**Interview 10**

**(person with MND)**

**I:** Yeah, so this this is the first page. Um? And I guess before looking at it, I wanted to ask you what you thought of the name, coping and living well with MND.

**P:** I think, I think it's good. I think it's very clever and I like the CALM you know, the acronym. I think that's great. I like your picture as well, it puts you in the right frame of mind.

**I:** Thank you

**P:** It's a bit like, um, the, an estate local to where we live that has public footpath through it, but it's lovely and quiet so far in this context it's nice and quiet. But for people that live in the estate, it's got electronic gates and you have to wait for the gates to open. And funny enough while we were wandering around this morning having a lovely quiet walk, a car pulled over to the side and I thought, ‘Oh well, that's nice I’m gonna get me wheelchair past’ and then the window wound down and head stuck out and it was a GP that I used to work with who lives in the estate, and what she said was you know, after all the stresses of work, when you've got your mask on and your vizers on and what not, and she said you come home and she says, just the time it takes, a few seconds it takes for the electric gates to open, and you're driving into the estate and she says, your sort of going [breathes a sigh of relief]. And you know your picture’s a bit like that I think it's good. Yes, they put you in the right frame of mind.

**I:** Thank you. Um, yeah, I guess does it from this first page is well, does it come across that it's focusing on the emotional side of things?

**P:** Umm…Yes, I think so. I mean, I think it's a good summary that going through difficult thoughts and feelings is completely normal with MND. I think you know, it's good to reiterate that 'cause sometimes you know, we need to stop and remember that, so I think that's good, yes. [reads] Some suggestions on activities to keep a positive outlook.. yeah, yeah, I think that's good for the leading.

**I:** Yes, if you click on to the next page.

**P:** Hopefully I can manage that without messing it up…

**I:** Yeah, this is about who built the website..

**P:** [reads] CALM website was made by psychologists at the University of Southampton. Are all based on research evidence… the website… Oh yes, that's very good. Yeah, I'm friends on Facebook with [name of PPI member], so yeah. Some of the culprits I know vaguely. [laughs]

**I:** [laughs] Yeah.

**P:** Yeah, and I think again you can't beat that and I think you do need, you know a reasonable number of interviews, because MND varies so much. It varies hugely, you know. I mean, I've made several friends along the way. You know and people are affected in various, very different ways, so yeah, I think it is useful to have a selection of interviews sort of thing. Yeah and everybody is different. You know they're all different people. Before they had MND as well..

**I:** yeah… so if you click on the research team button, just tell me if everything on that page is OK?

**P:** yeah. Ha ha…right. Oh, that's interesting, yeah so you’ve got previous experience with neurodegenerative diseases and Dr Dennison yeah, actually has family experience of MND. And I think these things really make a difference to having a proper handle on it. So yeah. When we've got a world leading experts in developing websites, so you can't knock that. [laughs] Yeah yeah, an interesting team by the look of it, yes.

**I:** [laughs] If you go back, I think it's back.

**P:** Yeah yeah

**I:** and then next I think it takes you to how to use the website.

**P:** How to use it? Yeah, yeah, and we've got… Headlines are building positivity, adjusting to changes, dealing with worry, and stress all activities and other support, yeah

**I:** Yeah, I guess I might just give you a bit of time to read the information and just a sense of whether it’s clear what is in the sections…

**P:** yeah, I mean the other thing that I would say and this is just me anecdotally, it is amazing how quickly you can swing from feeling sort of quite positive you know, on a nice sunny day when I'm trundling around on a nice route on a wheelchair for example, to 2:00 o'clock in the morning when I can't sleep 'cause me ankles are hurting, and you know. And then you start thinking about things and that's when it's… it is more difficult and you've got to remember to, you know… Tips for staying positive that’s gonna come in handy at 2:00 o'clock in the morning particularly, I think.

**I:** Yeah. So it's a little bit of all of these things at different times…

**P:** Yeah, [reads] activities used for dealing with feelings… and so I mean one of the things that I have found is that sometimes if I can't concentrate and sometimes there's so much buzzing around in your head, I can't actually concentrate on reading a book. But to do something like, you know, playing Scrabble online, it's very immediate, you’re just thinking about what's in front of you and it takes you away from not being able to concentrate and having sort of unpleasant thoughts and sometimes something quite immediate like that is good. Grandchildren are the best therapy of all that. [laughs]

**I:** Yeah, that's true. I might use that example actually, if you don't mind [laughs]

**P:** Yeah please do. Because you're right in the moment and you can't possibly ignore their performances between the three grandchildren, 2 girls in one household and a little boy in the other. And they're all actually very fond of each other, and it's hilarious when they meet up. Especially when the, you know the only opportunity we've had for meet up recently is outside for a walk somewhere, so they've all got the puddle suits on and they're looking for who can jump into the deepest puddle and splash the other the best, you know, yeah?

**I:** Yeah, they keep you see amused.

**P:** They certainly do. And even actually, you know remotely, because the elder one she's 7 and she's got the hang of Skype and she knows how to send all the silly emojis as well. So she's dancing about and pulling faces at you, and you know, sending you kissing emojis and... [laughs] But yeah, they're good.

