**Transcription of Interview 13**

**[Beginning of file]**

**Interviewer:** So, I guess the first question for me would be if you could just tell me a bit about your experience with MND and wherever you’d like to start really. From diagnosis or slightly before when you noticed symptoms.

**Respondent (P):** Okay. Yep, okay. Um, well, I sort of looking back now, um, because obviously diagnosis takes a while, um I think I probably had some symptoms going back to October 2015.

**Interviewer:** Okay

**Respondent (P):** And, um, the first symptoms I noticed at that time were um I drove a car with a touch screen radio et cetera in the centre console and I started to find that I couldn’t reach the touchscreen. I couldn’t actually operate the touchscreen with my finger ‘cause I couldn’t reach that far, which I thought was a bit weird. Um, and then when it got to about um post-Christmas sort of new year, um, I was starting to notice um the fasciculations in in in my arm, so the trembling of the muscles um in my arm which I thought was a bit strange as well. Um, so I went to a, I actually went to, um, re-enrol at a gym in January as a New Year’s resolution to get a bit fitter again and, um, started doing some of the exercises or did the induction and then just realised that my left arm was incredibly weak. I really, you know, could move hardly any weight at all. Um, so having sort of discovered that I thought well it’s time to to get to the doctor really.

**Interviewer:** Yeah

**Respondent (P):** So, I went to the doctor and explained the symptoms and then I guess it was it was about six months of a battery of tests and stuff but eventually, um, I’d kind of reached the conclusion before we reached the conclusion, as it were with the consultant. And in July 2016 I was sort of formally diagnosed with MND.

**Interviewer:** Okay

**Respondent (P):** Um, so uh, so what the the the effect it’s had on me physically so far is my left arm is now completely um as the say clinically non-functional. Um and my right arm is going the same way and I’ve just got I reckon probably like 10 to 20 percent or 10 percent really left capability in my left and my right arm.

**Interviewer:** Oh, gosh.

**Respondent (P):** So, um, and it’s started to move into my left leg now as well. So, um, I perhaps don’t uh sort of there there’s a number of ways as you know that the the condition can go, um, and generally people sort of seem to end up in wheelchairs first. It tends to be the legs first, but in my case it’s the arms. So, um, and having uh sort of being advised to do voice banking because of my v- you know the loss, potential loss of voice and stuff. Um I did all the voice banking but actually at the moment my voice is is re- well it’s good. There’s no no change. Um, hence I can do this [Laugh]. So, um, so I perhaps haven’t followed um quite what most people would expect, but nevertheless it’s progressing in in its own way and I guess, you know, we get to July this year so that will be three years since the formal diagnosis and about three and a half years, bit more than three and a half years, since I believe it started.

**Interviewer:** Yeah, since you saw the symptoms. And have your, have your thoughts and feelings about having MND changed in these two years since you’ve been diagnosed?

**Respondent (P):** Mmmm, interesting question. Um, I think um that the nature, the nature of the disease means that, um, you kind of adapt, um, and to start off with you think well I I can adapt to sort of having half of my left arm not working and, um, and and things like that. But then as it goes on and you have to keep readapting so many times, um, I think I’m uh to start with when I got the diagnosis I kind of worked out through all the test results that were going on w-what the horrible inevitability was. So, it wasn’t a complete surprise to me but it was pretty devastating, um because I still feel at 57 now I’m I’m young as far as I’m concerned.

**Interviewer:** Yeah

**Respondent (P):** Probably a good deal older than you, but I’m I feel young. So, um, so I’m you know I had sort of planned and worked hard towards my retirement in my 60s. Um, lots of things I’d kinda saved to do and hobbies that I want to undertake when I was had more time, I can’t do any of them.

