**SMALLBIZ TRANSCRIPTS 01360 311155 and 07801 355 944.**

**Typed by typist A, checked over by typist B.**

**Interview 27 (person with MND and family member)**

**Okay. Put it here.**

**(Non-interview chatter)**

**Okay. So, firstly, thank you for agreeing to be interviewed. I know you did tell me a little bit, when we met, about how you were diagnosed and things like that. But I guess for the sake of the recording, too, if we could start from what your experience has been like with MND, and wherever you want to start, if you want to start from diagnosis, that’s fine, or if you want to talk about a little bit before, that’s also fine.**

Patient: Right. I’ll start a bit before that, because I think it will fit for you.

**Okay.**

Patient: The second week of Wimbledon, in 2013, we were on holiday in Wales. And Andy Murray was playing, and I wanted to watch the match. And we were walking up Snowdon at the time.

**Okay.**

Patient: And I said to my husband, “Can we go back now, because I want to watch this match.” And so that was fine. So I’ve been halfway up Snowdon and down, and enjoyed.

Carer: *Walking normally.*

**Oh wow. Yeah.**

Patient: No problem at all. And I remember saying to him, “We can walk up the other half at any old time, but we can’t watch Andy Murray playing again.”

**(Laughs) Yeah.**

Patient: So that was the second week of Wimbledon. It wasn’t the finals, when he won it, it was just, you know, whenever it was.

**Okay.**

Patient: Just a match. Six weeks later, August bank holiday, I was staying with my cousin in Suffolk, and I couldn’t walk half a mile along the flat, without being breathless. And we… I… they said they wanted to walk further, and I said “I just… I just can’t.”

Carer: *Mm.*

**Mm.**

Patient: So we sat in the pub, and he said to me “You’re not well, you need to go to the doctor.” And so that was that start of it. And then we went sailing with one of my brothers, and I said to him what had been happening, and he was furious that I hadn’t told him before. But he rang my son-in-law, who is a cardiac surgeon…

**Okay.**

Patient: And he said, “Get her an appointment as soon as you can.” And so then that was the start. I went to the cardiac people, and that was fine. Then they referred to me the respiratory people, and that wasn’t fine, but nobody knew quite what was the matter. I went through several tests, and that horrible treadmill thing.

**Yeah.**

Patient: Horrendous. And I couldn’t… couldn’t breathe. But eventually, they found that I only had half a diaphragm working.

**Oh gosh.**

Patient: And so then there was all sorts of extra bits and pieces, and eventually [name of doctor] said, “I’m afraid you’ve got MND.”

**Okay.**

Patient: Yeah. And that was a bit of a bummer. I knew I wasn’t well, but somebody along the line had said “I don’t think you’ve got MS, and I don’t think you’ve got MND, and I don’t think you’ve got Parkinson’s.” So in my head, I’d sort of written those off.

**Yeah.**

Patient: And was living happily and thinking, ‘well perhaps I’ve just got a cold.” (Laughs)

**Yeah.**

Patient: But no. And so yes, under [name of doctor].

**Okay. Was this the… is he a neurologist, or…?**

Patient: [name of doctor] is a lady.

**Is a lady, sorry.**

Patient: And – it’s fine – and she’s a neurologist.

**Okay. Okay. And how was your experience immediately after diagnosis, in terms of your thoughts or feelings?**

Patient: They were ama- they were ama- amazing, that unit is amazing to belong to, because they’ve got a… I want to call her a nurse, but she’s not, she’s a physiotherapist by training. But if you need anything, you’ve just got to ring [name of person/care coordinator], and it happens. She’s everything. And they put me in touch with the community physiotherapist, occupational therapist, speech therapist, and I can hear I’m getting out of breath, so maybe you need to… talk to him. (Overtalk) (Laughter)

**Switch to… that’s okay, we can take a break. Yeah, I guess, because even for you hearing the diagnosis, what were your immediate thoughts and feelings?**