**I:** Yeah. Yeah, I guess if everything's clear on this page we could move to the next maybe?

**P:** So next... Nature images I think you know, nature images for me it's absolutely perfect. You don't need to explain it to me. Interestingly that the Hospice, because had been… I had one session at the Hospice Day Center before lockdown and the hospice are now offering some online support. So a remote coffee morning, you know you all sit with your own cup of coffee and you can chat to each other online and the health care professionals there’s a senior hospice nurse and one of the OTS and so on. But when they're sitting talking to you as we're sitting talking to each other now, they’ve got a lovely picture not dissimilar to actually your first picture, the mountains one, you know, projected on behind them. And it's subtle but it you know, it does make a difference. Yeah, where as I said to the OT when she was talking to me one week and she did laugh about it. I said, you know, all I can see behind you is the fire exit sign and [name of the other HCP] had a nice, you know mountains and lakes bit. She says ‘Oh I've not switched it on’, you know, but it does make a difference it puts you into the I think better frame of mind, yeah. I mean you know, you’re preaching to the converted. I volunteered for the Wildlife Trust and I’ve had to finish work 'cause I'm not… the local nature reserve and one wall is made of glass, on the reception desk and if it's [inaudible] we used to look out of the window and it wasn't dissimilar to this one, that the lake comes almost right up to the building and it's very therapeutic. So it's a great approach, thumbs up to that one.

**I:** Good, thank you. Can we go on to the next page, I think that's last in the introduction…

**P:** [reads] ‘things to remember when using the CALM website. It's important to remember that everyone has their own way of coping and there's no right way.’ Absolutely yeah, that's 'cause we're all different people after all. Yeah. I think, yeah, that's fine. That covers it very well, I think excellent.

**I:** OK, yeah. OK, so if you click the next. [Yeah] You’ll see the different options.

**P:** OK, building positivity yeah.

**I:** So when… the first time that you log in you're taken through an introduction, but if you logged in again, you come straight to this page so you can just go directly to whichever section you need to

**P:** Right, OK, so click on one of these tabs sort of...

**I:** Yeah, which one…does any one particularly stand out to you at this moment I guess?

**P:** I think I would say it would be a toss up for me between adjusting to changes and dealing with worry and stress because I think in a way, building positivity, it's almost one in the same thing, because if you can build positivity, you are dealing with worry and stress.

**I:** Yeah yeah.

**P:** yeah. I think it is… I'm noticing you know, with my slow progression adjusting to changes I do find really difficult because I'm now getting deterioration in my right hand, being right-handed and you notice you know when your left hand disappears on you, you notice a lot less when it's not you dominant hand. You know, I almost feel as if I can, um, you know, the changes in function from day to day I can almost see a difference, and that's, that's difficult. That's quite hard to cope with, so I would say that the key one for me probably is adjusting to changes.

**I:** OK, um we can click on adjusting to changes. I'll just show you briefly, yeah.

**P:** Ok [reads] changes in how you feel, we’ve got a cloud floating by now.

**I:** Are you on the next page?

**P:** Just reading through changes in how you feel. Do you want me to go to next?

**I:** No, no. I'm just trying to see where you are at..

**P:** Yes I know, it's tricky. Yeah… [reads] feelings and thoughts usually happen when you notice any changes. I mean that sums up really what I was I was saying before I'd read that bit. I think yes, absolutely. Um... I think it's sort of it… it brings everything to the fore even more when I'm kind of thinking now I'm thinking, you know today is the best day that I've got left. But I can't do what I want to do with it 'cause of the wretched covid, you know.

**I:** OK, yeah.

**P:** It would be nice… I mean usually we meet up with our daughters and our grandchildren live so to 3/4 of an hour away and we meet up with them certainly every couple of weeks if not most weeks, even if it's briefly. You know, it's things like, I mean the girls do ice skating and go to ice [name of place] and watch them do rolling over and whatnot on the ice, but they just like to have you and say ‘oh that's my grandma’ and wave. So, and it's, it's… those things that I miss particularly because yeah some of it I don't know how long I'm going to be able to do it for, I mean very long term. Many years I've swum for exercise way before I was diagnosed with MND and go to the, in normal circumstances, the local leisure centre to do that and I can't do that anymore. We have a protected neuro swim which started off as the MS Swim but now they'll, you know MND will do as well, and predominantly it is MS as it's a common disease but we've got quite a lot in common because most people have got mobility problems in common, and the fact that it's a degenerative disease so… And I can't do that anymore, so that's… [shrugs]

**I:** yeah I think some of the suggestions and tips and stuff that I have suggested I've probably framed them pre-covid I guess there's that added, you know restriction..

**P:** Yeah, yeah, it's an extra thing to cope with on top of everything else. I mean, you know nobody's having a barrel of laughs over it, I'm sure, but Oh dear [laughs].

