**Transcription of Interview 6**

**[Beginning of file]**

**Interviewer:** So, I think I mentioned to you earlier at the coffee morning and things, but this is about your experience of MND and coping with it, um, feel free to, if you need a break or we need to stop at any point, I can just easily stop the recording, at any point, and if um, some of these questions will ask about how you feel about situations, so if you feel that they are too difficult or you don’t want to answer them at this point, you can just skip over or ask me to just move on. Thank you. Um, yeah and I think the only other thing is, all this information is confidential as well, so if you happen to mention say a person’s name or a hospital name, all of that will be treated confidentially.

**Respondent (P):** okay

**Interviewer:** so I guess I’d like to start wherever you want, to tell me about what your experience with MND is like.

**Respondent (P):** okay. So, I might as well start from the beginning I suppose. Uh, I was diagnosed in July of 2015 [pause] but uh, my journey really began, for sure, a year before that, when I first noticed [pause] something not right, with my body. And, indeed if I think more carefully about some years before that there were little things occurring which would, were not normal. Um, which [pause] you don’t think much about at the time, they’re just annoyances really. Hardly worth going to the doctor about, you just put them down to getting old, perhaps needing a bit more rest, things like that. But uh, a year before, for sure, a year before I was diagnosed, so roughly July 14. I was tripping up stairs, inexplicably, no matter how hard I tried to counter it, be conscious that it was a potential problem, which would send me sprawling sometimes up the stairs, uh, it still occurred. So, when the leg cramps started to occur around about Christmas time 14, okay so 6 months before I was diagnosed, I felt it was something beginning to go wrong, so I went to the doctor. She had no experience of MND, uh, which I later discovered.

**Interviewer:** this is the GP?

**Respondent (P):** The GP, uh, course at that point we didn’t know it was MND. And she just sent me, suggested I go to a sports physiotherapist, to try and eradicate my leg cramps. And lots of people do get leg cramps so, it’s understandable that she might be thinking in those terms. Uh, but it took me a long time to find the time really to chase down a sports physiotherapist, never having delved into that area of activity before. The time I did locate somebody, they were a lot worse, and I found it necessary to go back to the doctor, happened to be lucky enough in some sense to come across a locum, much older lady, who had much more experience. She was actually retired, but had come back as a locum, and within 5 minutes of examining me on the um, on the table, uhhh, she had gone onto her computer and booked me uhhh, an appointment, into the appointment system to see a neurologist.

**Interviewer:** oh okay

**Respondent (P):** So, by the time that appointment came through, it was July 15. And uh, I was booked in for uh, a few days, continuous assessment uh at uh the general, and uh at the end of those few days, I was given the diagnosis by one of the consultants. Uh, so that’s really where, you know…

**Interviewer:** the journey began..

**Respondent (P):** .. the journey proper began, uh so, the lady was very good in the way she gave, she delivered the diagnosis, she didn’t give me a prognosis, how long I might have, uh, which I was grateful for in a way because we didn’t ask for it, she just said it’s a life limiting disease. You can take from that what you will really, and uh of course immediately when we got home we went on the internet, started to find out as much as we could about the disease, um, and we’re fortunate that our, both our daughters are in the medical profession, one is an OT, and the other is a nurse, and my OT daughter had already had some suspicions that it was MND. From, from the early symptoms I was getting, um, so course although it was an indication of her suspicions, it was equally devastating for her to hear it to. Um, so she was able to guide us really, into the information on the internet, carefully, uh not all at once. Uh, I suppose within a couple of months we had got out heads around [pause] what the future could hold, both worst case and best case, everybody always used Steve Hawking as the touch [coughs] excuse me, the touchstone for best case as they perceive it, uhh, but I have heard people say to me, you wouldn’t want to live the way Steve Hawking had to live yet. Take that as you will really. Um, so we started to think about both short term and long term plans, short term if that’s what I had, long term if you know, I would and enjoy a much longer journey. So we thought about how we could live here, if, when things got difficult, and we started to put in place uh, a few of the self, uh, self facilitating adaptions, the through floor lift and special toilet.., we finished off jobs around the house, because it’s a self-built house.

