**Transcription of Interview 18**

**[person with MND]**

**Respondent (P):** No, no, no. Happy to just uh get going and, uh, yeah mm and uh make a start.

**Interviewer:** Okay. Are you happy that it’s audio recorded as well?

**Respondent (P):** Yeah, that’s fine.

**Interviewer:** Okay. Just have to check with you before. [Laugh] Um, so I guess, um, I’d like to know your experience about MND and if you could start wherever you like, whether it’s diagnosis or when you noticed symptoms before, wherever you’d like to start really.

**Respondent (P):** [Crosstalk] Okay. Okay, so you just want me to tell you about sort of from the start really, how what happened and?

**Interviewer:** Yeah, what what your experience was, yep.

**Respondent (P):** Yeah. Okay, um, well I was very active, did a lot of uh sports, football, um running, you know, distance running, that kind of thing. Um, so, looking back I probably had some symptoms which I just sort of brushed off, probably about 12 months before, very minor. And then I was saying around July, August of 2017, um, started to, you know, not feel quite right when I was playing football and my balance was a little bit off, and then I noticed um generally when I was walking round, sometimes my left foot would slightly drag on the on the floor, or just catch somewhere, when I was, you know, walking around. So, um, yeah, I went to, uh, we’ve got a private health care, so I went to um [hospital] in [name of location] and saw uh [name of person] who’s a neurologist there, um, have been referred by my GP. Um, he we did a a MRI scan, uh, there his tests and then he sent me for an EMG at [hospital] in [name of location]. Um, I think that’s about the 28th of November. And then he gave me a call, or rather the secretary did, and asked me to come in on the fourth, asked me to bring somebody with me, um, to the appointment, and uh yeah then, you know at the appointment, that was uh when I was told, you know, that it’s strongly suspected that it was MND.

**Interviewer:** Okay

**Respondent (P):** Um, yeah. So, that’s that’s up to sort of diagnosis, um.

**Interviewer:** Yeah. [Pause] And, um, how is your experience been like now?

**Respondent (P):** Uhh, how am I sort of generally now, or?

**Interviewer:** Just generally

**Respondent (P):** Um

**Interviewer:** Generally, how you cope and what your, your main concerns at the moment?

**Respondent (P):** Okay, so we’re sort of, what, um, 4th of December ’17 to now is coming up for 18 months. Um, in terms of my mobility and, you know, uh loss of function, not so bad. I mean, I can’t re- I can’t run any more, um, but I still keep active. Uh, get to the gym and uh and uh you know do that kind of thing. Um, I uh [Pause] you know, generally mobility walking around sometimes, um, uh worry that some days I’ll you know not to balanced, you know my balance isn’t great at times. Um, I have some cramping, uh, you know, maybe at night really, now and again. Um, it just in my legs. Um, I have, it started in my left leg, as my lef- but my right leg it’s, you know, a little bit stiff now from time to time and uh, and sometimes my arm is a little bit, you know, might get cramp in my arm or something like that. Um, got loads of twitching, um most days. Some days not, not so bad, but most days, you know, I’ll twitch sort of, my muscles will twitch pretty much everywhere around my body, um.

**Interviewer:** Yeah

**Respondent (P):** Yeah, so that’s that’s how it’s affecting me at the moment. Um, which to be honest, is, you know, having been told and and knowing what it was and knowing the statistics and that kind of thing at diagnosis, you know I’m quite sort of pleased with where I’m at really.

**Interviewer:** Okay

**Respondent (P):** Uh, in terms of, you know, not having, i- it’s not impacted hugely on my life at this point. Although, it’s had sort of had some impact.

**Interviewer:** Okay. So, you sort of read some information and then looked at what your situation was and compared to that?

**Respondent (P):** Yeah, well I I did that you know before, uh, diagnosis because, you know, you do, don’t you? Well, a lot of people do. I had a look and see, you know, what symptoms were, what the EMG test was for. Um, so I sort of thought well everything fitted, um, but then obviously, you know, when [Laugh] when you look anything up online to do with MND, you know, there’s not not a lot of positive stuff out there really. Um, so it’s, you know, you just gotta just kind of get over that and just uh realise that everyone’s different, I think. So, that’s, you know, how I’ve dealt with that side of it.

**Interviewer:** Okay. And how, how are your thoughts and feelings about having MND? Did they change from when you were diagnosed to how things are now?