**I:** Yeah does this information seem relevant to you and your situation as well?

**P:** Yeah, I think it… so I think the key thing for me is feelings and thoughts usually happen when you notice any changes, absolutely. The other thing that there could be changes in your symptoms, your relationship or how you see yourself. Subtly you know, your relationship does change because you've gone from being husband and wife you know, who care about each other but can do their own stuff if you like for themselves, independently. And gradually you feel as if you almost need you know, to be joined at the hip in order that you know, he can be there to help me with the stuff that I need. But I'm mindful of the fact that he needs a bit of space too, and you know, he until recently he hasn't been… used to being the guy who has to help me, you know, but at the moment it's you know me back and me right arm you know, that I just can't wash. And I suppose we are lucky in that we've been broken in gently to that sort of scenario. People with rapid progression have to get used to things changing a lot more quickly, both in terms of the progression and in terms of what, what support they need.

**I:** Yeah, it is hard. Yeah, we can go on to the next page. I think that works…

**P:** So you just need to change select an option… anger, sadness.

**I:** So I guess do these emotions also seem relatable?

**P:** Yeah, I think… I think probably what I tend to feel most or most frequently is frustration. But yes, anger and sadness sometimes too as well. So…

**I:** OK, yeah, OK, maybe let's have a look at frustration.

**P:** Ok. Frustration [reads]. Yeah. ‘Trying to just changes in symptoms and abilities. Yes, getting used to new equipment, yes.’ I'm trying to get the right support and trying to get the right support is, you know, even you know the last 10 years, 15 years of my career I was working as a nurse practitioner in general practice and in the GP out of hours service. So if I don't know how to work the system, you know [laughs] nobody does. It's horrible and the number of times I've said, yeah, but I know who to prod, I know who to go to and ask about that. And a lot of people just don't know where to start and I think that is… that must be very difficult to cope with. Because even you know, I find sometimes that I'll fetch up with one health care professional and then say ‘well no, I think you know it would be better if you talk to somebody else about that’ and the time it takes to you know, get from one referral to another and again, especially for someone with more rapid progression must be very difficult to cope with think and frustrating, yes! OK, so we've got suggested technique and practical tips, yeah..

**I:** so yeah, it's… the techniques tend to be more like psychological based activities I guess, but I also acknowledge that some people are more doers and like to do things. That's why you could either do a technique or practical tip based on whatever you like.

**P:** I think I'm…Um, I think I'm probably, you know, a little bit of both actually.

**I:** OK, we can have a look at both. Let's do the technique first.

**P:** OK, I'm looking at self-kindness… looks like another lovely photo. Where did you find the photos for the… are you photographer now?

**I:** Sadly I'm not that good…

**P:** [reads] And I friends are very important, very important actually. Because interestingly, in fact the lady that I used to volunteer with at the Wildlife Trust has her own problems. She's basically had glaucoma that went pear shaped and she's lost the sight in one eye. So she's restricted right by the fact that neither she nor her husband can drive now, and we actually agreed that we alternate weeks you know, one week I’ll phone her and the other week she’ll phone me and just sit in, you know. It's quite therapeutic. Just having a conversation with a, with a good mate, you know, um... And we've got common interests you know, when we can we’d, you know, go for a walk. I was and I always refer to it as a walk stroke trundle, cause I’m trundling in my wheelchair now. But you know, we enjoy doing that together and you know the wildlife so on. So that definitely helps and I think it's a two way street and I don't know, I think it is for a lot of people, I think particularly for me as a retired nurse. Yes, I would definitely say I get a kick out of feeling that I've done something useful for somebody, something helpful and supportive. So I think that that can be a two way street sort of thing… OK, so I will look at the practical tips, shall I?

**I:** If you go to the next page. Just trying to see are you on self kindness? [Yeah] if you could click next thanks you come to...

**P:** Compassion break Right, yeah, yeah.

**I:** OK, alright so this might be tricky to do now during an interview I guess, but essentially I don't know if you've tried these sorts of mindfulness or meditation kind of techniques. [yes] This is essentially a mindfulness technique, the focus is on self kindness and self compassion I guess. Um I wondered what you thought of doing this kind of exercise to help with…

**P:** Yes, certainly when I was first diagnosed. It's amazing how things change and how support has changed over the last sort of eight nine years, but the Hospice was offering mindfulness courses, which I think there was a group of about sort of six or eight of us and the lady leading the group. It was really good, it was. Because at that time I was at the stage of coming to grips with my diagnosis. Um… I mean, before I was diagnosed it was March when I first noticed symptoms. It was the August before I was officially diagnosed. But given my background I kind of I knew what was coming, to be honest. I mean in a way you don't know whether it's a relief or a kick in the teeth when actually the neurologist that I fetched up with was an MS specialist and I'm thinking I just hope it's MS, not MND. I knew really, you know, so…and in a way you know, I can hear myself. In the past I've often said to patients it's amazing what I've seen people, seeing patients cope with in the past, when they can get their head around what the coping with, when they know what the coping with. Actually what is most difficult to cope with is the unknown, you know when people haven't got a diagnosis and can't get a diagnosis and that you know over time I've seen, I think, understandably people really struggle with that. And even if it's a fairly you know, grotty diagnosis, at least you know what you're dealing with when, when you've got that. Although I did tell my consultant off the last face to face consultation we had last but one and I sort of parked up the wheelchair outside and actually walked into the consulting room, 'cause I'm still walking about the house, that's OK. And he just looked up at me and he said, ‘oh, you're doing really well’ and I said ‘hang on a minute. You haven't asked me how I am.’ I loved your smile then actually when I could see you [nudging me?] yeah. And he did, he needed, you know, he said sort of ‘yes point taken absolutely right [name of patient]’, yeah and he's a good guy really is.