Carer: *Well I do remember the afternoon when [name of neurologist] told [name of care coordinator], and she came out to collect us from the waiting area, and I knew it was bad news. I mean, I know there’s a thing about breaking bad news, and she did it with her face.*

**The doctor?**

Carer: *Yeah.*

**Oh, okay.**

Carer: *And I knew it wasn’t good news, I had… when she said it was MND, I hadn’t got a clue what that meant. Because I’ve never done one day’s biology, I’m a ignoramus when it comes to these things. But obviously very quickly, [care coordinator] sort of filled me in and [name of care coordinator], I should think – that’s the nurse, [name of care coordinator], the physio who [patient] is talking about…*

**Okay.**

Carer: *...who, she… if I call her – if she’s employed by [charity organization], and she is a… a general factotum, to make things happen.*

**Okay. I think… (Overtalk)**

Carer: *And she does it brilliantly.*

**Like a care coordinator, or something?**

Carer: *That’ll do.*

**Yeah. Okay.**

Carer: *I’m not sure what her title is, but she just pulls all the strings together.*

**Okay. Okay. I think I know what you mean. Mm-hmm.**

Carer: *And the rest is history, to some extent.*

Patient: Yeah. We…

Carer: *You haven’t mentioned [name of psychotherapist].*

Patient: No. I had been seeing the psychotherapist.

**Okay.**

Patient: And you probably haven’t met him. [name of psychotherapist]

**No I haven’t.**

Patient: The muscular nurse that I’d been seeing before my diagnosis said, “John’s got spaces, do you want to see him?” And coming from the talking professions, anyway, I was very happy to go and talk to him.

**Okay.**

Patient: And he knew that I… well I told him that I had this appointment with [name of neurologist], and he said “Why don’t you come to me just after?” And so we had an hour, I think, to fill in, and I said to [carer], “You go and phone my brother,” who is a neurol- neuro-surgeon.

**Oh, okay.**

Patient: “And tell him. And I’ll go and see [name of the psychotherapist].” And so that was… that was lovely, straight after the diagnosis…

**Oh, okay, this is immediately**

Patient: ...I had a session with him.

**Yeah. Okay.**

Patient: Yeah. It was really, really good. Good timing.

**Okay. Sorry, I… if this is too personal, then feel free not to answer, but just an idea of the kind of things that you spoke about, or dealt with at that session?**

Patient: Well the immediate thing, ‘what does it mean? Am I going to be dead in two years?’

**Okay.**

Patient: ‘Should I be… be dead in two years?’ And so basically, we’ve… the whole time we’ve been speaking with, working with each other, we’ve worked through how I’m going to die in two years. But I didn’t. **(Okay)** So now I’m working, how I’m going to survive with what I’ve got left, and what is meaningful to do, and what isn’t.

**Okay. Okay.**

Patient: And we go together. So we’re working through all sorts of things.

**Okay. So it’s… it’s more… more of the preparing yourself mentally, rather than actual practical planning? Or is it a combination? (Overtalk)**

Carer: *Well… a bit of both perhaps.*

Patient: Both.

**Okay. Okay.**

Carer: *And I think I should add for the sake of the tape* **(Yeah)***, before you were diagnosed, I think she was called [name of person], the nurse came to see you. And she was extremely good at getting [patient] something called Attendance Allowance at the higher rate. And it’s when you get professionals like that, who know what the correct answers are… because the, some of these questionnaires are not easy, in the benefit system.*

**Yeah.**

Carer: *And she… and you had done it, when you were a home care sister for the hospice. And for anybody who doesn’t have that input,* **(Yeah)** *they’re not going to get what the State wants to pay her.*

**Yeah.**

Carer: *Can I put it like that?*

**Yeah, I know, it… that’s a whole other system, and unless you know something** (Mm-hmm) **about it, it’s really hard.**

Patient: Have you… have you come across it?

**I’ve… only through people telling me what their experience is like. But I haven’t had to…**

Patient: No. Because you get the book to fill in, it’s quite amazing.