**Interviewer:** oh okay

**Respondent (P):** Finished off jobs that I’d been trying for years to finish, to find the time to finish in amongst my business activities. Um, we had my daughters wedding, uhh September 15, so not long after the diagnosis [pause]. We went on holiday to see my relatives and our friends in Germany, with our caravan. Uh, and then we came back, we settled down really to [pause] seeing various professionals, establishing appointments and getting to know people really that you will be spending quite a bit of time with in the future. And obviously all the while you’re also having to deal with the emotional side of things, and uh, the increasing stress that it brings, uh, as your body weakens, you can do less and less for yourself. Uh, even in the early stages with the leg cramps, it’s a disturbing event, it disrupts your sleep, it disrupts your partner’s sleep.

**Interviewer:** okay, its mostly while sleeping then, okay.

**Respondent (P):** yeah, um so you wake up in the morning really quite shattered. And uh, by Christmas of 15 I had to stop work, I knew I would have to stop work anyway. Regardless, I knew I couldn’t possibly sustain a business, uhhh for very long. So, that whole 6 month period up to Christmas 15 was about changing lifestyle, and altering focus, completely. Uh, and finding new ways to, to live, really, um, you know we tried to be honest with ourselves that um, it wasn’t going to be possible to carry on as normal, so you either take the bull by the horns and say ‘right, this is what I’ve got to do to get the best out what’s coming’ and what’s coming is one a very depleting uh scale, of course. Because you can do less and less as time goes by.

**Interviewer:** so from the emotional side of things, was that more of um, like a sense of frustration or how…

**Respondent (P):** ohhh a whole myriad of emotions actually, none of them good. No good emotions, lots and lots of anger, which I still have, lots of anger. But it is the anger with this disease that drives me forward. Without anger, without the.. and the anger comes from the frustration of not being able to do things on an ever increasing level, but without the anger I.. I think I would be [pause] just curled up in the corner, uh, with no hope at all.

**Interviewer:** okay, so the anger almost.. keeps it…

**Respondent (P):** the anger is a driving force, uh, you see that in all sorts of walks of life, people need anger sometimes, directed, not just uhhh broadband scatter gun approach to things, because I’m not a violent person, but um the anger towards the disease uh, in your head, dealing with it mentally [pause] helps you deal with it, on the physical level. Uh, there’s a lot of bad language, we use, in the house, a lot of bad language, which isn’t pleasant for either of us, we don’t like it. But um, it vents the frustration, and it doesn’t impinge on other people, just between the 2 of us, just in our private home, it’s just the way it is, the way we deal with it.

**Interviewer:** okay, so it’s almost like it gives you, in a sense, some energy to deal with the problem.

**Respondent (P):** yes that’s right, it’s it’s... I don’t really understand it, I don’t really understand it, but.. it’s almost like it uh.. clears the air, it stops the depression, which it can bring, from descending upon you. [pause] uh, I often, and this sounds ridiculous, I often visualise the disease as an individual, I give it form.

**Interviewer:** okay

**Respondent (P):** I give it form and destroy it, in very violent ways in my head, uh, and throw it away, burn it, bury it whatever. That probably sounds very weird to some people, but its..

**Interviewer:** no..

**Respondent (P):** ..uh for me it’s a powerful tool, and uh, I don’t do it all the time, just when things get really difficult.

**Interviewer:** did you.. did you figure out how to do this or did someone mention that this is how… a useful tool to cope with things.

**Respondent (P):** I’ve always been a very independent person who doesn’t like being told what to do, always, uhh, although I’m a quiet person I am very driven inside. And I’ve used that throughout my life to achieve whatever, uh, so like I was saying before, recognising that the focus needed to be completely changed, I brought those old familiar tools to bear on, the only thing that mattered anymore.

**Interviewer:** yeah, and to help you with that

**Respondent (P):** that’s right, business was gone, uh.. you know being able to drive and go wherever you wanted of your own volition, gone, so [pause] it’s it’s how to make best of what you’ve got left.

**Interviewer:** okay, um are there any other emotions besides anger a swell?

**Respondent (P):** oh, a lot of sadness because uh it’s taken so much away [pause] the personal relationship, intimacy [pause] um… interaction with people, interaction with people.. with my children and grandchildren, uh, being able to go places and visit people without having to give things immense amounts of forward planning to get there, you know it takes an hour just to get from this chair, into my power chair.. and into the back of the van…. An hour. You don’t say to yourself, ‘oh I’ll just pop down to the shops’ with [partner] to get a bottle of milk, or for [partner] to get a bottle of milk, even if it was a corner shop where I could go with the chair to do it, which there isn’t but if there were it’s not feasible, it’s just not feasible. So yeah, a lot of sadness about what’s been lost. Uh, but of course I have the memories of how it was, which I can pick and choose, some things I put to the back of my mind because they’re too painful, and others I I try and keep closer to me, in in, not in the forefront of my mind but, just there when I need to draw upon them. So, uh, again it’s like I was saying about changing one’s focus, it’s uh picking and choosing what is really relevant anymore. Putting it in the pot, in your new pot of tools and [pause] life experience.