**I:** Yeah, no we all need to be reminded every now and then too. [Yeah, yeah.] Um.. I'm sorry I forgot where we were…

**P:** We’re on compassion break. Yes, yes.

**I:** If you go on to the Next... [Self kindness]. I guess this is just a kind of a reminder to do these sorts of exercises and be kind to yourself, even if it's…

**P:** yeah. And I think you know, we talked about relationships and so on. I think it's important for both halves of a relationship to practice self kindness, because I think sometimes it's easy for my husband to think ‘oh he should be doing this, that and the other,’ you know. But actually he's a person too and you know

**I:** Yeah, just outta curiosity, do you think he would be inclined to look at a website like this? I know it's difficult to say to someone else.

**P:** Oh yeah, I think it's…. I mean it's they’re all the sort of things that I think subtly, hopefully as a reasonably caring human being you're aware of, a thoughtful and caring human being you are aware of, but it's sort of crystallized really in your pages here, you know, yeah.

**I:** Yeah, if you go on to the next [next we have frustration] it goes back and then maybe click the practical tips.

**P:** OK practical tips. Give yourself a bit of a break. Yeah. Yeah, I think the second ‘change expectations of what you can do so you're not disappointed,’ for frustration that’s.. and I have sort of started to say that actually one of the reasons why I like to go out in my power chair is that whilst somebody's fastened my coat up for me and I'm sitting comfortably in it. And I've got me wet weather gear and I know I can do that. You know, I know that I'm not gonna be coming up against something that I can't do. I know the routes that are OK for my wheelchair locally and I can control the wheelchair independently and that independence is really important. You know, because the, uh, the frustrations in everyday tasks, for example have… and actually I find it better, easier... I have an electric toothbrush because it requires a lot of you know arm and hand action otherwise, but I've recently the recent chang is that you put the toothpaste on it and then you have to press with the thumb and that's this useless thumb that has very little grip and you can't, you can't press it with finger and hold the brush so you can't put the… You would normally put the brush in your mouth and press it with your thumb. So if you can’t do that and press it with your finger the toothpaste sort of hits the walls of the bathroom, you know. I can turn it off because I can take it out of my mouth and lay on a towel on my lap and push the button with my finger. That works, but turning it on and that is one of those stupid everyday activities that a) it's the frustration and I think there's a degree of sadness thinking, you know, I could do that two or three weeks ago and I'm struggling to do it now. So yeah, there's a little bit of various strands come into that sort of thing. But to do something that you know is not going to be challenging to do is, you know, is nice to do. You know, there’s a certain amount of that, so that you know you’re just not frustrating yourself really.

**I:** Yeah yeah, that's true. This was told me by people who have MND as well, so it's not my advice.

**P:** Yeah yeah. This is why talking to people that are in it is so important I think. Yeah. [reads] Adjusting to new ways of doing things and new equipment, yes, and getting the best out of the equipment as well I think is can be a bit of a learning curve. Yeah. Yeah, the best photo actually when we’re talking about equipment and I told you that I used to volunteer at the Wildlife Trust and there's a sort of bog really that has all sorts of plants and stuff in it. And tadpoles and frogs at the right time of year, which the kids love and it's got a boardwalk. My husband is quite keen on his camera and photography. An elder granddaughter who was barely six at the time and as kids do she’d be watching me with the joystick controls on my wheelchair and she just marched up to me as I was going across the board walk which is only got… it's got a sort of rim of about a couple of inches at either side. But you know, my power chair would go and she just went ‘I could do that for you Grandma’ and took hold of the joystick and started controlling me. And the picture of me going [whoah] and sort of my concentrating face doing it, yeah. She’s got to grips with my equipment as well, you see so OK. [laughs]

**I:** Fair enough. Yeah, what do you think about the last sentence as well?

**P:** [reads] OK, to ask for help. That's it, I think it’s subtle isn't it, and I think you do get clues. Some people are more open to offering help than others are. And I've certainly had instances I’m often out in my wheelchair and, and I've stopped for some reason and people say to me, you know, ‘are you OK? Do you need any help?’ and you think oh, that's so nice, yeah. And sometimes I think you can tell by body language who are not the right people to ask for help, for example. It is, ‘I've dropped my glove. Could you pick it up for me? Would you mind?’ and stuff like that but yeah, I think you know, I wouldn't be afraid to ask for help if I needed it. It of course… it depends what help you're asking for, you know, but yeah, yeah.

**I:** Um, yeah, we could click the next button… Back to frustration.

**P:** Oh yeah. [reads quotes] No, I would, I would never sort of wake up and think ‘I wonder what I can't do today.’ I get frustrated when I have a go at it and find I’m struggling with it certainly. And yes, I would say I've always been very independent person, but when you talk about asking for help, well again, [name of person, granddaughter?] she's the one earlier on, mind have to say her dad is a very caring person and her mum is a paramedic so she sees… and her aunt is an OT, so we're all in healthcare one way or the other so it rubs off a bit. But one of the quotes earlier on was ‘I can help you with that grandma, 'cause that's your silly hand, isn't it?’ That's my silly hand, and [taps hand] it's too cold. It's not only somebody actually helping you, but it's that nice feeling that sort of flows

over you when somebody is really aware and kind, it really does make a difference.