**Respondent (P):** Um, yeah, I mean, you know, there’s some there’s an acceptance now, I think. Um, when the diagnosis first came up obviously it it’s fairly sort of devastating to comprehend and, you know. I’ve got two young children and, you know, my [Short Pause] my first thought was, you know, will I be around to see them grow up, that kind of thing, and, um, and you can’t help but speculate about the future when you’re, you know, when you’re first diagnosed. It, you know, that’s all you think about is what what will happen. Will I be here in three years’ time? Will I be here in ten years’ time? You know, will I be, you know, what my level of function be, um. So that all, and I and I still have all those thoughts, you know, uh that, you know, from time to time, but at the start that’s all you can think about and all you can focus on is, you know, the bleak sort of future which y- you know you see and read online and and that kind of thing. So, yeah, I think, you know, there’s obviously an acceptance to this point, and uh I’ve learned to cope with my, you know, any negative feelings that come, you know, which do inevitably come, you know, from time to time. So, you know, being able to, you know, cope reasonably well and and just get on with life really.

**Interviewer:** Okay. And when I can- when you’re diagnosed, um, I can see how you immediately think about, you know, the future and all of these negative thoughts as well. Um, say now or in your daily life, do you know roughly when these come up or are they triggered by something or?

**Respondent (P):** Um [Pause] I think about it most of the time [Laugh] to be honest still. Um, you know it’s just always uh it’s really, you know, dominates my thoughts. Um [Pause] sometimes, you know, there’ll be a trigger and that, you know, if it’s a sunny day and I like to go running down on the river front, and I’ll sort of think well, you now, I’d love to go and do that today, um, love to still be able to do that. So certain things do, you know, trigger off, you know, uh some of the more negative sides and negative thoughts. Um, you know, when you when [Pause] the problem is when you focus on the things you can’t do anymore, then it does sort of it gets you thinking. So, you know, I sort of, well actually if I can’t do that I’ll just, you know, go and have a walk around or, or try a clear my head or think of something different, really.

**Interviewer:** Okay, okay. So that’s roughly how you cope, you try and do something different and?

**Respondent (P):** Yeah, try and do something different, think of something different, focus on what I’m doing in, you know, in the next few days, you know. Plans I’ve got with the children, with the family, um, and just focus on those. Live in the, you know, sounds a bit cliché, but live in, live in the moment really, rather than rather than think about, think about the past. What I used to be able to do, or think about the future, what I may or may not be able to do. You know, just think about what I’ll be doing in the next few days and next week and that kind of stuff.

**Interviewer:** Yeah. Yeah, no, a lot lots of people say the similar thing as well. Um, and are there any sorts of concerns or worries also besides what you mentioned, um, that you face on a daily basis?

**Respondent (P):** Um, sometimes in work, in my work life, um, or just generally, you know, people’s perception of, you know, everyone will ask me ‘oh, have you hurt your leg?’ you know, or are you, you know, what what have you done, what’s wrong with you, you know. That kind of throws you because sometimes if it’s someone I’m not going to see again I’ll just, you know, brush it off and sort of, you know, say ‘oh, it’s nothing really, I’ve hurt my [Mumble] I I’ve hurt my leg playing football’ or something like that. But someone I know, who doesn’t know about it, then, you know, that’s I’ll have to sort of explain and, and that’s quite hard and, you know, if I go for a meeting now with work, you know, it comes up and I have to sort of explain and makes it a bit, you know, can make you a bit difficult, awkward. People don’t know how to take this sort of y- you know people either don’t know much about it and they’ll ask you about it, or people know about it and say, you know, y- you get quite a lot of sort of sympathy then and, um, you know, people react differently to it, you know, and it’s, it’s just something that you have to deal with in in working life, really.

**Interviewer:** Yeah. That’s the other thing I was going to ask you as well about how um you manage work and uh do your, the symptoms don’t really interfere with that at the moment, or?

**Respondent (P):** [Inhale] Not really, no. It’s more there sort of [Pause] you know, being able to focus and uh concentrate on your work and you know, it’s quite an intense job there doing, you know. [Pause] And I used to do a lot of work at home, a lot of extra hours, that kind of stuff. And uh it really changed, you know, the way I look at work now and, whilst I still work hard, um, and hopefully do this the job this to the same level, you know, I haven’t, you know, don’t really work at home. I don’t, don’t stress as much about some things um, you know, in work, which could go wrong or or that kind of stuff. So, yeah, physically it doesn’t stop me doing my job, um, just you know being able to cope with uh the actual [Pause] uh stress of being at work and, um, but luckily I mean, you know, all my colleague are are great, so uh that’s a really um really good thing, a real bonus in that everyone’s so so uh understanding.