**Interviewer:** Mmm

**Respondent (P):** So, I think, sorry I’m rambling a bit, so I think to start with you kind of, you kind of adapt to stuff and you think alright, okay I can live without this bit and I can do that. But then as it goes on and you, you know, to get to living with no left arm you think well okay I can manage stuff just using my right and then obviously I’m now in a stage now where I can do very little with my right arm. Um, and I think I’m actually in a more angry and negative state now in some ways than I was back at the beginning. I think because it’s just um all the things I’ve, perhaps silly things you know, silly things like to other people like gardening, like other hobbies that I had, I can’t pursue any of them because I just don’t have any capability enough in my arms now to do that. So, I think mentally, actually, I’ve seen a dip in the last six months into a much more kind of negative and, um, angry stage really. Um, so I’m actually got to the point of sort of mentioning that to like my local clinic, um, MND, well she’s a she’s a neurological nurse, and so I’m I’m arranging some counselling at the moment just to kind of help me uh kind of re- reframe things and get a bit more positive. But, um, yeah so it’s it is it is a rollercoller, everyone says this, it’s a rollercoaster of emotions because every time uh I feel that functionality steps down in distinct steps so, you know, one day one week you can carry, I don’t know, two mugs of coffee on a tray, the next week all of a sudden you can’t. You know and, um, and so you yo- things step down uh or you might truckle along quite happily for for a month or something and you can do something and then the next week it goes and I think each time you lose that little bit of capability, you sort of try and mentally readjust, but then i-i-it’s sort of through the cumulative effect I think. If that makes any sense at all to you.

**Interviewer:** Yeah. So, just in just so that I’ve understood you correctly, um, in the beginning you sort of knew this was happening but because the change was manageable, um, you adapted and adjusted to that but as as it kind of gets worse and worse, then um there’s more negative emotion that comes with each change?

**Respondent (P):** [Crosstalk] Yeah, yeah. Yeah. Uh I think that’s a a fair point and and it you know it’s the kind of relentless nature of it. I mean it’s only gonna go one way. It’s not like, um, it’s gonna level out or anything, there’s just this relentless kind of degradation and I think that’s that’s wearing. Uh, and of course the longer it goes on the more you think about where you’re gonna end up and we know we all know what the end looks like, um, but we all we don’t know when it’s gonna be. So, it’s um, you get preoccupied sometimes with kinda thinking yourself to the end which a good friend advised me never to think yourself to the end. Just get up and do what you can today and don’t think any further than that and I think it was wise words actually.

**Interviewer:** Yeah. So, it’s a bit of worrying about the future as well?

**Respondent (P):** [Pause] Yeah. You simply can’t, you simply can’t because you, no one can tell you exactly the path this is gonna take because it’s different for every single person and you know at three and a h- three years since formal diagnosis I’ve already perhaps lived longer than a lot of people. So, you know, you can’t uh there’s no point in trying to anticipate it.

**Interviewer:** Yeah, yeah.

**Respondent (P):** You know you know that intellectually but emotionally it’s a it’s another matter. Intellectually you know what you should to do but emotionally it’s a different game.

**Interviewer:** And how how do you sort of um, I know you sort said intellectually you know what to do but then to convince yourself to, um, do it emotionally as well, is there anything that has helped you? To get-

**Respondent (P):** Um. Um [Pause] I think um o-obviously that that the care of friends and that is i-i-is is immense, um, and that and a very important part of it. I’m I’m married, been married for 30 something years um, clearly my wife is a is a major source of, um, help to me. Um, we also we took the decision, we were living in the [name of area in UK] when I was diagnosed, we were living in [name of county], and um we took the decision to stop working and to move to [name of another area of the UK], which is where both of our daughters live just coincidently. They were both brought up [name of area] girls but they’ve ended up with [name of another area] lads. So, um, they’re both down here and, um, one of our daughters, uh, husband have uh two children so we’ve got two grandchildren here. Um, so we made the decision to to up and move and to, um, be close to the family, um, to to sort of make the most of the time and I think that’s been helpful but mostly because the girls I know, want to, want to know how I am and kind of almost want to keep an eye on me. So if I’m around and nearer, and and in reverse you know I love to see them and I’m I’ve I’ve, you know, I’ve had the time which I didn’t have perhaps even with my own children, to absolutely enjoy my grandchildren and that’s been a tremendous sort of emotional lift, um, to spend time with them and um and just have you know noth- literally nothing better to do than to spend a day with them. It’s great and and we’ve managed, we’re fortunate we’ve managed to square the finances so we we we managed to stop working early enough to do that. Um, but, so certainly the the close family has played and enormous part, uh my wife plays a fantastic part day to day. Um, and I think it’s just um progressively trying to sort of delight in the small things. You know we all talk about this mindfulness approach to life and I think there is a s- a strong element of truth in that which is, you know, sort of enjoy um the things you can enjoy, keep doing the things you can do, rather than sort of ruminate on what could have been and what you used to be able to do, um, as that kind of gets you nowhere.