**I:** Yeah, I wondered do you think quotes like this help reinforce the point?

**P:** Yeah, I mean I do think some people are more reticent than others about asking for help if they need it. Yeah the second quote, the family member of somebody with MND yeah physically demanding and that gets you frustrated 'cause you’re thinking you know every task. Yeah this is interesting because we’re just getting to the point where before long I think we're going to need to recruit a carer if nothing else. Just to give my husband a few hours break now and again, so he can go off and jump across fields and do… go places that I can't go in the wheelchair. But actually what I said only this morning was I think the best way a carer can get to know my needs would be literally to come and to shadow [name of partner] for a morning so he can… they can see what sort of problems I have, how we work around it and how we manage to get things done because I do think everybody has the… Well, as we've said it, you know you never know which way the MND’s gonna affect next. Everybody was a different person before they were attacked by it and you know… So I'm very mindful of the fact that it must be a very tough job, but I've heard some horror stories from people with MND you know when they've gone into a care home, for example, for a respite break and carers just haven't had a first clue about. What they need help with, what they need support with Um…

**I:** Yeah, there's still a lot of... People still don't know a lot about MND

**P:** I must admit, every time I've seen Rob Burrow on telly recently, I'm going ‘Just tell them, you know, we can see you sitting in the wheelchair, but say a little bit more about, you know the sorts of problems that that you encounter.’ Yeah. He’s doing a good job,

**I:** yeah yeah, he has. If we click next it takes you back. [crosstalk] So I, we probably won't be able to go through everything because it's quite a long website and I don't wanna keep you for too long. But um, for anger and sadness as well, this is a similar format, so it gives you a bit of information, has a technique and some practical tips. But I wondered, I actually wanted to show you another section. If… can you see the home button at the top if you… [Yeah] if you could click.

**P:** OK, yeah. So we’re back to the CALM homepage.

**I:** Yes, if you click building positivity. [Yeah.] Um, I'll just let you read this...

**P:** [reads] you hear a lot of bad news, yeah. Yes, yeah yeah, I think that's very true. Actually. What I do really like about your website overall is that it's not too wordy. And yet you know there isn't a wasted word really. Every sentence is succinct and says what it needs to, which I think is great because joking apart it can… it's tiring MND is, you know I do a fat lot of very little and I feel you know, worn out by it. So you don't want to be reading through yards and yards of unnecessary elaboration, really. I think it's succinct and it says what it needs to which is great, yeah. And I still like the pictures.

**I:** I thought you might like this one too. If you go to the next page. These are couple of examples but I guess if you don't want to look at them, that's also fine. [Yeah] it's just a few quotes. Um, I wanted to take you to a technique so um, that's why is it OK if we just click next?

**P:** Yeah. OK, so we've got pleasant activities, benefit finding, and values and goals.

**I:** Yeah, I've not got a lot of feedback for values and goals, so I was wondering if you could look through it for me?

**P:** [clicks] Oh I'm in Switzerland now it must be. [reads] Yeah, yes. Yeah I would agree with that. Yeah. Definitely. Yeah. Yeah, and again I think you say it very succinctly it's you know… but the message is there, I think you're absolutely right. And I think maybe, uh, values is part of what friendships do because don't you tend to make friends with people who have similarsort of values, have similar interests you know that you have things in common with and that's why friendships work. Yeah.

**I:** yeah. If you finish reading that we can go to the next page…

**P:** [reads] Values and goals, what's most important to you? Passionate about and what do I want to be remembered for? Yeah. [laughs]

**I:** I guess this is just stimulate people to think about this.

**P:** Yeah, yeah. And I think they are to some extent tied up together. And yes, I think things like being a good parent, it's still, you know our daughters are in their 30s now and they’re parents themselves. But when I look at the way you know, I would say they are good parents and they're good parents because hopefully our parenting skills were good when we were bringing them up, and that's how kids learn parenting skills. Certainly, having freedom and making my own decisions, although you do, that's one that you feel your wings are clipped, making your own decisions because it becomes.. decisions, that decision isn't even an option, for example. Um, I mean we live in a fairly rural area to give a simple example, there are nice quiet lanes that I can go round in the wheelchair, but also going off these quite, nice quiet lanes. There are footpaths over stiles and the number of times I've looked longingly and gone and never been down there and I'm never going to and I wish I had, you know.

**I:** I see what you mean, yeah

**P:** So some decisions are just taken out of your hands at yeah,

**I:** I'm thinking maybe that's not the best example. Probably because you're right, it does take away from you so then you're thinking about that again…

**P:** Yeah, yeah, but I think you can't. I mean, it's part of having freedom, isn't it as well? But doing things the right way, doing the right thing by people, by others. Those are the things I think that are important to me, certainly. And there doesn’t it flow on, what’s my passion and what’s important doing. Yeah, [reads] wildlife and helping people forget sports cars. Yeah, and an all-terrain wheelchair would be good, I don't know. Expensive, probably. But yes, very.. wildlife and um.. the planet really, I think. It hammers it home when you go for your Morrisons click and collect and you got about 20 plastic carrier bags, and you’re thinking ‘I don't want these. I don’t want them’ but there's no other option. Yeah, and I would hope I think I think what is is most important to be remembered for I would say is being a kind person, being there a nice person to know really, I would hope.