**Interviewer:** and drawing on them when you most need..

**Respondent (P):** drawing on them when things are tough, drawing on them even when things are going well, and using skills to achieve things that you need to do, like, I was in business for over 20 years, and that does equip you with certain skills, so when you need to achieve something with an agency, whether it’s a care agency or local council or whatever, it equips you, that that life experience equips you with the tools to get things done in an efficient way.

**Interviewer:** so is it almost like you’re reminding yourself about um, the skills that you had or could do and how they can now translate into these new situations.

**Respondent (P):** exactly that’s right, yes. It’s not saying to yourself, or allowing yourself to believe that because you can no longer do very much, can’t work so you can’t do very much, that that’s the end of it… it’s not. And with the help of my partner, your family and you know people from all your care agencies, you can still achieve a lot of important things, so yeah.

**Interviewer:** yeah, I guess it’s as you said, just a shift of focus to what’s important and yeah…

**Respondent (P):** and not giving up, not allowing it to put you away in a corner somewhere, waiting for the inevitable. Which comes to us all, but potentially with this much sooner, not allowing that to define what you do with whatever time you have left.

**Interviewer:** thank you, that’s really helpful to understand how people use different methods and strategies, to cope with things. Um, I guess we have covered pretty much the emotional side of things as well, um, just in terms of does this happen on a daily basis as well, or is, are they certain points where things are really bad, do these thoughts and fears come up almost daily?

**Respondent (P):** okay, I wouldn’t say it’s necessarily daily, and uh, quite often when it does occur it’s inter-related with how [partner] is coping as well. If she is not coping well because she’s had some had some bad nights, I would because I have been wakeful with problems, or she’s got things on her mind that have kept her awake, the following day or days can be very difficult and not being able to help her deal with that as I would have done before is intensely frustrating. You you feel, uh, like you are a burden upon her. Or upon your partner, uh, but you have no choice in the matter and that’, that is very disempowering. Watching your partner have to cope [pause] with still getting you to the toilet and back again, which can take an hour, and involve an awful lot of effort, with all the hoisting [pause], clothing, um, and time consumed, the consumption of time or someone else’s time looking after you, is um it’s a difficult thing to [pause] allow to happen. Um, you know you’ve been independent people, suddenly to have to rely on someone else to do something simple as I’ve just described, it’s uh it’s a tough one. And uh, to be totally reliant for that function, it doesn’t feel right, it’s not fair on them, it doesn’t feel right, but as I said, what choice do I have?

**Interviewer:** yeah

**Respondent (P):** So, when she’s having a good period of time with it all, it’s easier. When she’s not, it’s difficult, more difficult, so um when we get a lot of help, a period of a lot of help, not just from uh the carers that we have, but also maybe from family, maybe also from something uhh as simple as better weather, that may sound silly, but if the weather is better, [partner] can put the washing the out to dry, rather than having it piled up in the corner waiting for better weather. So, she’s able to process her day in a more efficient way, gives her just a few extra minutes here and there to herself, little things like that mean a lot, in amongst it all,

**Interviewer:** and, you mentioned some of the strategies you use and is there any other bits that are helpful? Could be people, could be things, that just help you cope better.