**Oh gosh.**

Patient: It is amazing. You’ve got to mention how many GP appointments you’ve had in the last two years, and what doctors you’ve seen and what investigations you… oh. My word.

Carer: *And you’ve actually kept a record, and every letter, and you’ve filed them in the sequence.*

Patient: Did I?

Carer: *You did, you… (Stutters)*

Patient: I was very efficient, wasn’t I?

Carer: *You’ve been very efficient. (Laughter) Well, I come from the world of paper, and from many years, you don’t want to know. But you keep a record. And dealing with the benefits system* **(Yeah)** *it’s a bit like that. If you don’t keep it, you don’t get it.*

**Yeah.**

Carer: *And I’m sure you’ve heard people talking about Universal Credit?*

**Yeah.**

Carer: *Not politely.*

**(Laughs) Yeah.**

Carer: *And I’m aware that… I understand why they’re being careful, giving money away. But I think they could do it more elegantly. Can I leave it like that?*

**Yeah. Yeah. Well, had that been quite challenging, until you met this person to help you with it?**

Patient: Mm, never thought about it. But she said, “Have you applied for?” No.

Carer: *And we didn’t know.*

Patient: But thinking… I didn’t think about it, there’s too much going on at the beginning. And I know I felt quite bemused about, ‘oh golly, what… what have I got to do, what’s the priority here?’ The priority of course was to tell my family, and it just so happened that we were seeing each of our… we have four children, and we were seeing each of our children that weekend. I’ve forgotten what day it was, we… we saw [neurologist]. But we’d seen them all, and it… you know, the two from [name of place] were here, and… yeah. Fitted in very well. So it’s… it’s a whole family adjustment, really.

**Yeah.**

Patient: Lots of black humour. (Laughter)

Carer: *To give you a (mumbles) One granddaughter, then aged, I’m going to say twelve, maybe thirteen, [patient] was having one of her choking fits, and [granddaughter] says in a loud, clear voice, “Granny, will you please die quietly.” (Laughter) Well, her mother is a GP…*

**She’s kind of used to…**

Carer: *We have a… we do have a black humour between us.*

**Okay.**

*Carer: But you were asking about her.*

**And how… how have your thoughts and feelings about it changed now? Have they been like almost three years, three or four years, since the diagnosis?**

Patient: It’s… I’ve adjusted. Some days. Some days not. Depends on how difficult I find just living. Getting up in the morning is sometimes so slow. Our son calls me ‘Flash.’ (Laughs) But life is difficult, it’s… it is difficult, I can’t stand for a lot. And so [husband] has had to take over cooking, at which he’s amazing at.

*Carer: Well supervised.*

Patient: (Laughter) Simply amazing, you’re amazing.

*Carer: I would like to think most spouses would do that sort of… take… take over. Having been a vicar for a long time, I’m aware of how people do… they do adjust. Where we… I think the one thing [wife] was angry about, and I was angry with her about it, was, we’d been looking at… or, perhaps there was a time, caring for her mother. And when she died in 2013 – and you’ve put it in these words – you were hoping for a few years to just enjoy life.*

Patient: Yeah.

*Carer: And it’s been enjoying life with limitations instead.*

Patient: Yeah. She was a hundred. And didn’t really enjoy the last two years. But it was… it was a difficult time for all of us, she lived in [name of place]so we were up and down the motorway. And had she died a bit earlier, we would have had a bit of time to just have fun. Instead of that, we had every spare moment that we were there, going to [name of place]. So…

**Okay. Was this… was this while you had the diagnosis** (Just before) **then? Did the…**

*Carer: Immediately prior to it.*

**Oh, okay.**

Patient: Just before.

**Okay. Okay, I see.**

*Carer: You were being investigated.*

Patient: So the… instead of being able to go off on holiday, the money that we had went to [name of place]. So, you know, I don’t begrudge it, but it’s a big niggly.