**I:** I guess I've given just a couple of examples, but like from your own life as well, would you add anything to this list?

**P:** I think… I think they’re all good and it is amazing actually how they are all interlinked in ways because what's important… So obviously, if I would say I'm passionate about wildlife and the environment, which I would say I am. Then it's important to me as well. They are interlinked but I think they’re good headings for you know, to… for reflection really yeah.

**I:** OK OK. If we go to the next..

**P:** I can see it getting awfully dark behind me 'cause I'm sitting in the conservatory with the lights off and if I get up to put the lights on, then I'll drop both iPad so..

**I:** Don't worry. The light is reflecting on your face so I can at least, I can see your face…

**P:** Scary. [reads] …is try to find more things in line with your values, click buttons to the right to see how people have tried to do things that align with their values, what would you like e to do, click on Nick or Jo?

**I:** Yeah, you can click on anyone you like..

**P:** Yeah yeah, I would say I can identify with Joe, I mean I managed to carry on working as a nurse practitioner for almost five years after my diagnosis, part of the reason that I managed to do that was by then I was working with the GP out of hours service, which is quite a large organization with a lot of employees and several bases, and so basically because they have trouble recruiting and keeping both GPs and nurse practitioners they want to hang on to those they got which is, so you're starting from a good point. But 'cause they didn't want me to just say I can't do it anymore, but for example, the first thing that we did was we said that I wouldn't do any visits anymore because we.. it could be, either clinician could be out in the car doing home visits. But of course you don't know what you're going to encounter in terms of accommodation, how many steps you've got to go up go down and, equipment that you've got to take into houses and things, and it didn't seem sensible. So that was the first thing that went and then we realized it was sensible for me to work at one of the main bases, because some of the peripheral bases I would be the only clinician there. And it was getting to the stage with my hands, where if somebody needed a physical examination I might not necessarily be able to do that whereas we agreed when I was working at the main base, I could literally look at the patient information from the triage notes and go, ‘Yeah, I'm gonna be able to see that person OK.’ So I could literally pick the patient from the waiting room if you like that and I knew I would be able to examine and treat properly. They did also offer for me just to do clinical advice, but because I like face to face, I've always enjoyed the face-to-face interaction with patients. I thought that would be difficult and it was getting to the point where the update requirements to stay on the register and the places that I needed to travel for to do courses and whatnot were beginning to get unrealistic. So we just… at that point said, you know, I'm gonna have to accept that my working life's over so. And then I started to do voluntary work both at the Wildlife Trust and also I was volunteering for a local charity that gets a lot of its funding for from Macmillan that supports people with cancer diagnosis or a lifelong condition. It was me walking in the door as a patient first off, and then I finished up sitting behind the reception desk. But it's a two-way street thing I got a real kick out of um… I vividly remember I had a lady came in and she got a new cancer diagnosis and she really struggled to pluck up courage to walk in the door because she, you know, it's sort of the stigma around the Hospice as well that some people really struggle. Walk through the door and she came in and I said ‘sit down and you know how can I help you’ and as soon as I said ‘how can I help you’ she burst into tears and I said ‘don't worry you know we've got quiet corner here,’ and you know, handed her tissues sort of thing. And she explained that she had a diagnosis of breast cancer and a bit like you know the… But part of it was saying at least I know now what treatment you know been told what the treatment plan is, what I'm going to need to do, and so on. And so we worked through all of that and then I was able to say to her as well ‘what a lot of people don't know is that you get a cancer diagnosis and people tend to think that people get ill and they get iller and then they die.’ You know, I said actually my breast cancer was, you know, at the time it was 30 years ago. I was 30 when and she went ‘what! You had cancer?’ I said, ‘yeah, you know, the left one is silicone.’ You know, it's not mine. It's a process really. She's going and you know it, just you don't always want to share that with people but it just seemed the right thing in the right time. And you know, ever after, you know when she was coming in, we had a tea room with therapists and whatnot on site and she’d always come in and sit and have a chat with me. You know, and update me on, you know, where her treatment was at and you know, how she was feeling and so on which… it’s lovely and it's a two way street that sort of thing I think.

**I:** Remind me, which page are you on?

**P:** I’m on CALM I went into Joe..

**I:** OK. If you could go back maybe [Yep]

**P:** Nick [reads quote] I always like to learn and solve problems, really! I'm playing games in all chats oh scary. Yeah, I must admit I'm into, I'm on the [name of place] MND research advisory Group as well. I do like to understand… I was actually watching just before I connected with you, the RCN has actually got the... what's going to be the annual Stephen Hawking lecture which is about respiratory management in MND. And I'm thinking, is this going to be too scary for me to watch? And then I thought now I can. I can always opt out if it is, but no, it's actually really interesting. Actually, what one of the things that I thought was most interesting was we’ve got a neurologist saying that sometimes it's better you know there does come a point where you're better off as they have someone living with MND, if you’re starting to get respiratory involvement being referred to a respiratory specialist, you know they’re far more useful than neurologists. And this is a neurologist speaking and I'm thinking that's a laugh I like that, yeah. And then the local MND branch that I mean that is something we miss really at the moment and take part in research wherever possible. I would say so yeah, I would say I'm fairly in tune with Nick. Yeah

**I:** OK if you go back, then go to the next page. [Next, yeah, values and goals, yes] so this is 1 example, but um… you could come up with your own as well, but it's just to get people thinking about their own.