**Interviewer:** Did you

**Respondent (P):** [Crosstalk] Not sure that answers you question, but anyway.

**Interviewer:** [Crosstalk] No, it does, it does. I’m actually more interested, um, to learn about where where you heard about mindfulness and how it helped you as well.

**Respondent (P):** Um, well I’ve spent, um, I’ve spent all of my working life in industry, um, and in the latter, ohh I don’t know, 15 years or so things like coaching, business coaching, and mindfulness approaches to work had had sort of started to permeate. Uh, and indeed as, um, I I actually uh trained as a uh as a business coach, not a nothing you know I wouldn’t get into sort of mental health or anything like that but in terms of he- coaching people in the workplace and helping them with issues they were facing in the workplace then I I trained to do that. And and of course mindfulness has become one of the things we uh in a number of places we’ve tried to sort of encourage people to take up and to um practice but it is remarkably difficult I think to, as human beings, to still ourselves even for a fraction of a time to actually indulge in it. But, um, but but no I cert- I certainly find um it’s been helpful, I’ve read about a lot about that in the past and it’s helpful now to sort of um, there are places like, we’re, we’re very close to the the sea down here which is lovely, and just when you’ve lived in [area of the country] for 30 years when it’s three hours to get to the sea, it’s a novelty to be down here. And it only takes half an hour and I find, you know, spending time near the sea very kind of mindful.

**Interviewer:** Yeah

**Respondent (P):** You know there’s something about it that um we- we’re planning to go down later on today to [name of place] because we just felt we haven’t seen the sea for a while and I know it will be I’ll come back feeling better for it. Um, inexplicably but, um, but yeah, I think it’s just that taking that time and sitting and um relaxing and enjoying, yeah.

**Interviewer:** Yeah and focusing on the present I think that’s also part of it.

**Respondent (P):** [Crosstalk] Yeah. A-a-absolutely, just literally enjoying the day and the moment and the the fresh air and the sea and the the whatever, yeah.

**Interviewer:** And, um, can I ask you also about, you mentioned the counselling that you have been using recently, so how how has that been for you?

**Respondent (P):** [Crosstalk] Yep. Well I, I’ll be honest, I haven’t started yet, so this is something I’m I’m literally going for an initial session on Wednesday, um, to sort of have an exploratory talk with someone to see whether she’s a sort of person I think I can work with. But, um, but I’m I’m hopeful it is. I mean we had sort of two options, either go down the national health rout, um, which could probably be four or five months before I could see someone, or I pay for it privately. Um, or in this case, um, I I’m I’m I’m looking at private options but the local [charity organization] branch has said they would provide a grant to help to pay with so many sessions so that will be brilliant, you know, to have that support to them.

**Interviewer:** [Crosstalk] Okay, yeah that’s really good, yeah.

**Respondent (P):** So, I haven’t started it yet. I’m, um, I have to say I’m apprehensive because, um, I I I want I want something. The outcome for me is to help me to sort of live more in the moment and to kind of reframe where I am and get more positive about things. I don’t particularly want something that’s gonna delve backwards, ‘cause I don’t see any point really in going backwards. The whole thing for me is moving forwards how I sort of just regain a bit of balance and perspective and a bit more kind of living in the moment as we’ve talked about. So, for me it’s, um, I need to, if I someone to work with you have that mindset, I don’t want to go drifting back to my childhood and all sorts of stuff. I don’t I don’t think that’s gonna get me anywhere. Um, so, um, so yeah, so so I’ve actually not I’ve not you know started yet, but I will be over the next couple of weeks I expect.