**Yeah. Yeah.**

Patient: But… but the biggest adjustment, I think, was the wheelchair.

*Carer: Mm-hmm, you hate it.*

Patient: That was really awful. The man brought it, and I burst into tears, and he had to go out of the room. It was really terrible for him. He said to [husband], “Is… is she all right?” (Laughter) “No, she’s not.” But yeah, so first the walking stick, and then a wheelchair, and now an electric thing.

**Okay. So it’s the idea of just losing independence** (It’s just…) **and** (Yeah) **yeah.**

Patient: Yeah. And it’s the progression of the disease.

**Yeah. And… because you… at this point, you, you seem to have kind of come to a stage where you… you know this is going to change and things like that, and you have kind of accepted or adjusted to it. Was that harder at first, or how did that happen? I’m just trying to figure out if there’s certain things that helped, or certain things that didn’t?**

Patient: It happened slowly. For me.

**Mm-hmm.**

Patient: I was very shocked. I think it was before Christmas, when I met somebody, and she’d g-… she’d been fine the last time I saw her, and then she’d gone off her legs, and she was a different person. And I thought, ‘oh, that could be me next week,’ because apparently MND goes off quite quickly. It can do. And so you… it’s always there, [name of researcher], at the back of your mind, whatever you’re doing, it… ‘am I going to be here next week? Am I going to be here next year? And can I really plan that holiday, in case?’ And all those sorts of things. So it doesn’t ever leave you, I don’t think.It doesn’t leave me. It’s always there. Sometimes I’m… what I call on a plateau, so I know that last month I could do what I can do now. But sometimes I look back on a month and think, ‘oh, couldn’t do that before, can’t do that now.’

**Okay. Okay.**

Patient: We were on holiday in August… no, I’m not talking August… March. March/April, with our youngest daughter and her family. And I could get in to her car, she’s got a Discovery, big four wheel thing. And when she was here at Easter, I couldn’t get in to it, I didn’t have the energy to get…

*Carer: Only three weeks later.*

**Gosh. Yeah.**

Patient: Yeah.

**Okay.**

Patient: So that’s a change **(That’s… yeah)** and I’m not shut up now, and I think, ‘well I won’t be able to go in that car again.’

**Yeah. And it’s… (Overtalk)**

Patient: Unless I have a stepladder.

**(Laugh). And it’s also, so not knowing when and how things are going to change, is it?**

Patient: Yeah.

**Yeah.**

Patient: Just cope with the day, whatever it brings.

**Okay.**

Patient: I’m lucky, I can talk. I’m very lucky, because people can’t talk.

**Mm-hmm.**

Patient: And I can still walk a bit.

**Yeah. (Overtalk) I’ll talk to… (Laughs) And how… how has it been for you as well, with the… the changes and…?**

*Carer: Well I’ve become, technically, a carer, which as [wife’s] obviously said I now do most of the cooking. I do quite a lot of the sho- [wife] does the shopping online.*

**Okay.**

*Carer: So she’s still in charge. And that, no that’s quite important.*

**Yeah.**

*Carer: Because I’ve been a vicar, I’ve been visiting families where somebody has had an illness of whatever shape or form. And I’ve seen people sort of take over, and I’m trying hard not to.*

**Mm-hmm. Okay.**

*Carer: You get angry with me sometimes for… I think, taking over too much.*

**Taking over. (Laughs)**

Patient: You don’t.

*Carer: No, no. But it’s…*

**But you try to give a bit of say space, or…?**

*Carer: I try. But I can see your frustration.*

Patient: Well there’s certain things I can’t do. I’m losing the strength in my hands, and I can’t take, for instance, the top of a yoghurt pot… I can do it with my teeth, but I can’t do it with my… with my hand.