**P:** Yes, yeah, yeah. Actually the one thing that I need to get to grips with because having volunteered for the Wildlife Trust I’m very much into bird life and actually our garden here backs onto the canal. So through the hedge at the bottom of the garden is the canal. So we… here we got the ducks squabbling on the canal and the coots calling and gulls overhead and whatnot so. Love that! But what I would like to do, I can… I'm better at particularly if I can get the other half to take a good photo of birds, I can identify from a photo a lot of them, what they are. What I'm absolutely useless at, and what I would like to get better at is recognizing their calls and I’m thinking ‘I can hear someone chirping away there, but I can't see it and I don't know what it is.’ So yeah certainly is doing things like that for me.

**I:** OK. So just if you go to the next, I think that's the end of this exercise. [Positivity meaning] yeah, but I wanted the values and goals sort of, to focus on your values as opposed to things you can do, do you think that's a useful strategy?

**P:** Um… So values and goals have a look at that?

**I:** I'm just saying overall that overall, values and goals, is it something you would use or find useful?

**P:** Yeah, definitely yeah.

**I:** OK.

**P:** Yeah I would... I would definitely hope so because I think it's so much part of the person you are, isn't it? Values and goals in life, yeah.

**I:** OK. I’m just mindful of the time, so maybe let's go to the home page. [Return to home page Yep] So I guess you've kind of got a flavour of the sorts of information and activities so if you want… if you are experiencing anger, sadness or frustration, or any other difficult worry or stress, you could still use the website, but you could also use it if you just want to focus on the positive things and building more positivity in your life. So..

**P:** I think. I mean, I do remember actually very early on the care coordinator from the MNDA who's she had to retire, very sadly her husband had early onset Alzheimer's but she was a lovely lady by profession, she was an occupational therapist and I remember [name of OT] saying to me, ‘You're amazing, [name of person with MND] because you, you, you think in front, you’re sort of planning for the problems that you might encounter and a lot of people with MND can't bear to do that. They don't want to think of what's happening to them.’ And I'm, I actually said to her, and I think that is because I did my share working on the district.. as a district nurse and you know you go into somebody's house, you know the key’s in the key safe they know you’re coming and you find him on the floor. And a lot of, so often that's because forward planning hasn't been thought through or acted upon and so that person is being left high and dry on the road, unable and at high risk of falls. I know as a nurse I’m paranoid about falls. My daughter is the paramedic as well, 'cause she picks up people off the floor, but I think part of my need to plan in advance. It's sort of almost like a security blanket because if you know that you've got mechanisms in place that can work for you then it's better. It is like a security blanket, it's nice to know that. I gave the example, the most recent example, I'm sort of thinking my hand function is getting so rubbish, I can just about still emerge from the public toilet looking dressed rather than dishevelled. In other words, you know readjust me clothing after been properly one other. I think before long I'm gonna get to the stage where I can't do everything. I'm not going to be able to wipe myself properly after I've been to the loo, you know. And so the upshot is, we're looking at there's a gadget called a wash and dry toilet, which basically washes you and then blows hot air at the necessary bits so you don't need to worry about. And so I can maintain independence going to the loo for a lot longer than I otherwise would be able to. And so that to me is a… I would describe it as my security blanket. It's not sort of scarily looking at what might happen, it's far more scary to me to think that I haven't got the right plans in place. But we’re all different.

**I:** Yeah, I've heard mixed stories from people who have been [inaudible] as well but for some people it's almost too difficult even to think about

**P:** Although I can understand that point of view as well, I really can. I mean, there's been occasions when I think I just wanna bury my head in the sand and not think about it, but yeah.

**I:** Yeah, I guess that's why there are variety of suggestions and tips because no one thing work for.. Hum.

**P:** Yeah, we’re all slightly different persons to the one we are on other days of the week I suppose.

**I:** Sure. Um, I guess overall I wanted to ask you whether you'd see yourself using a website like this and if, um, in what circumstances, I guess.

**P:** Yeah. Yes, I think so. Yes, I certainly could as a sort of almost like a you know, a reference guide to nudge yourself in the right direction rather than going off at a tangent and taking a wrong turning, an un-useful sort of way of doing things. So yes, and I think it's quite user friendly in that it's not too wordy and it's quite easy to navigate around as well. You know you’ve got nice big buttons on the tabs that were easy to hit when you hand function ain’t good, which is, you know, it really matters that yeah.

**I:** And similarly when you were moving from one page to another or clicking the buttons, it was all fine with your hand and the iPad and?

