**Transcription of Interview 10**

**[Beginning of file]**

**Interviewer:** Okay this is interview 10. I’ll just keep it here, so it picks up both of our voices. Just a couple of things I forgot to mention before umm, if we want to stop this recording at any point, just let me know. We can take a break, get some water or something like that. If there are any questions that you feel are probably too difficult or you don’t want to answer them, we can just skip over. Just let me know and also, another important thing is that most of what you’ll tell me will be confidential, so, just feel free to say if you name a hospital or a hospital’s nurse, it will all be confidential.

**Respondent (P):** That’s fine.

**Interviewer:** So I guess… I did speak to you a bit earlier but I just wanted to know what is your experience was with MND and from wherever you like to start whether it’s diagnosis, before or…

**Respondent (P):** Probably the symptoms when things first happened. But at the time, you obviously don’t think it’s MND because you’re not being diagnosed and it was when I was playing cricket, June 17 and I’m the main bowler in our team, [team name], main bowler in our team and I remember it was an away game. I specifically remember where we were, we were at [name of place] and I ran up to bowl, it was like running through treacle and I thought this doesn’t seem right. And I just put it down to either hangover or I was tired or because I wasn’t feeling quite right that day. But every sort of effort that I was doing, even when I was fielding it was treading water or such, it felt like that. And the following week when I played again, it had same feelings. Different place but it was, again it felt like treading water, so I thought you know what I’m not enjoying my cricket at the moment so I’m gonna say to them, I’m unavailable for the rest of the season. So that was that sort of first instance that I can recall. Then there were other times, dates I don’t quite know but we’re probably talking not much longer after that. And I was putting together flat packed furniture, sat on the floor, crossed legged as such, with all the equipment there. Every now and then, I sort of find I’d stand up because I was getting a cramp in the arch or cramp in the calf or something. And I thought, I just have to get up and stretch and move about a bit. Those weren’t alarm bells at the time but I could remember back why these things were happening. Umm, and the first real sign of it and I remember where I was again, I was up in [name of place] at a climb, I was going off to get my lunch at the local Sainsbury’s and stumbled on a paving stone and I fell over and nobody .. yeah on the side of the road, fortunately. I was looking around to see if anyone just saw me fall over and I got up. But I thought to myself, that was odd, because normally when you stumble, you stumble forward and stay up, but my legs just went (made sounds like he gestured the movements) as I stumbled. I just tripped my left foot on the raised curb, slightly. Didn’t think much about it and that’s probably August-September time, 17. And then it happened again, not in the same place, but it happened again… again it’s this foot. Stumbled over, fell over. I never really fallen over, probably since I was a child, you know? It was twice of a fall over in a month but again, you’re thinking I’m just being clumsy or something like that. Then I’ve had a third fall when I was in London but I was dragging a suitcase trolley with a laptop in it. I was in the underground and again I just stumbled over where they did the barriers across the line and there’s a little bit at the bottom like a lip and I stumbled over that and I went flying. Again, I had suitcase with me, somebody had to pick me up and I thought I told [wife] when I got home, “do you think we should just check this out now?” you know, and this is about November time. I said, “well let’s just get Christmas out of the way”. This is all during Christmas, “I’ll make an appointment to see the GP early January” and so that’s what I did then. She looked at … she just asked me how I was…I said more or less that I have been falling etc and said, “okay I’m not completely happy about this. I’m just going to speak to another GP about this, who is more experienced,” and then they both came back with a conclusion, they said, “I think what we’ll do, we’ll send you to a neurologist. Consult a neurologist because it’s not quite right and I think that further testing need to be done.” So, I went online, they gave me these options for about 4 hospitals where I can almost choose where I wanted to see a neurologist and all I did was just picked the one that looked like it had the best lead time, the shortest lead time which was 84 days or something. I wasn’t actually gonna be due to being seen until about mid-April and then obviously because of the referral from GP, they fast tracked it thinking this is probably a bit more serious, maybe. Then I saw them in February so it was only about a month after I had seen the GP and that was over at [name of place] and umm, he did various tests on me. So, he did reflex tests and all the usual things, walking up and down to see how my gait was. My foot was dragging by then, I was starting to do this floppy leg, floppy foot. And also that day what we’ll do was also blood tests. 