**Respondent (P):** okay, um, quality equipment and timely provision of quality equipment [pause] is very very important. When you’re first diagnosed, you don’t really know, if you don’t have the benefit of someone in the family, as we have, whose worked with server disability, quadriplegics for instance, you don’t really know what equipment you’re going to need. So, for your care professionals to give you the heads up on what you’re going to need and the reassurance that it will be there when you need it, is is, I feel in hindsight, vital. There’s nothing worse, as I’m sure you can imagine, getting to a point where, shall we say, you need a stand-aid so in theory the time before you can no longer stand, but walking is very difficult, just to get you to the toilet, is vital. That wasn’t mentioned at all for us, but my daughter knew that a stand-aid would be a very useful tool, uh beyond the point where I could um stand, even though you’re not meant to use it for that, you’re only meant to use it up to the point where you can no longer stand. So she actually acquired one for us on the internet, for next to nothing and uh we’ve only recently had to stop using it, because my core strength has gone so I just fall up when I’m using it, which is very dangerous so, we just keep that back as an emergency now really. So, that’s one thing, um, the coffee mornings, which enjoy at the [hospice] [pause] also, a very vital thing to get involved with, most people who are diagnosed don’t want to join straight away, they are quite rightly frightened by what they’re going to see, because they’re going to be looking at their future, as if they could look into the future, um that’s an unsettling thing. But I have to say, once the once you’ve had this for a while maybe a year, things started to get very difficult [pause] you are, you feel not compelled but you feel the ownerless nature of looking into that future, perhaps a little less difficult. And with a bit of persuasion, from uh the volunteers, one is our case, the volunteer, uh going along is not so bad because they will be there to introduce you, uh, and what have you, and once you’re there it’s such a useful thing because you see others at all stages and in all different forms, because of course there are 5 basic forms of MND, so you see people with all sorts and you see where you are compared with them, some are not so bad as you but an awful lot are actually worse than you. When you think about it that’s quite logical because they’ve been going for longer, generally, they have been going for longer,

**Interviewer:** okay, so they’d have more symptoms.

**Respondent (P):** yeah they have progressed further, so uh, yeah. But with some forms like bulbar, it’s it’s very sad to watch, when you haven’t got that one [pause] it makes you, sounds horrible but it makes you grateful that you haven’t got that one.

**Interviewer:** yeah

**Respondent (P):** I mean you get a little sense of hope from it, that you know, you haven’t got that one so you are, you have got longer. But um, yeah it it you rapidly find yourself as part of a family, um, when you go to these things, very rapidly and uh you know, if you can bring some of your enthusiasm, shall we say, hope by going along, and make other people feel a bit better, that’s, you know, that’s also a good thing, it uplifts you a bit,

**Interviewer:** just for helping someone else

**Respondent (P):** yeah for helping somebody else, that’s right yeah.

**Interviewer:** is there, is there any help that you didn’t get that you felt would be useful, to help you cope with things?

**Respondent (P):** we were offered help with uh um [pause] the uh, I forget what the term is but I suppose you might say the psychiatric side,

**Interviewer:** oh okay, psychological help or.. counselling

**Respondent (P):** yeah psychological help, psychology sort of thing. There are people at the um [hospice] way where you can drop in and what have you, but we felt, we did consider it very strongly, very carefully, but we did felt, feel that that uh we had each other, we had the strength to deal with this, and uh the family and stuff described uh very knowledgeable and very supportive [pause] so we we decided not to go down that route, we know it was there if we had wanted it.

**Interviewer:** okay

**Respondent (P):** um, but no we’ve had excellent support from uh our physiother- our our OT, who we initially who was our initial contact for OT needs [name of OT] at uh CNRT, and uh [name of consultant], I should say, the consultant um and the physiotherapist from [location name] neurological unit.

**Interviewer:** all at the hospice

**Respondent (P):** and and then we were referred to the hospice as well

**Interviewer:** oh that was later okay

**Respondent (P):** so I acquired a second OT, [name of OT], and the uh care nurse um, [name of care nurse]. So, by the time all those people had come into our lives, we felt very very supported uh, both in terms of equipment needs and getting it for us when, otherwise it might have been very difficult, uh, I think they have swung a bit of led as we say in England,

**Interviewer:** I’m not sure I know what that means

**Respondent (P):** you’re unsure what that means? It means um,

**Interviewer:** were you lucky or..

**Respondent (P):** yeah uh gone through some back doors, to get some things

**Interviewer:** oh okay I see [laughter]

**Respondent (P):** uh that um might otherwise not have acquired, uh I think [name of OT] all for breaking rules, that’s what they’re there for

**Interviewer:** [laughter]

**Respondent (P):** so you know, I would say for the most part we have received.. all the support we could have hoped for, but it it some of it we’ve had to bang the door for, and uh it was tough doing that because you know we recognise that these agencies are very stretched, and uh there are thousands of people they’re trying to look after but it has to be done. It has to be done.

**Interviewer:** if you need it then yeah

**Respondent (P):** that’s right. So that’s where I was saying earlier that uh early heads up, knowledge, what you’re going to need and the reassurance that it will be there when you need it, is vital.