*Carer: But the most difficult thing are your earrings.*

**Okay.**

*Carer: As a mere male, it is very hard putting a… I don’t know what you call it, a studded earring through an ear…*

**(Laughs) Okay, yeah. Okay.**

*Carer: ...and then put the backing on. It’s difficult. And it may sound stupid* **(Yeah)** *but that is the tip of the iceberg of many other issues.*

**Yeah, but I mean, you don’t realise this until you reach a point where you have to do it, and then… yeah.**

*Carer: That’s right.*

**But even for you adjusting to all the changes, how has that been?**

*Carer: That’s a very good question. Disappointment, anger, I was looking forward to a disgraceful old age together. That’s a gross simplification. We’re still able to make the most of a lot of our life together. We have a lot of laugh. In a way, I’ve taken to myself the role of court jester.*

**Mm-hmm.**

*Carer: Because I think it’s… I can’t imagine how difficult it is for you. It’s just…*

Patient: What do you mean by court jester?

*Carer: Oh, being the funny man. Sometimes saying things in jest, which I couldn’t say straight.*

Patient: Do you?

*Carer: A bit. To enjoy life, actually, one of my roles is keeping your morale up. And I don’t know how other people cope, but I can imagine a lot of people – and I’ve seen it – I won’t say depressed, but certainly… not depressed at a medical level* **(Yeah)** *but just bloody hell.*

**Mm. Yeah.**

Patient: Yeah, well, it’s quite a lot for you to take on board, isn’t it, really?

*Carer: But we’d always… always assumed that I would die first.*

Patient: We did till death.

(Laughter)

*Carer: That’s the sort of, sort of humour.*

**Yeah. Yeah.**

*Carer: Now, I have to assume I may not die first. I can’t guarantee I won’t. At my age.*

**But no-one can.**

*Carer: Mm?*

**But no-one can predict in that…**

*Carer: Exactly.*

**...sense. Yeah.**

*Carer: But we live in an age where the culture is we’re not allowed to die. The NH-… NHS are not allowed to let us die. That’s… that’s a spoof of a bigger issue, I know it is.*

**Yeah.**

*Carer: But I’m having to accept I might have a lonely old age.*

Patient: Older age, I think. (Laughter)

*Carer: All right, older. Older.*

(Clock chimes)

(Non-interview chatter)

**Okay. And I guess, and… you’ve both spoken about it from your own perspectives as well, a couple of the emotions that you go through along the whole journey, like anger and disappointment and frustration, and that sort of thing. Is there… are there any ones we haven’t spoken about, any… any more light that you could share on any… the emotional side of things?**

*Carer: We could talk about [name of grandson].*

Patient: [grandson?]

*Carer: Grandson. At school.*

Patient: That’s not my emotion, though, is it?

*Carer: That’s not yours, is it? Is it? But looking at the wider family. You know…*

**Yeah, but if it somehow links to how you feel, then (Overtalk) talk...**

*Carer: Okay.*

**Okay.**

*Carer: Perfect.*

Patient: You… you mention a word, an emotional word like frustration or any of those things, and yes, they’ve been there.

**Yeah.**

Patient: Not all the time. Resentment. Yeah, all… everything, you have the whole gamut of it. And happiness, extraordinary thing, but yes. This is what I can do, then I can do it, like my talking.

*Carer: Yeah.*

**Yeah.**

Patient: Otherwise I wouldn’t be sitting here with you, I don’t think.

**Yeah.**

Patient: It would be too difficult. I can still eat. I don’t have to be fed. I sometimes have to have my meals cut up, but I don’t have to be fed. That’s happy.

**Yeah.**

Patient: In a very bizarre sort of way.

**No, I… I see what you mean. It’s… within the space of what you can or can’t do** (Yeah)**, looking at the positive side of things as well.**

Patient: Yeah.

**Yeah.**

Patient: Trying to be positive, because you could sit – I could sit – there, you know, and… but who would want to be with me?

**Yeah.**

Patient: Thank you very much, I’d be five minutes, and then they’d go. So I’m much, much happier talking about somebody else, and… and being relaxed about it.