15 blood tests, nearly passed out because so many vials of blood that was being done and that was the worst part of it. Poor arms, quite tired by then. I left it at that, they say “what we’ll also do is that we’ll book you in about 2-3 weeks time for EMG test, the electromagnetic test” and they were saying to me, “what do you think it is?” as such. I’ve done the usual googling things and I said, “it can be anything from sort of umm, twisted backs and neck injuries and all sorts of things that can be affecting that and I said I also looked at other things that looked quite nasty that begun with M and I don’t want it to be one of those. And as soon as I said that, he went, “umm” and then I thought “Uh..no, no, no, no, no Please don’t frighten me”. So we had all these electrical tests done and a month later, we have another follow up appointment, and he says “I’m suspecting it is Motor Neurone Disease”, but without actual proof at that time. So, a couple of months passed, I did have to chase him up quite a lot about this actually and all the blood tests were coming back as negative. All the blood tests that we did say probably some of the nastiest things that we’re testing for. They were all coming back negative, which is good in certain ways. he says. The worst thing that I had about it was… my follow up appointment was 7th of June, diagnosis day. But I didn’t know it’s gonna be diagnosis, I thought it was just a follow up and chat about things, because I had a letter through say, “your electric magnetic test were normal but that does not allay my fear of MND” and I thought that was contradictory because I thought normally with the EMG test it means that’s okay. But anyway I left it at that. When I saw him on the 7th of June, I went on my own because [wife] was working and umm sat me down and went like this almost, and he said “Right, I’m going to come out straight away, I don’t want to beat around the bush or gives false hope”, he says, “but it’s MND”, and I gone… jaws dropped. And then the next sort of 20 minutes of whatever he was talking about, I’m barely taking anything in. I’m hearing the thing about 40% last 1-3 years after diagnosis, 10% last 10 or more years. And I go there’s a wall in my mind. Starting to tear up by now and he says “where’s your wife”, and I said “she’s working. I didn’t think I’ll get a diagnosis today”. I said, “but what about the electro magnetic test, that being normal”, and he looked at his notes and went “Ahh sorry that was a typo. That should’ve said abnormal.” And I’ve gone [makes exasperated expression]... and other people I had spoken to subsequently about said “that’s horrific. That’s so fundamental.” He said, “I didn’t type that out”, and I thought, “that’s not my problem is it, it’s still gone out to me.” If I’ve had known it said abnormal and then my mind would have been more adjusted to know I’m going to take this diagnosis. So I was still expecting this to be like a slip disc or something, but apparently that can cause these things to happen but I’d almost be happier if it had been multiple sclerosis but that’s not fate isn’t. So, he just sort of left me at that and I walked out numb… that’s up to the point of diagnosis then. First couple of weeks after diagnosis, I was useless, really. I told one of my clients, I said “look, leave me alone for a few weeks, I’m just not feeling like working or doing anything, really.” I was a bit rubbish to be around but that time passed, few weeks later. I am more or less have the attitude I have now ever since where I go, “okay it is what it is now so I’m not going to die or keel over in the next couple of weeks, so let’s just sort of made the most out of what we got”. Come to the hospice etc which is really good. It’s nice to be around professionals that understand and it’s good to keep to these MND groups because they are sufferers and they know exactly how you are feeling. They are all at different times and different levels of it. It’s good to share experiences with them and then you it’s just… you realising that… The problem is that when you were told in the beginning, it’s like I remember starting taking my exams, at the beginning, you’re seeing the end. When it’s time to do my accounting exams, looking at paper 1 and then looking at people doing paper 14 and thinking I’d never be able to do that but what happens is that you adapt every stages you go along don’t you? So that’s what I’m doing with this. I’m not seeing, at first you see 12 stages down the line because that is all what your mind thinking about, is at the end you know. Whereas now you’re like okay, so now that leg isn’t work, but that arm doesn’t work as well, and you adapt because these things don’t just happen and you suddenly fall off a cliff. This arm weakens and it weakens over time. One day you can’t do your laces up, so somebody else has to do it for you. You get used to the slow changes, I mean obviously some people have it much more rapid than I do. Especially if it’s bulbar onset that’s more aggressive, I’ve been told that so...(tap wooden table). Well you can actually tell, I’m not affected in any way in the middle part yet, yet… that could be years.. it could be years, umm, so I’ve learn to not panic about things now. I’ve almost got more positive in a really sort of perverse way where things that bothered you, worried you, it’s not important. My football team losing was something like that, whereas now I think it’s just a game. It’s not important. You end up focusing your time more on who are important to you, what’s important to you and how are you feeling and let your body tell you how it’s feeling as opposed to… I’m done with accountancy when sometimes you’ve got clients that are at you. So yeah, I let my body do the talking and I was advised as well by the OT lady saying, “you can’t work an 8 hour a day anymore because you’ll just be exhausted at the end of it”, so work an hour or two, have a half hour break, especially when working from home, so I go and sit on the bed and sort of just chill out for half an hour, till my hands and everything sort of go back to normal again and carry on with it. It’s because of hand fatigue, but on the laptop it’s not too bad. Umm, yeah what else?