**Interviewer:** Yeah. But, no, it’s useful for me to get an idea of what you’re expecting out of it as well.

**Respondent (P):** Mm hmm

**Interviewer:** Um, and this this was sort of triggered by say your…

**Respondent (P):** Yeah, this is, wait we see the, yeah, I see the neurological specialist nurse. There’s there’s um there’s actually two in [name of area], um, who um one was financed by the [charity organization] to start with, um, and then the health service realised they could actually occupy too. So, again the local branch of the [charity organization] has done a lot to to to support people in [name of area] in that sort of way as well. So, this lady we see uh about once every two to three months. Um, I see a consultant probably once or twice a year, but I see her probably four or five times a year. And, um, so we have a general review and um, so she checks out all the physical stuff and then sort of sort of enquires into my wellbeing and I think this time for the first time I said, you know, I think um I am becoming a bit of a grumpy old man to live with and I think it’s having uh an effect on my wife. A negative effect because I am being more negative, which is not good for her, but also it’s not good for me. Um, and sort of said I, you know my my spirits have been a lot lower. I’ve been doing pretty well up ‘till now, but now I think I’m feeling a bit sort of beaten. So, um, so she said well what we could do, you know, here are the following options, let’s talk about those and we decided the best approach was, um, to go for the private counselling and to also see whether we could get some funding from the [charity organization] as well. So, yeah.

**Interviewer:** Okay

**Respondent (P):** That’s the route we’ve gone down.

**Interviewer:** So that’s how it how it led the referral, yeah.

**Respondent (P):** Yep

**Interviewer:** Um, I think you mentioned in terms of, um, how emotionally challenging MND is, you mentioned a couple of things like, um, anger and feeling a bit down at times.

**Respondent (P):** Yep

**Interviewer:** Um, is there any others other emotions or any other worries linked to this side of things?

**Respondent (P):** Um [Pause] uhh I think I think one of the big things for me is just disappointment, you know. Um, that kind of, w-we all think we kind of got, well not that we’ve got life planned, but that we we sort of have a kind of view how we’d like things to to turn out and, um, disappointment I feel, you know, is a big thing. We we’d um, just to give a little context to that, um we lived in [name of place] for for many, 20 odd years, and then um it must be nearly six years ago we move to [name of area] to the [name of another area]. We we enjoy walking and out- being in the outdoors. Um, walking is becoming a problem for me now, so that’s a that’s an aside. But, um, but we moved to [name of area] and to be honest it was the first time we’d moved house, um, purely, well I say we, my wife and I, purely because we wanted to. The rest of the time I’d been changing jobs or being made redundant or whatever and we sort of had to move to different places. But this time we’d really sort of said yeah, we actually want to be in this beautiful part of the UK, and we found ourselves a house and that was, um, was great and really got involved in the in the small town where we live. And I think having to give that up was a was a massive disappointment. You know, we we felt very very happy there and we knew that we would one day move nearer to our daughters but that would probably be when we were in our late 60s, early 70s. Um, so we, you know, we were very much involved in the community and we had a great time and I think it was a massive disappointment have to give that up, but it made a lot of sense. But I think the other disappointments are that just, you know, um we’ve this week um we’ve put our camper van up for sale, which was a a classic Volkswagen camper van that we’ve enjoyed lots of holidays and exploring in, but there’s no way I can either drive or live in it anymore, so that’s got to go. And, as I say, the sorts of things I used to do to relax were physical things. So, I, you know, I enjoyed gardening, DIY, walking, going to the gym, that’s how I relax. Now I can’t do any of those things. Um, so relaxing [Short Pause] you know, my my cure for for being stressed or worried was to go and get some energy out in the system right out the system. But I can’t do that, and I think that’s, all those things are disappointments so there’s an overwhelming feeling of ahhh, you know. This is, all these things have gone so there’s that sense of loss and of and of disappointment. Ohh, you know, this was, you know we were’t the sort of people that said ohh we’re gonna go round the world when we retire and we’re going to, you know, live in a, I don’t know, exclusive beach house in Cornwall or something. You know we didn’t have grand plans, we’re not like that. All we had was little plans to just carry on in our 40-year-old camper, messing about in Europe and doing small doing small stuff, you know. We’re not, we’re not not one of these glamorous couples. And and that’s all gone and I think you feel sort of you get you you’re either you’re either disappointed or you get disappointed and then angry [Laugh] and bitter about it.