**P:** Yeah yeah it works fine. Yeah, I mean I don't know they were talking about planning ahead and devices, assistive technology and did originally gave me a smart pad for eye gaze and then it kind of dawned on them that you know, I don't need that yet. So it was actually a frustrating device for me because I don't need to use eye gaze, I can still either speak clearly to, you know, use voice recognition or I can touch the screen for a lot of things when it is just a touch and a nice big key. I mean you know there are some trickier things that I can't do obviously, but I don't think I'll be able to do it on a smart pad either. And in a way the smart pad was just shoving more frustration at me. It's good to know it's there if that's what I finish up needing, but at the moment, I don’t need that and ipad’s the best device for me.

**I:** OK, yeah, I guess were there any other comments about the overall website just from the short snippet of it that you've seen that either you liked or disliked or could be improved maybe?

**P:** I think a lot of the websites that you know I’ve tried to find my way around for various things in the past and are nothing like as intuitive as this. I think it's nice and clear and easy to use. As I say it's not over wordy, but it gives a good, succinct, thoughts, advice if it's that. Um, I think it's good and I love the pictures.

**I:** Thank you, I’m glad.

**P:** Just when you’re doing this you need one you know behind you on the wall. [laughs]

**I:** Yeah I know I chose an office one rather than... [laughs] I guess actually this is not really.. well it is sort of website related, but on the on this main menu can you see there's an other support button you don't have to click it, there's nothing in there but that that's a section I'm trying to develop as well because some people told me beyond the website, they wouldn't know where to go to get psychological support if they needed. And I have some ideas, but I was wondering, as a nurse practitioner as well if either you've seen… for MND specifically, if you've advised anyone else?

**P:** Yeah, I've just looking at the ‘befriending yourself’ I like that…

**I:** Oh it currently links to the wrong section. I'm sorry, I need to add information in there. I was thinking things like the MMDA coffee mornings and [yes] That's if you want..

**P:** I think you mean how to access other support that's available kind of thing. I think… I'm biased, but you can put like the Hospice, for example, because interestingly I had to ask my GP who 10 years ago was my GP employer. That was my first nurse practitioner post there and I said, ‘you know, I think it's getting to the stage where it would be useful.’ And he sort of went ‘Oh yeah, the Hospice. Yeah, that's a good idea, [name of person with MND]. Yeah, I can refer you no problem sort of thing,’ but I had to sort of go… and some people find it really difficult to do that. But I think you know a section that gives ideas on where to go to find appropriate support. I mean for example, during lock down the other thing is I've contacted Marie Curie who provide volunteer support either well over the telephone at the moment or face to face. You know they have volunteers spread across the country basically and they look at your address and try and team you up with somebody who's got approximately similar interests and so on. And so I've started talking to a lady who lives relatively local, certainly within easy traveling distance when we can meet up face to face and that's nice. And you know, it's just again you match up, a bit like volunteering you often fetch up as well volunteers in a place where there are other people with similar interest to you, which is nice. You know you make new friends basic.

**I:** Yeah, is it like a befriending service or is it called the volunteer…?

**P:** Yes, yes that's right. It is a befriending service, but they do all sort of, you know..

**I:** I hadn't heard of that...

**P:** Yeah, yeah it's lovely, but again, it's something you have to dig a little before, but I actually I think I contacted, sorry on Facebook or something stupid and went into it, click the link and you know, you can sort of a request somebody get back in touch with you and, um, you know one of the organizers gave me a call instead and said we will put you in touch with somebody which they did and these sorts of things often you know, really do really do make a difference. I think it's… what is sad and I think what is very difficult with MND is… and I could see it coming years ago when the decision was taken to split healthcare and social care. Because you know, I mean my husband really well, in a lot of ways what he would most like is a decent break knowing that I'm OK, knowing that I'm properly looked after. But that's really quite difficult, quite difficult to access and we had a lengthy carer’s assessment over the phone the other day. Basically the upshot is he can have 100 and 150 pounds to do what he fancies with, but you know, I mean, there's the stipulation actually on paper is that he can't use it to pay for care for me, but actually what he most wants is somebody to look after me so he can go into his own thing. And it is that sort of support that is really lacking. But even being able to, I mean like the charity that I was a volunteer for that has funding from Macmillan, there's all sorts. I mean, there's loads of people that volunteer there that came through the door first of all his clients. But there are, you know, for example, there's a group called Knit and Natter, not one you'd want to do with MND, 'cause I'd finish up strangling myself with the knitting needles but having said that, you can just go and drink tea with them and you know and, and sometimes just knowing that there’s a safe, supportive environment where you can go just for an hour or two um, for a change of scene. So sometimes I think charities that are small charities that are local to people can be just as useful as somebody like Marie Curie or Macmillan, or the MNDA. Yeah.

**I:** Sorry, even if it's not MND related, it still could be useful...

**P:** Yeah, yeah. And obviously the basics of how many people… I mean the number of times I've had my daughter screaming in my ear all about, you know, don't people know that you should see your own GP with this or that you can ring the GP out of hours service. They just call 3 nines and it is sometimes about distilling for people how the system works. It's particularly important when you, as you care needs escalate to have access to the right information about how to access the right sort of support when you need it.

**I:** I agree. I'm going to stop the recording, but I'll still be on the call with you…