**Interviewer:** There’s lots of… I think umm, like a really nice timeline. When it started till now and how things have changed.

**Respondent (P):** That’s probably the easiest as well that I could described it, because it’s chronological isn’t?

**Interviewer:** Yeah there a lots of follow-up questions that I want to ask from a different time points as well. So, initially when you said… so you were first diagnosed and just after that, that was a particularly low time for you. Just so that I know what people like you and also other people are going through. What are the main kind of thoughts and feelings around that time?

**Respondent (P):** I was, probably looking back at it now, I was probably grieving. Grieving for myself in many ways because there’s one thing where you never ever… it’s always gonna happen to somebody else isn’t, these things? So the last thing you ever get told, you got something that is terminal. You’re thinking life is not gonna be the same again, now is it? Even though physically, you know say that first month afterwards there was almost no change but my mind’s thinking quite morose almost. You almost think of death at that point and other people I have spoken to, they were not unlike that at first. They were a little bit in a state, they don’t know what to think or how to think. It’s not even anger at that stage, it’s just hopelessness at that point because you’re just thinking oh that is it isn’t it? It’s all over and essentially you get passed that stage and actually, it’s not. There’s still a lot going on and whilst you could still do things then make the most out of them. [crosstalk] There’s two ways to look at it, I could get up and get on with it and carry on with my work etc or I could go sit in a corner and wallow away and feel sorry for myself… which I do at times, but not all the time. Then I get half an hour and then sort of slap myself on the face and get on with it. But [wife] is very good at sort of boosting me back up again. So yeah, it’s tough but that first period is the worst.

**Interviewer:** And coming out of that as well, was it just something clicks one day or maybe what help…?

**Respondent (P):** I don’t know what it was… whether it was just sort of I looked up and saw the sun shining or something and thought “right, I’m ready again.” I’m ready to get back to living again as supposed to just suffering. It seemed like 2-3 weeks to me when I was ready to approach things again. Acceptance is a different thing because acceptance of the illness, some people take weeks, some people take months, some people take years to accept the illness…they almost refuse to, and there’s that ‘is it really happening? Or tomorrow morning I’m going to wake up and it’s not gonna be there anymore.’ So I wouldn’t say it was acceptance but it was 2-3 weeks where I got to “just pull yourself together and get on with it.”

**Interviewer:** So like moving on and getting on with it. Yeah acceptance is a tricky one, sometimes it can be helpful, sometimes it’s not so helpful.

**Respondent (P):** Yeah, some people said you’re giving into it a little bit, if you’re accepting it. And umm, I wouldn’t say I’m giving into it but I do take the opportunity to make my life easier and things that help my life easier. I know a lot of people, especially the old people I find. They are very reluctant on going on a wheelchair or using mobility aid whereas I said “look, my legs are exhausted so, I need that, and then I can get a good day out as supposed to struggling around”. Anything that makes life a little bit easier, I’ll be much better for it.

