’t it?**

Yeah, it was, and I… I didn’t have any serious challenges. But now it’s faster, and it’s… takes you by surprise, things happening quite quickly. It changes…

**Okay. So you have to be on top of it? Yeah.**

Yeah.

**Okay. So initially it was slower, but then…**

Yeah.

**Yeah. Okay. I see what you mean. Yeah. I’ve asked most of my questions. Just because everyone’s story is quite different, and… you mentioned to me also, you’ve been… your story is quite different compared to other people, have we not covered any aspects of your experience?**

Well I suppose my own circumstances. I… I suppose I’m relatively young, still, have a young family.

**Okay, okay.**

And I was fortunate I could retire at the end of last year.

**Okay.**

And I’m financially completely independent, I’m… don’t have any financial concerns whatsoever.

**Okay. Okay. So that… (Overtalk)**

So that sort of combinations I don’t think you’ll find with any other… or very rare, with MND people.

**Yeah. Yeah. So… but you have the additional concerns of a young family, and…?**

I do, exactly. Somebody of my age with it, and that… the children are thirteen and sixteen, **(okay)** and one’s doing exams at the moment. So whereas a lot of people my age would have older children.

**Mm. So… and what are some of the concerns with that as well? I know we covered some financial bit, but is that…**

Well it’s just to make sure they’re okay, they’re not… I mean, it’s obviously more difficult for them to understand what’s happening.

**Right.**

At that age. They’re still at school.

**Right. Yeah. So communicating it to them, and…**

Yeah.

**Yeah, making sure they are not worried or something like that, yeah.**

Yeah. Mind you, lots of people might go off and travel the world or do things on their bucket list, but… we… we can’t do that, because we have, you know, our children to look after.

**Okay. Okay. I see what you mean. So you have all this, but they also are your priority in that sense.**

Yeah.

**Okay. Okay. So just looking after family and…**

It is my naturally, main focus.

**Mm. Okay. Does that… does that also… does it kind of give you more… like are you more worried about that situation, or does it also in a strange way help you cope with…?**

Yeah, it’s sort of helpful, really.

**Okay. Okay. Yeah, it’s good they’re around, isn’t it?**

Yeah.

**Okay. The other thing I wanted to mention was… I, I spoke about this in the initial part of the interview, that we’re trying to build some resources to help people cope with MND better. And I was just wondering if you… like with your circumstances and things like that, do you think you would access support for how to cope with MND online? Or if there’s something you probably wanted…**

Yeah, no, no, I’m… I’m… definitely… definitely access it. I like to get as much information as possible.

**Okay. Okay. And I know it’s hard to say when you don’t know what exactly I’m… I’m suggesting, but are there are any things we need to keep in mind if we create information about how to deal with any emotional concerns that come up with MND, and this is how you cope? If we had to show that to people who had MND, is there anything particular we needed to keep in mind, do you think?**

Ah… ooh… I’d just say, main thing is focus on what you can do.

**Mm-hmm.**

Don’t dwell on the past.

**Okay.**

And what you can’t do.

**Okay. And that is like a key message.**

Definitely.

**Okay. Okay, that’s really useful. I think that’s about it, in terms of my questions.**

That’s all right, that… that’s fine. I mean, email me if you think of anything else.

**Okay...**

(END OF RECORDING)