**Interviewer:** okay, that’s really useful to know as well um. Have I missed out any other elements of your experience so far? I know it’s probably a lot to cover but um, just anything you wanted to share.

**Respondent (P):** off-hand I can’t think of anything. [pause] I I know that uh genetic testing is a fairly new thing and expensive, well it’s becoming less so, but I think it would be useful if in the future, people who are diagnosed were offered a genetic test, so that they could understand exactly which form they have. Because outside of the bulbar which is obvious when you’ve got it, it’s often difficult to differentiate, uh [partner] and I signed up with uh a test, not a test but a research project in [location] soon after I was diagnosed, and the uh the project was to do with finding markers for motor neuron disease. So the person was referred to a consultant and the consultant couldn’t quite find enough evidence, which is the way they do it at the moment, they accumulate evidence to say in all good faith you have got MND or you haven’t. The uh project was going to try and find markers through the use of spinal tab, blood tests, maybe some form of MRI, to say to the individual, right you have got, or your genetics test show that you have got this particular type of MND, and this is what you can expect typically [pause] to experience as time goes by. Some people probably never even want to know, because it’s so frightening.

**Interviewer:** but you’re saying you would have preferred to know?

**Respondent (P):** to have the option, to be able to, for the consultant to say do you want to know? ‘yes please or no thank you’, would be very useful. And of course also it would go into the uh general bank of research uh, to try and find the causes and a cure of this disease in it’s various forms. Um, that’s where I would like to see the future go with this until it’s nailed.

**Interviewer:** yes, more effort then

**Respondent (P):** more more joined up effort with identifying exactly which types people have, and maybe a more in depth investigation into what their lifestyles were. What things did they experience in their lives, illnesses, places they’ve visited…

**Interviewer:** if there’s a link with anything

**Respondent (P):** yeah, that’s right. I know that sounds an awful lot of work, I’m sure it is and expense [pause] but uh, that’s my thoughts.

**Interviewer:** [laugher] no that’s all valid and useful. Um, so I guess I just wanted to talk about what we’re doing briefly, and just get your thoughts on certain aspects. Um, it’s hard for me to explain without actually having a prototype or something in front of me, but um, to help people cope with the illness we wanted to develop some kind of online support but to help with more the emotional side and the challenges, and that kind of thing. And we thought of um having it on a digital platform so that it’s easier for people to access wherever, whenever they need it. But um, I guess I wanted to know your thoughts on potentially, would you have found something like this useful? And knowing your journey as well, do you think there were points when you probably didn’t want to look at it, or other points where you might have found it more useful?

**Respondent (P):** I think it’s something that we probably would have dipped into, just to see what help it might yield. Um, [pause] you know, I I, as an individual I’m not one for giving up, of losing hope, uh so to have something to support that attitude, mind, how do I get over this hump I’ve got at the moment with some sad thoughts or whatever, yeah I think that could be very useful.

**Interviewer:** okay, do you think more um, closer to, I know it’s hard to say but closer to the diagnosis stage or maybe later on when you’re actually experiencing the difficulty and…

**Respondent (P):** I think uh [pause] when you’re first diagnosed, your head explodes, so does your partners, so does your families, you’re in bits, and I’m sure that’s the same for many many other disease, anything that’s life limiting is going to do that.

**Interviewer:** so it’s probably too much at that point

**Respondent (P):** uh, yeah. Well you go through a whole range of emotions, anger or course, questioning ‘why me?’, um ‘what did I do?’, ‘what did I do wrong?’, you start to look at all the things you did in your life, course you get no answers, um, so I think probably early on not a lot of use, not a lot of use at all. I would think probably about a year in, for me, might have started to be of some help

**Interviewer:** okay, that’s really useful to know

**Respondent (P):** yeah, I I was still able to walk a year in, uh but it was going. So, at that point your independence is really starting to become eroded, and uh yeah that’s when you need answers.

**Interviewer:** okay, well that’s really useful. I’ve asked all my questions, I don’t know if there is anything else you wanted to add or we can stop the recording.

**Respondent (P):** No I, all I would say really is that that, it’s wonderful that uh you know, all this research is going on, not just in the uh base causes and treatments but helping people with the mental side of it, uh and how do you get through everyday physically, is is really good and uh the more that can be done the better, hopefully they’ll be a day when it’s not needed, but [pause] whilst it is still there, whilst the need is still there keep it coming.

**Interviewer:** thank you for your help as well with… I’ll stop and then I’ll chat with you.