**Interviewer:** Yeah

**Respondent (P):** And it’s unfair and and it’s also the the the, you know, the the disease as you probably know, um, is I I I had heard a great presentation by one of the leading kind of clinicians I think based at [name of place] who sort of said well if you’re a couch potato you’re never gonna get this. It’s only gonna happen to people who are reasonably fit and active, probably never been to a doctor in their life about anything, which is the pattern I fit, you know, probably try to lead a good and healthy life and, you know, and all the rest of it. And those are the people that will will get it and and that’s what I’ve got. And, you know, they whilst they don’t know at the moment why some people get it and some don’t, it’s almost a com- it will be a combination of factors. Um, nevertheless that also, things like well, you know, if I got lung cancer but I smoked, or I got liver disease and I drank, um you’d think well I probably ought to take up smoking and drinking just to make the most of it now, what the hell, you know. [Laugh] So I so I think that adds a little bit of it, you know, that um it’s only gonna happen to fit people makes you think ah, god why did I bother? [Laugh]

**Interviewer:** Yeah. It’s ‘cause you can’t see a link between why it’s happened.

**Respondent (P):** No

**Interviewer:** Yeah

**Respondent (P):** No. And of course there’s lots of people, you know, nowadays, well not lots but there are a number of people now, it’s gone from being an old man’s disease to being some very young people and a and and women as well, obviously very young women.

**Interviewer:** Yeah

**Respondent (P):** [Cough] sorry, excuse me. And obviously very high-profile sports people as well involved, so. You know, you you can’t rationalise it, but I think to go back to your original question, I think disappointment, frustration, um, yeah, anger and those things right now I think are the sort of major feelings.

**Interviewer:** And I know you mentioned um say your wife and family and, um, other things that help you, but in the moment when you do get those thoughts and feelings, is there anything you either tell yourself or any strategies used to help you readjust?

**Respondent (P):** [Crosstalk] Yep. I think, um, it i-it is about bro- drawing things back to today, because I think, um, it [Sigh] the temptation is if you are feeling a bit down and a bit weary and when you tried to pick up the mug of coffee this morning you dropped it, um, in those circumstances you you kind of have to go back to, if you can, and what I’ve told tell myself is yeah, but I’m still here, I’m still alive, um I’m still having this conversation with you. I’m still, you know, I can, I’m looking out of the window at the garden and the birds and the flowers and, um, we would normally have our grandchildren today, um, but they’re actually on holiday, so they’ll be back next week.

**Interviewer:** Okay, yeah.

**Respondent (P):** Um, and I think oh, it’ll be nice to see them when they’re back next week and I’m seeing the other daughter at the weekend for a barbeque and you think well there’s, I’m still doing those things. It might not be easy, um, but I’m still here [Laugh] you know. And I’m and I I do, um, my wife and I both um volunteer at citizens advice bureau, although it’s citizens advice, I think is the strict name now.

**Interviewer:** Oh

**Respondent (P):** Um, so I, and I can still just about manage that, I can certainly give people guidance and and use a mouse and website and that and the typing up’s a bit difficult. But I’m still doing something that’s of kind of value to somebody else, you know, and I think um. So, all those thoughts from the very small things about well I can still see out the window and I can still enjoy the scenery through to there is something I can still do. Well that’s kind of gets you out of the the mire I think, most of the time.

**Interviewer:** Okay. No that’s that’s really interesting to to understand from your point of view as well.

**Respondent (P):** Mmm

**Interviewer:** Um [Pause] uh I think I’ve asked most of my questions about what your experience is like.

**Respondent (P):** [Crosstalk] [Exhale]

**Interviewer:** I don’t know, because everyone’s situation is different, is there any aspect that I haven’t covered or that you’d like to talk about?