**Interviewer:** Ah, that’s good, that’s good, that there’s that support, as well.

**Respondent (P):** Yeah.

**Interviewer:** Um, and for a lot of people as well, um, just having MND and managing it as well can be quite emotionally challenging. I know we spoke a bit about um worrying about the future and how things are going to be like, um, but are there also any other sorts of emotions that you go through?

**Respondent (P):** Yeah. I mean it it’s, you know, it’s difficult with, you know, sometimes at home my wife’s great. She, you know, we don’t really, uh, talk about it loads or dwell on it, but she’s, you know, mainly supportive. Um, but sometimes, you know, we can, she’ll try and do things for me like carry bags and and I’d say oh I’d rather I’d rather help myself and, you know, we can have a little sort of disagreement about things, or, um, you know, that that kind of stuff. Um, she wants to help, whereas I want to do as much as I can myself. You know, while I can. Um, and it’s i- i- it’s, you know, we, we get on great, but it’s sometimes it’s a little bit difficult to manage that side of it.

**Interviewer:** Yeah, yeah. Just, um, asking for help all the time and things like that, yeah?

**Respondent (P):** Yeah, yeah. You know I, she she’s very good, you know, she knows when when I need help with something, or, you know, she knows her normally when I’d, you know, I’d rather not have help but it’s difficult because, you know, she keeps asking me if I’m okay, you know. It gets to a point where you say oh yeah, just stop asking, I’m fine and that. You know, I’ll uh I’ll I’ll say I’m not, but then I’ll feel bad for, you know, you know, sort of being short with her because, you know, she’s trying to do her best and it’s incredibly difficult for her.

**Interviewer:** Yeah. Okay, um, and I know you mentioned your wife is, um, one of the places where you get support. Um, is there any other sorts of sources of support for you?

**Respondent (P):** Um, as I said, my work colleagues are all are all great, you know. I’ve got certain people who if I’m in a bit of a tough day I can go and speak to. Um, uh and just chat things through with them. Um, you know, that’s, that’s really really important. Um, I’ve got my mum and dad but they uh I don’t really like to, you know [Pause], talk it about it too much with them, because I think it’s been really hard for them and I don’t want to [Pause], you know, I think they’re they’re coping, you know, as well as they can. I don’t want to [Inhale] upset that if you see what I mean.

**Interviewer:** Yeah, yeah.

**Respondent (P):** You know, I’ve got plenty of other places I can go to, to to speak to people and colleagues uh my wife, you know, uh that kind of stuff’s around. So, so yeah, that side of it is fine.

**Interviewer:** Okay. And, um, have you had any professional support from any health care professionals or, um, would, if not, would you like to potentially get some support?

**Respondent (P):** In terms of uh emotional support or or mental support, um.

**Interviewer:** Yeah. Um, yeah. More in terms of uh emotional support and coping with things.

**Respondent (P):** Um [Pause] no, not really. Um, we we went to uh an appointment in January, and one of the MND nurses, they arranged um a visit for a physio, which happened. But then they said they would refer to maybe speaking to someone, but uh nothing’s really happened with it, so. Haven’t heard, so. Um, someone was on maternity leave who they’d normally ask to do it, so uh you just got got left, really.

**Interviewer:** That sounds familiar [Laugh]

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

**Interviewer:** Um, but did you, did you feel like you might have, um, benefited from something like that, or did you feel you didn’t need it at this point?

**Respondent (P):** Um, I didn’t think particularly you know, I was really struggling. But, you know, it’s uh I wanted really to- would’ve minded speaking to someone because there’s certain things you can’t say, you know. So, you’d rather [Pause] you can speak to someone who’s a stranger, uh that you wouldn’t say to your friends or family or colleagues so. You know, i- it would have been, may may have helped with some aspects, you know, to do that, think.

**Interviewer:** Okay, okay. It sounds like um you’ve you’ve got some support and um strategies in place as well to kind of help you already. Um, just in terms of uh anything else that you either tell yourself or an attitude that you have, something like that to help you cope, just so we can, you know, use similar things like this to tell other people with MND.