**Interviewer:** And on a daily basis, what are your main worries or concerns?

**Respondent (P):** Main worries… I call the morning routine is my toughest thing. So waking up, [wife] has to help me dress. It’s basic things like to the toilet because my hands are that much weaker, without being crude it’s the cleaning up that’s not so easy and then it’s a case of, I need to say to [wife], “can you help me pull my trousers back up” because if I start bending down I would start to tumble forward. So it’s those sort of issues. [Wife] does all my cooking for me. When I have a tea or coffee first thing in the morning in bed, I now got this sippy… plastic sippy cups so I can pick them up with two hands. Those sort of things made life a bit easier but morning routine the hardest thing. Once I get going, because I’m working sedentary anyway, so I’m always sat down. You’d never know there was anything wrong with me, once I’m sat down with my laptop until I take those breaks. I’m more concerned if I’m at home alone all day, so what we’re trying to do, is for [wife] not to be out or if she has clients… she’s a mobile hairdresser. So we try to get people to come to our house for her to work, so she’s there if I need anything. Like at the moment we got these two double sofas, umm I’m quite often working on those but I can’t always get up off them. So if I’m there on my own, I have to be there all day on my own, so I have these plastic urinal things if I need to get to the toilet suddenly. It’s an issue like that, she often leave me a flask of tea that I can pour for myself and leave me snacks or something. At least I’ve got something next to me because I’ve actually…we’ve had an outside office built and, like a summer house, but it just needs an access ramp so I can’t use it at the moment until there’s access ramps done for my chair to get down to it. But it’s all fully insulated, it’s got full electric, half dozen double sockets down, it’s all lit up. I’ve got everything in there you know, and it’s so much bigger than my third bedroom where I used to have my first, so I’m just desperate to get down there. And that’ll make life a lot easier, I can just zip up and down with my powered chair. I don’t really need anyone to be there, at home, because I could get about. It’s just nice if she’s there because if I fall, if I fall anywhere, I can’t get up. If I haven’t got my phone on me, then it’s like, “what do I do?” I’ll just lie here all afternoon. Well, that’s the main concern, falls. Because I’m not bulbar affected as such yet, those sort of concerns aren’t too bad yeah? Eating is a little bit more tricky at times. [wife] tends to cut up food for me now, and I tend to use a fork and use two hands to feed myself, otherwise I’m a bit floppy with trying cut things etc. but they are my main concerns. There’s no really other concerns like sleeping, anything like that.

**Interviewer:** So it’s all the worry about falling…?

**Respondent (P):** Falling is the worst thing. Because obviously most people generally fall over, they use their arms to sort of help them fall whereas mine are much more weaker now I’m afraid they may break, or a sprain or a twist or something, and the last thing I want is to be set back with a physical injury when there’s enough going anyway? So I’m quite careful with how I get about.

**Interviewer:** And even from like the emotional side of things, even now, are there ups and downs or does it…?

**Respondent (P):** Not many downs. Not many downs. Sometimes I suppose it is a way that it might just be a trigger watching something on tv, or hearing a song that you remember. Sometimes I go into… sort of slump about it, I get more tearful about things that not necessarily has to do with me but say something fairly, like watching comic relief and they go on about a story about a person with cancer and I’ll find myself getting upset about it. It would’ve just washed over me a couple of years ago, but now because I’ve got my own issue umm, I’m relating to it I suppose a little bit. And you’re seeing where people are suffering, I’ve probably become more… what’s the word… empathetic towards things. So then probably I get slightly more emotional but it’s not a bad thing. But I don’t tend to get overly down about myself, if anything I have gallows humour about my…you know, we talk about, “can we buy this stuff for my funeral”, that sort of thing and [wife] would say, “we never talking about that” [laughs]. That’s for another time…

**Interviewer:** But do you find that helps with coping as well?

**Respondent (P):** It does, yeah.

**Interviewer:** Talking about things openly.

**Respondent (P):** Yeah it does. When I’m sat there, tears rolling down the face and “what are you crying about, what’s the matter”. And you sit up and you’re feeling a bit more umm, free in a way. [sighs] ‘Oh, so it’s not just me, there are other people suffering out there and hey, I’m still breathing and I’ve got friends that I’ve lost in the last few years and they’re not here anymore but I am, so we’re getting on with it.’ I know by looking at it, other people say “you’re so young to have this illness”, and I go, “I am but you know, it’s not childhood cancer, it’s not people in their 20s that are ill, I’m 51” If you’re talking about the 3 school years and 10 average age whatever, I’ve had two thirds of my life, you know. So it’s not the same. “How do you think of it like that?”, I go, “It’s a way of coping with it”, like you say. Life’s there to be lived, even if it’s not right. They say one in every two people get cancer, so everyone’s a little bit affected, whether they are suffering or no one’s suffering. So, it’s hard enough to have the illness in itself, so kick it to one side and still get on with your life and live it, makes your life a lot easier with it.

**Interviewer:** Almost not acknowledge.

**Respondent (P):** It’s not, not acknowledge, but you think it’s umm… it’s marked with MND, but MND is not ruling me. It’s… I’m living with this illness, but it’s still me and this thing on my shoulder called the illness.

**Interviewer:** Okay I see what you mean. That and look for positives in situation.

**Respondent (P):** It’s like I’d love to play cricket again but what I said to the lads over there, “well I don’t drive now, so I get a lift down here, a chair and a pint and I could watch you play”, and sometimes I wish I could’ve done that, but now I can. So, I still take part in the social side of things. And I want to as well… but I don’t want to push myself in situations that are awkward to me. I still want to… like last Friday, I went over to [name of place] where I always used to go and meet my friends for drinks. But we obviously find the pub that’s got the best access to it, so I can get in nice and easy and I don’t even have to go to the bar anymore, I just hand a bit of money to people and they get my drinks. But I felt included again, I felt like a human again with all the abled bodied people around me, it’s nice to umm to take the disability off me sometimes, and just live a normal life as much as… rather than being stuck in my little bubble with it.