**Respondent (P):** [Crosstalk] Yeah. Um, [Pause] That there there’s one thing that, um, I I don’t know whether might might be of interest. Um, when we, when I was first um diagnosed um, we were immediately given the sort of the information about the local [charity organization] uh branch in this was in [name of place], um, and urged to make contact. But almost your inclination when you get a diagnosis like this is not to want to make contact. Um, and um and n-not to want to go to meetings and things.

**Interviewer:** Okay

**Respondent (P):** Because, um, what you’re afraid of, and we we still are to some extent, is you’ll go there and you’ll see people in a lot worse state than you and think hmm, this is a picture of the future. And it’s one of those things, isn’t it? It’s human beings sometimes you think oh, if only I knew what the future held, it’d be so much easier, you know, if I knew what was gonna happen. Well, frankly I think with this sort of disease you really don’t wanna know what’s gonna happen in many ways. I-i-it’s helpful to know and and and it and and it’s um [Pause] yeah, it’s important to know but actually facing it is really hard. So, actually you’re instinct, my instinct and I know, I mean some people don’t even admit they have M- you know, this used to happen in the past I think, that a lot of people don’t admit they’ve got MND and just go to ground. They don’t want to see anybody, talk to anybody, um and I can understand that because the act of seeing and talking about it is very painful and then if you go to a meeting where there’s people who are worse off than you, you get a picture of what the future might look like. It’s really scary.

**Interviewer:** Yeah

**Respondent (P):** So, i-i-it [Sigh] it’s a it’s an odd thing that I had never expected. But, um, and certainly my wife, you know, we really didn’t want to go to a branch meeting and see lots of people in wheelchairs or having to use oxygen or having to be fed through a tube in their stomach or whatever else it is. Because it’s like okay, ‘cause that just forces you to think about what the end might look like instead of kind of saying well where we are today we can still do x, y and z. So that’s a kind of a weird, perhaps not an obvious side effect. You know, ‘cause you might think from a kind of a therapy point of view and from a mental health point of view well you need to get people out and meeting others. Um, they might not want to. I think that what the association provides by way of visitors is fantastic and [name of person] is our local visitor and comes to see us and he’s great because he just doesn’t force anything on you. He just listens and talks and and we know he’s there and if we need any help, practical help, we know who to call and sources of advice, um, and that’s really really valuable. Um, but that is something that I’ve, as I say, n-not perhaps an obvious reaction that you might expect.

**Interviewer:** Yeah, that different people cope differently. For some it’s helpful and some it’s probably more problematic to see people further down the line.

**Respondent (P):** [Crosstalk] Yeah, absolutely.

**Interviewer:** Yeah

**Respondent (P):** Yeah

**Interviewer:** Okay

**Respondent (P):** It’s actually the same going to see the nurse, going to see the neurological nurse ‘cause what she does is go through a tick list which, um, every time which basically sort of have you got this, have you got that, have you got the other and you think oh, have I, I don’t know. And, um, and then you start thinking about it and then you start to think oh, well perhaps I have got that a bit, perhaps that has stopped working and and so. Actually, we have to kind of kind of um the English phrase is ‘gird your loins’ isn’t it? It’s just got sort of um beef ourselves up to go and see the nurse ‘cause we know actually it’s gonna be quite depressing ‘cause she’ll go through this list of things and you think well I haven’t got it now but she probably thinks I’m gonna get it later. So, you know, cheer up. They said things can be worse and low and behold they were worse. So, um, so yeah that’s a we have the same kind of love hate relationship with seeing her, uh [name of person], the medical nurse yeah.

**Interviewer:** Although everyone’s pattern is quite different though.

**Respondent (P):** Yes, that’s right. And that’s what she’s trying to tease out but from our point of view it sounds like a a tick list of the top 10 most things you don’t wanna have tomorrow, yeah. But there you go, there you go.

**Interviewer:** Okay. Um, I guess is there anything else in terms of what’s helped you cope with, um, MND? I mean we did cover quite a lot, but just in case I missed anything out.