**Respondent (P):** Yeah. Um, [Pause] I just sort of try and try and so everything I can, you know, not be not lose confidence with uh, you know I, with going, you know, sort of places I always would of, um, you know, going for nights out and that kind of thing. Going to watch football matches, going to, you know, places, you know, with my friends that kind of stuff. So, I try to, not challenge myself, but make sure there’s nothing I’m not doing because of it. You know, almost in a way to say, you know, it’s not going to control me or control what I do. I won’t let it, and this, you know, certainly not at the moment. Um, and that’s just uh just alongside, you know, um trying not to speculate, because I thought I’d be in a worse position now when I when I first had the diagnosis. So, you know, focus on the positives, all the things you can still do. Um, focus on, you know, the good things in my life and um how lucky I am rather than, you know, seeing myself as unlucky. Which, you know, there’s always people who are [Pause] who are getting on worse, I think.

**Interviewer:** Yeah. Yeah, no, that’s that’s really really helpful, um, to hear from someone who’s actually going through the experience that things like that help. Um, and even just trying to keep things as normal as possible is also quite helpful, isn’t it?

**Respondent (P):** Yeah. Definitely, yeah.

**Interviewer:** Yeah. Um, I [Pause] I was just wondering if there’s anything else um that we haven’t covered about your experience or [Pause] um how you cope with things? Because

**Respondent (P):** Um

**Interviewer:** I kind of ask my questions about that, so if there’s any- everyones situation is different so

**Respondent (P):** Yeah

**Interviewer:** There may be places I haven’t… things we haven’t spoken about.

**Respondent (P):** Okay, well uh uh when, sort of initial diagnosis stage, um, [Pause] I feel there’s a, you know, felt there was a real lack of sort of support at that stage and I don’t know if that was because I was diagnosed by a, you know, uh uh in a private clinic. Um, and then there was sort of a, you know, they sent me, you know, to the NHS hospital the next day, but it was then a month, you know, before I could see anyone. You know, a a consultant or anything like that. Um and during that period there was no, uh you know if you if you if you wa- got any questions call this number. You know, if you’re struggling, here’s who you can speak to. You know, no sort of information was given really, and no, you know, uh I didn’t feel it was appropriate to have to wait a month to go and and see, you know, someone who is an expert because during that month I was okay, you know, because I had all the support. I had family, colleagues, friends um but I- I, you know I was just I was just thinking you know if somebody didn’t, if somebody didn’t have that network, or or not didn’t have a family and that kind of stuff. To be just left on you own for a month there, especially if it’s around Christmas as well. So, you know it started in December and then I didn’t see anyone until the start of January. I just thought you know that’s quite uh this sort of a bit of a gap in the in the care there. Um, and it was okay for me, as I say, but, you know, people who perhaps more vulnerable or didn’t have people they could turn to, you know, may have really struggled with that gap in the care.

**Interviewer:** Yeah. Should of joined up a lot better.

**Respondent (P):** Yeah. Um, the other thing I’d maybe say is that I, you know, I don’t know whether there’s a duty sort of, of the GP for [Pause] you know, if someone’s diagnosed with with a condition like this, which is, you know, uh and, and technically you know i- it’s palliative care, isn’t it? Although, you know for me it’s not sort of what I understand of the word palliative at the moment, but, you know, because there’s no treatment and no cure then it is deemed as palliative. Um, whether the, my GP should be more involved in terms of, you know even checking, calling me every three months or maybe saying come in a see us, see how you’re getting on. Um, I don’t know whether that’s supposed to happen, but definitely hasn’t for me.

**Interviewer:** [Crosstalk] Ah, okay. So, linking up to the GP as well?

**Respondent (P):** Yeah

**Interviewer:** Okay

**Respondent (P):** But I almost feel they, you know, do do they even know [Laugh] know that I, you know, that I’ve got this condition. And I mean obviously they do because they’re prescribing, you know, medication monthly for me so they they do obviously know the position but, you know, there’s no uh contact at all, so.

**Interviewer:** Yeah, ‘cause you mainly go to a neurologist I see what you mean. Yeah

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

**Interviewer:** Yeah, and did you, how did you then, did you link up with the [charity organization] at any point?

**Respondent (P):** Um, I’ve been on the website, I’ve had a look on the forum. Um, I haven’t, um, you know, sort of contacted them directly. Um, uh uh what something I did do, actually, was um [Pause] had a friend of a friend who is uh at um [name of place], [hospital] Um, [name of person] so uh he put me in touch with him at the start. Um, I e- I was emailing him before I saw [name of another neurologist] at the [other hospital]. So, in that period from the start of December to the start of January, I was emailing [name of person] and he sort of helped me with a few uh eh, you know, few queries I had because at the time I could still run, you know, I was still active, um, and I wanted to know whether I could still do that, you know what sort of training I should be doing, exercise. He helped me with that. And he also said, you know, you can come down and we’ll have a look at you if you want, which I did do. So, I went down to [name of place] um at the start of February. Just, not so much for a second opinion because, you know, but yeah just to have someone else have a look at me and see what they thought really, and just get someone else’s take on it.