**Interviewer:** The social side helps as well. Okay. I guess you’ve told me a lot of different strategies you use as well. Is there anything else that helps you on a daily basis? I’m just trying to learn from…

**Respondent (P):** Working helps. Working keeps… the cognitive side of things. Well they say generally like, I know there’s a few that 15% go down the dementia line, but cognitive I’m absolutely normal and working keeps me normal, keeps the mortgage paid etc, etc. But it tires me which is important because I can’t physically do so much now. If I wasn’t working, I think I would just be sort of sat there and doing crosswords or something like that. Something with a mild…or just watching TV, probably sleep at night would be more difficult. But I know if I’m working during the day, it’s actually physically tiring me, so in a way it’s a good thing when I do get to 9/10 at night, I know I’m ready for bed, I’m ready for a good night sleep and I generally have a good night sleep so it’s… I wake up in the middle of the night but I think it’s an age thing. But umm, that side of things keeps the day going. And also my wife and son there, seeing them there, I don’t want them suffering too much, as much as possible. So the more they can see me being normal and happy. I don’t want to scare my little boy, he’s only 5 and a half so… but he’s quite understanding when I’m sat on the power chair, he’ll put the foot plate down and lift my leg up, we’re telling him what he needs to know without frightening him and he’s fine with it. He goes along with it, so that is all the daily coping mechanisms.

**Interviewer:** Are there any other sort of people besides your wife that help?

**Respondent (P):** I’ve got a couple of friends, one of my good friends whose father died from MND so he’s very understanding… and another good friend whose mother died of it many years ago. So they get it they know what’s going on, so they’re good. My parents are a lot older so they’re old school so they… I tend not to divulge too much with them because I don’t want to worry them too much. I’ll get phone calls every week or so and they’ll be, “How are you?” “Yeah yeah nothing much to report. You know, just getting on with life. How are you?”, and that sort of stuff but [wife’s] parents are very good. They’re early 60s so they are a lot younger, they’re more physically capable to look after [name of son] every now and then so we can do things, we can go out and about. And they’re both retired as well even at that age, so they’ve got a lot more of time in their hands, they’ll come and help us with mowing the lawns and things like that. So that’s the support group yeah. And obviously, the professionals here.

**Interviewer:** Yeah that was gonna be my next question. So in terms of healthcare professionals as well, did you get any support in terms of how to cope with the illness or maybe even how to deal with the difficult emotions?

**Respondent (P):** I never really had that side of things. I know [names of two people] here, they’re very good with physical occupational therapy side of things, any exercise that I needed or breathing exercises or the seated yoga I used to go to once a week. But they’re good on the practical side of life, supplying me with crutches. Things with mobility aids around the house, special knives and forks and that sort of things and they’re good on that side of things. And [name of HCP] will come around to the house. She just says, “look I can see you’re having a tough time now. I’ll come over with [name of HCP] and have a chat with you”. They’ll talk about things like…get some access rails to the toilets at home or ramps, threshold ramps and we have been talking about having a wet room in our ensuite etc. just to help me with things like that, seat legs raisers and those little bed, the table that goes over hospital beds, things like that so I can eat nice and easy. So they’re good with things like that.

**Interviewer:** But not in terms of emotional support.

**Respondent (P):** I’ve not had an awful lot of that. I suppose I’ve just coped with that myself in a way.

**Interviewer:** Did you feel you needed any of that or would you have liked…?

**Respondent (P):** Probably that first couple of weeks when I was a bit all over the place. You were sort of left to your own device a little bit, because you don’t really know which way to turn, or who to turn to. It was only until I came to the hospice. I can’t remember, somebody recommended the hospice to me and said, “oh they’ve got an occupational therapy team there, they are very good,” and then once you’re in the system, you’re looked after then, but it’s getting into the system in the first place. So that probably helped, and that takes the fear out of it, as well.

**Interviewer:** How did you hear about either the hospice or [charity], was it?

**Respondent (P):** I think… I’m pretty sure I went to [name of hospice] in [place] initially because that’s the one I knew about. I went to speak to the lady there, I think that was 3-4 days after I was diagnosed because I thought about what is the next step, because if there are any exercise classes that would help, specifically, for my sort of needs. And she said, “oh where do you live?,” and I said where, she said “You’re actually not in our catchment area, I think you’re in [name of other hospice] area. If you contact them, they’ll talk you about things” and that is all how I started things. It’s all off my own back that I went to [name of hospice] in the first place. No one said, “go there”.