**Respondent (P):** [Crosstalk] Yep. Um, I don’t think so I’ve not mentioned the fact that um, a-a-and this is a a neither one way nor another really, I think, I am I I am a Christian, I do belong to a local church. Um, we have some good friends at the church there and they just they form part of that network of people that um care about you and do what they can for you. Um I won’t delve into whether I think Christian faith is a particularly helpful or unhelpful thing in this matter. I think personal faith, you know, is is is personal faith um and and sometimes it’s helpful, sometimes it’s not. You know, because you y-you’re not gonna get any answers about why you or why anyone else and in fact it’s not helpful to start saying well why have I got this, why why why’d it happen to me. That’s not gonna get you anywhere. Um um not for a long will they know why anybody gets it at all and even then, I think it will be very fractured. But, uh, but no I think that’s all, for me it’s all part of having a good circle of friends who just um know and care and, you know, will find ways to help and and do stuff, you know, is really positive.

**Interviewer:** Yeah, yeah. Having that support at hand, yeah.

**Respondent (P):** Mmm

**Interviewer:** Um

**Respondent (P):** Otherwise I think that’s that’s probably the only thoughts I had, I think.

**Interviewer:** [Pause] Sorry?

**Respondent (P):** I think that’s probably

**Interviewer:** [Crosstalk] Is that it? Okay [Laugh]

**Respondent (P):** I think that’s the only only thoughts I got in my head at the moment.

**Interviewer:** Okay, that that’s fine. Um, I guess bringing about bringing it back to the project, um, so what we’re trying to do is try and help people cope with MND better by providing some kind of online support as well.

**Respondent (P):** Yep

**Interviewer:** Um, and I know we haven’t, um, actually shown you what we’re gonna develop and things like that, but I just wondered if you had any thoughts and feelings about whether you might use something like that or, um, [Pause] like whether you might access online support in in that way?

**Respondent (P):** [Crosstalk] I think, mmm. Um [Pause] I guess um um [Pause] I don’t know what to think really. I I think there is there is room for that. I mean there’s a lot of there’s a tremendous amount of information provided through the [charity organization] about the kind of practical stuff.

**Interviewer:** Mhm

**Respondent (P):** But that there’s very little I think about you kind of emotional mental wellbeing, I think that’s that’s a lot lot harder to kind of put into words. But I think, um, there is definitely a place for that. I don’t know what it looks like, I don’t know what the resources are in there.

**Interviewer:** Yeah, it’s tricky to um to ask you to talk about without sho- actually showing it to you.

**Respondent (P):** [Crosstalk] Yeah

**Interviewer:** But, um

**Respondent (P):** But, but, but I think there’s definitely a place for it and I think, you know in-increasingly um that’s your first go-to place nowadays is to is to search the internet or to use internet-based resources. Um, I’m fortunate that I can still um use a mouse and everything on the computer. Um, but with voice activated computers now um readily available and our beloved Alexa and all the rest of it, then um then, you know, the the the scope now for people um to operate a computer in a number of different ways is is better than it’s ever been.

**Interviewer:** Yeah

**Respondent (P):** Um, so I think I [Sigh] I can’t imagine what it’s going to be like but I can imagine there’s all sorts of things we talked about, um, and and other resources maybe self-help, questionnaires, maybe um whatever maybe thoughts and and poems or reflective things provided by people. Um, I don’t know it could be anything from uh from a very practical kind of guide of do this do this self-questionnaire and do these things through to here’s a collection of poems and reflections by people who’ve been involved in this and see what helps you. I don’t know.

**Interviewer:** Okay. No, those are all really good ideas. Um, can I just ask out of curiosity how how do you operate the computer or answer emails and things like that?

**Respondent (P):** Um I’m I, as I say, I’ve got e- I’ve got enough left in my right arm at the moment that I can easily use a mouse. Um, typing is becoming more awkward just because I’ve gone from being able to use two hands to using basically one finger. So, it’s it’s kind of it’s very laboured. But what I have started to experiment with and quite successfully is being freely available voice to text software. So, I’m using, the best one I’ve found so far is google documents.