**Interviewer:** Yeah. And to have your questions answered and things like that too.

**Respondent (P):** Yeah, that was it, you know. Err [name of neurologist] is great, you know, she’s very um answers any questions you’ve got, and I’d seen her by that time. But then, you know, I went down to [name of place] as well just to, you know, everyone has a different sort of style don’t they almost. You know, uh a consultant will will tell it talk about it one way and then a different consultant will talk about it a different way and, you know, some people are more receptive and understand better what a particular person [Pause] will explain things to.

**Interviewer:** Yeah, I see what you mean. [Pause] Yeah. Um and at the moment do you feel you’re getting enough support?

**Respondent (P):** Yeah. Um, yeah, I don’t sort of here from um the [hospital] really. Uh, I had a call, well it was, they’re they’re looking to doing a trial actually. Um, and they sent me the paperwork and I called them up and said yeah, I’m interested in getting involved, and they basically said oh it’d be two three weeks before anyone comes back to you, and I haven’t heard now and that’s probably about six weeks ago. So, you know, i- i- I don’t know whether, don’t know what’s going on with the trial or whether um, I know it’s definitely happening but um somebody left, you see, out the team and it wasn’t really passed on so. Actually, that reminds me I need to call, call them again. See what the position is. So, um yeah, I don’t really hear from them, don’t really hear from the GP. I mean I’m sort of expecting a a letter probably in the next month or so to go in to [neurologist’s] clinic and and catch up with her. She was off sick in January, so I saw uh one of the specialist nurses instead. Which was, um, which was okay.

**Interviewer:** And you usually like to take part in research as well?

**Respondent (P):** Yeah, yeah. I’m keen to. Um, we had uh, we had a sort of the uh the [name of trial] trial results came out from Australia so I got in touch with them and said, um, you know when’s phase three, you know, when can other people get involved, is it g- and they said oh we’ve got enough people in Australia to do it, so, um. But hopefully, you know, something will happen with that and then there’s a couple of other things which are really at that stage three tr- trial sta- uh sorry phase three trial stage which promising so, yeah. Um, always looking to get involved in something. And the lack of alternatives is, you know, it means you you’ve gotta try and think outside the box, really. I’m seeing a physio next week and uh uh who I’ve seen before and he’s giving me a program of e-, you know, things to do, so go back and see him. Something I feel that’s always always [Pause] always wanna think I’ve got options, got somewhere to go because think at the point where you think well I’ve got nowhere left to go with this, that’s when you may sort of deteriorate and let it get the best of you. But I think if you if you say right well I’m going to, you know, there’s this trial, this might happen, I’ll go and see a physio uh I, you know, I I’ll put real effort into doing a physio every day and that kind of stuff and just see if that helps me. So, always, you know, looking for options really.

**Interviewer:** Yeah. Almost like having the options there rather than just um seeing there’s nothing more you can do or something like that.

**Respondent (P):** Yeah, because y- you sort of get that, you know, [Pause] I know I know it’s difficult because, you know, from uh a healthcare point of view and terms of licensed treatments and that kind of stuff, there isn’t a great deal and, you know, so the MND team, you know, they’re- they’re sort of well, just go and get on with it really. Uh, it’s almost that that’s the that’s the sort of feeling you get. You’re sort of left to just just get on with things and, you know.

**Interviewer:** And at the- at the moment it’s do you feel like it’s more you taking the initiative to search for alternatives, rather than um the doctors telling you or something like that?

**Respondent (P):** Yeah. I recognise that they can’t really because, you know, they uh I only see them every six months, um that they can’t you know go and say do something which is not approved, because er well, you know, that’s not that’s not how they sort of operate. You know they there they, you know, well they these are the approved treatments and, you know, anything else yeah you can look at but, you know, we can’t really advise on. Uh it’s very much the, you know, the clinical viewpoint. Is it unless something is is achieved. FDA approval or whatever it is. Um, I think that’s in America, isn’t it? But i-, you know, same thing. Um, then then you know they can’t comment on it really because it’s not approved and it’s not proven, you know. Whereas I look at stuff, you know, which is anecdotally worked or or um, you know, that kind of thing which I think you’ve got to really.