**Interviewer:** No one told you how to.. you looked it out for yourself.

**Respondent (P):** But I’m like that as a person, I always try find out things myself.

**Interviewer:** I guess, linking back to our project and things like that we are trying to develop some kind of online support as well. Mainly to help with the psychological and emotional kind of things, and I just wondered because from your experience as well, if you had any thoughts on when it’s best delivered or like… is it something you would look for?

**Respondent (P):** Even now…online. I think it’s nice to be able talk to somebody, face to face. Even when it’s on the phone or something. I wouldn’t even call it counselling but sometimes… what was very good here, I do remember the first meeting I had… first MND meeting I came to. Through the hospice they said, “would you like to come to this monthly MND meetings?” they said, “oh next one is on Thursday, xxx” and I spoke to, the first lady I spoke to was [name of person] who’s very good with helping you out with what forms to fill in, what things you should be claiming for. She sort of just sat down and she didn’t know who I was. She just started talking to me about stuff, nothing.. not necessarily about the illness. Because we’re talking about this in pieces, it made me open up a little bit and then we went to the line of talking about the illness and it was at the end that I thought “ahh I see what you sort of just done there. You’ve got me talking, but talking about me, we’re not talking about the illness” and how you are, ‘You’re working aren’t you? Oh, what do you do?’ and it moved on to different things. So, the conversation has led that you then start opening up with different areas rather than just sort of saying “how you feel?”, it’s too direct isn’t? So that could be helpful, I think but yeah I’m not sure how that would affect the first couple of weeks. Because I think the first couple of weeks, you almost want to be left to yourself. I’m not sure if it’s for everyone.

**Interviewer:** No, no that’s good to know.

**Respondent (P):** To have your own coping mechanism because you don’t know what to think at first and if you’ve got somebody said to you, “have you thought of claiming PIP?”, you wouldn’t even know what PIP is at that stage. You just come to terms with being told you’re dying, basically. That’s the first thing you think of. And so yeah, after a while you think I’m not actually dying, am I? So online might help, it’s nice if you’ve got…online that might help earlier on actually where you’re a little up in the air and you don’t really want to talk to people straight away.

**Interviewer:** Earlier as in say, before you come to a group like this.

**Respondent (P):** Yeah almost like questionnaires. That type of thing, your views on… that works both ways, so you’re get feedback from a number of people. Because I think this MND is as rare as it sounds. It’s more people, 300 or something, the number varies. It’s more prevalent isn’t it? Other ways I look at it, HIV. 30 years ago it was a death sentence and people live with it now don’t they? So fingers crossed something like that happens with this. But how many years it’s gonna take, I don’t know. But that’s the hope you have to have, a little bit.

**Interviewer:** That’s really important.

**Respondent (P):** The hope…the diagnosis was brutal. That’s what I found, it left me with no hope, I think. Sometimes the consultant neurologist… I don’t know whether they’re so sort of intelligent that it’s not always the empathetic skills that they have, maybe the nurses have more of that. Sometimes they’re very clinical with how they go about things.

**Interviewer:** With the communication.

**Respondent (P):** Yeah, it’s just the case of telling you the facts.

**Interviewer:** This is just to recap the last.

**Respondent (P):** Key thing is to have lots of little goals, lots of little hopes of things to do, normalities, weekends away, holidays but not in the far future. Everything’s in a couple of weeks, 2-3 weeks, something to look forward to. And it can be something trivial, but it keeps the mind occupied to know that there is something coming up as supposed to just sitting in the four walls.

**Interviewer:** And that’s because of the hope element.

**Respondent (P):** It’s a little bit of hope element and it’s while I can still do these things, it’s… I mean I don’t walk up steps anymore. So I now, I don’t do steps and that means that eliminates that danger of falling etc. So I know where… if we go somewhere for a meal or whatever, it’s a lot of forward planning we have to do as well. You can’t just spontaneously go off and do things because physically somebody has to put my shoes on, and that sort of thing. So yeah, if I go to a restaurant and they’ve got a step, I would say I can’t come in, they have to put a ramp out or something like that for me. But otherwise, the steps are my enemies.

**Interviewer:** So you have to do a little bit of planning before.

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

**Interviewer:** Okay, I think we covered that.