**Interviewer:** Okay

**Respondent (P):** And I’ve found that can pick up my voice pretty clearly and pretty accurately and I can get decent sentences rolling out of that quite quite easily. So, I’m sort of, uh, doing more work with that really and getting that punctuation working and so, I I’m anticipating using that a lot more.

**Interviewer:** Okay

**Respondent (P):** Um, but for most the time I still use um my mobile phone more than anything else for for emails and then you only you can only use one finger anyway, so.

**Interviewer:** Yeah, yeah, that’s true.

**Respondent (P):** Yeah. I I can manage that, I can manage that fine.

**Interviewer:** Okay. And, um, even in terms of when you when you did look for help or information online, um, just thinking about you’re your journey, do you think there were times when you were more, um, like you more readily access help? Or, um, say around diagnosis was it probably too much information and you didn’t want to look for things?

**Respondent (P):** [Crosstalk] Yep. Yeah when, th-th-that’s exactly it. When we, when um I got the diagnosis, the consultant at the hospital handed me the, um, centimetre thick um file from the [charity organization] and he said there’s a lot of information in there about M-MND. He said don’t read more than the first two or three pages at the moment.

**Interviewer:** Yeah

**Respondent (P):** And and it was a very wise piece of advice. Um, bo-both because you, th-there is too much to take on board and because, um, how it’s going to affect you um is completely different to the person standing next to you. So, so you probably don’t need to pick out half the stuff, or three quarters of the stuff, um before it starts to happen, you know. So, so the, yes there was so initially relatively little because to be honest the only thing that sticks in your mind is you’ve got life expectancy of two to five years um and nobody knows what’s going to happen and that’s about all you can remember and that’s all that’s worth remembering. Um, but then as time goes on and you kind of want to find out about more specific things, then yeah get more specific information and I’ve just gone through the routine of um applying for benefits for the first time in my life. I’ve never had benefits before so I’ve got a personal independence payment and um there again the uh [charity organization] has a benefits team. I talk to them and they gave me some extremely helpful advice that that got things done nice and quickly. Um, but also, um, I’d also looked at, I spent quite a lot of time looking at different sorts of potential treatment, um, uh across the counter available treatments. So, people are constantly experimenting with with different kind of food supplements and things like that. So, I’ve I keep on top of that through ALS untangled, um and I’ve looked, keep up to date with the research projects and things, um, which is why I responded to you. And, um, and so for instance I looked at curcumin um and I’ve been taking some of that. I’ve also, um, recently started taking cannabis oil.

**Interviewer:** Okay

**Respondent (P):** Um, so, um, things like that I then investigated a lot, but with the cannabis oil, because my um clinical nurse was a little bit sort of unhappy about me taking it or I think was more protecting making sure she didn’t give me any of the wrong advice. I actually rang [charity organization] and the, uh, clinical team there, the research team actually came back to me and gave me their view that it was never going to be harmful and it might just be helpful, but it certainly won’t be harmful. Um, so, you know, uh i-it’s all kind of, when there’s something specific then delving into it and and and getting more information. But, uh, you’re absolutely right, the biggest mistake is to try and read everything at the beginning ‘cause to be honest if you did that, I think you’d go and find the nearest cliff and go and throw yourself off.

**Interviewer:** Yes.

**Respondent (P):** [Crosstalk] So, um

**Interviewer:** It’s more as things happen or as you notice symptoms, yeah.

**Respondent (P):** [Crosstalk] A-a-as and when, yeah.

**Interviewer:** Okay

**Respondent (P):** It’s really, it’s sort of, yeah, menu driven if you like, yeah.

**Interviewer:** Okay, no that’s all really useful. [Laugh] Um, I’m pretty much done with my questions, so.

**Respondent (P):** Good

**Interviewer:** Um, I can, I’ll I’ll still chat with you, but I’ll stop the recording i- unless there was anything else you wanted to add?

**Respondent (P):** No, I don’t think there’s anything else, thank you.

**Interviewer:** Okay