**Interviewer:** Mhm [Pause] And do you, um, do you look for a lot of help online as well?

**Respondent (P):** Yeah, yeah. I’m always at things online, yeah.

**Interviewer:** Okay

**Respondent (P):** Yeah

**Interviewer:** Well the reason I’m asking is, um, ‘cause we’re approaching it from more um the psychology point of view and providing help for dealing with difficult emotions and stuff like that.

**Respondent (P):** Yep

**Interviewer:** Trying to provide it on an online platform so people can access it wherever they are, at whatever stage they are as well, so.

**Respondent (P):** Yeah

**Interviewer:** I was just wondering what your thoughts were on this. Is this something you might access or use.

**Respondent (P):** Yeah, I think so. It’d be great to have somewhere to go, I think. You know, my sort of motivation for getting involved and and saying I’d get involved in this is obviously not really, you know, it’s not something that’s gonna help me directly necessarily, but I’d rather, you know, I wanna w- want to share my experiences so, you know, things can maybe change for other people, and and maybe there is some more support out there that can be given or from initial diagnosis much better things can be put in place. So, that was my sort of motivation to do it. So, yeah, I mean I, there was something there, like an online platform which uh I could go to that would be just another option, as I say, you know.

**Interviewer:** And do you think there’s anything we need to um, I know it’s tricky to say it when you sort of don’t know what it is or looks like, but, um, say are there certain times where [Pause] you you wouldn’t access information online because there’s too much information, or?

**Respondent (P):** Yeah, um

**Interviewer:** That you needed, maybe?

**Respondent (P):** I’ll have days where I deliberately avoid looking at anything and trying just to have days or a couple of days where I don’t think about, you know, MND and so uh you know I- [Pause] you know.

**Interviewer:** It’s difficult, yeah.

**Respondent (P):** Yeah. I I sometimes you’d prefer, you know, just to hide from it really. Um, so yeah there are times where I don’t want to look at anything really.

**Interviewer:** Yeah. And do you think around diagnosis there’s sort of a l- lack of information so people would um look for some help online or is there probably too much information that it’s not the right time to?

**Respondent (P):** Um [Pause] I mean it’s all there if you wanna look for it, but the problem I think is that if you just stick it into a search engine then you’ll get loads of pages about how bad it is, loads of pages about you know it’s one of the worst things you can have. You’ll be dead in three years, you know, you’ll you’ll be trapped in your own body, all that kind of stuff.

**Interviewer:** Yeah

**Respondent (P):** And it’s all, it’s all negative. Um, you know, uh I think [Pause] people get, you know, a shock when they look it up and they say oh my god, that’s it. Right, done. Whereas you might wanna, it’d be better if you could look it up and it could say, um, you know here there are examples of people, we just have to be unrealistic, but we can say there are examples of people who are long survivors. Everyone’s a different case. Um, you know, all this support is out there, this is the position with research. I mean the [charity organization] website does do that in a way, and it’s kind of one of the mo- more positive sort of places out there, but you know I y- you almost want to be something see something which says well, you know, research is up to here, these are current research programmes, here’s the drugs that are in trial, um, this is where we’re up to with this, this has got funding. Um, you know, if you want to speak to someone go here. You know, something like that was- would be a real a real help.

**Interviewer:** Yeah. Have more like a, um, a more optimistic spin to it rather than [Pause]

**Respondent (P):** Yeah, definitely. I mean m-m-m my wife and myself have talked about it quite a lot and that, you know, you know the sort of what’s out there is pretty horrific really and, you know, y-you know, the first thing you see and, you know, that sticks with you. So, you’ve got to, if you want to get the less negative side of it, you know, you’ve got to really go a bit deeper and look further which if you didn’t have to do as much of that then, and it was there, there in front of you, you know, because there are, there are some positives there to think about. You know, I think I’m a very different person than before diagnosis and I think things differently and a lot of that’s positive so, um. You know, I’m not saying it’s a good thing to happen, but it’s not doesn’t it’s not always as bad as um what’s out there.

**Interviewer:** Yeah, yeah. Yeah, that’s really useful to hear from your experience of going through it as well and yeah. Um, I’ve kind of finished asking all my questions, I wondered if um there was anything else you might want to add?

**Respondent (P):** No, no. I think, you know, that’s just that those last bits that that was everything I thought of really, so, um yeah. Hopefully you got some good sort of feedback from you know what it’s like and, you know, I am lucky, uh, in that, you know, I appear to be progressing slowly. So, you know, it’s obviously different for people who are, you know, in a worse position than me, so. But, you know, I count my blessings I am lucky in that way so..

**Interviewer:** Yeah, um.

**[End of recording]**