**Yeah. Yeah. That’s true. Do you… thinking the same way, or…?**

*Carer: Well… (Stutters) You still enjoy going to a formal meal like Trafalgar Night.*

Patient: I do.

*Carer: And we’re talking about the next one.*

Patient: Yeah. At the back of my mind is, will I be here?

*Carer: Probably.*

Patient: Who knows?

*Carer: We don’t know. But we’re still talking about it.*

Patient: We’re talking about your emotions, darling. Dig deep. (Laughter)

*Carer: Dis- just disappointment. More than anything else.*

**Okay.**

*Carer: That… we, we had been growing old together, and it’s… we’re still growing old together, together, but somehow there’s a… an extra bite to it* **(Yeah)** *with you being ill.*

Patient: Which can be positive.

*Carer: We’re making it… I… I’d like to think we’re making the most of every day.*

Patient: Mm.

**Is that how you cope with things as well, is to try and look at the positive side** *(Yeah)* **and take each day as it comes?**

Patient: I have the down days. I burst into tears on [husband]. And he’s not burst into tears on me, yet, because men don’t do that, do they? So… (Laughs)

**How do you cope, then?**

*Carer: Em… I suppose… I do discuss, or did discuss this with [name of counsellor] the other day. Thou shalt bash on. You’re dealt a hand, you get on with. And I come from an environment, my first career was at sea with aircraft. And when the ship sailed from the UK, you knew that not all the air crew are coming home. And that was peace time.*

**Okay.**

*Carer: And I’m not saying you ever get used to it, but there was definitely a spirit of… what’s the right word? Yeah, you’ve got to enjoy today.*

**Mm. Okay.**

*Carer: And if you don’t enjoy today, you don’t… you don’t get it again.*

**Yeah.**

*Carer: And I suppose that’s sort of fairly fundamental to my way of life.*

Patient: Mm.

**So you’ve been doing that for a while, and that’s just how…**

*Carer: Most of my working life. Yeah.*

**Yeah. Okay.**

*Carer: Working at sea with aircraft, there’s an unfortunate song called the ‘A25 song...’*

**Okay.**

*Carer: A25 is a form.*

**Okay.**

*Carer: The accident form. And the versus were like all the accidents that were fatal.*

**Okay.**

*Carer: It’s quite a long song. And the verse that… the chorus is, ‘cracking show, I’m alive, all I have to do is to render my A25.’ You… everyone wants to render, put their own accident form in, otherwise you’re dead.*

**Mm.**

*Carer: It’s the black humour* **(Yeah)** *of a dangerous world.*

**Yeah.**

*Carer: And I suppose that does infect… and, you were friends with some of these guys. As a nurse, and as a hospice nurse. You were quite fr-… you were generally friendly with some of the people.*

Patient: Yeah.

*Carer: They mattered to you.*

Patient: Yeah. They did.

*Carer: Somebody called [name of person], I seem to remember who I met.*

Patient: Yeah.

*Carer: And… I think when you’ve worked in scenarios where you’re going to have live without people, you never get used to it, but you learn to… I think the modern word is ‘resilience.’ Which is not an avoidance of the issue* **(Yeah)***. Em… And thou shalt bash on. But it does affect people.*

**Yeah.**

*Carer: I mean, we had a, a bad five days in the ship I was in, we had two accidents, one, one accident involved two aircraft. And there were three air crew who were killed, and the ship was whole… well, the whole ship was shaken. You could feel the ship* **(Yeah)** *was getting edgy, what’s… who… what’s the next one?* **(Yeah)** *There were, there were no more fatalities, I’m glad to say, in that collision. And we sort of quietly got better. But it does shake people.*

**Mm. Yeah. So just… yeah, just… maybe a bit of time with getting on with… okay.**

*Carer: Mm. And you don’t forget them, I can tell you the names of the… the people who, those three who are… [name of person], I had breakfast with. [name of another person] I didn’t have breakfast with. And the third one was, [name of still another person]’s observer. You remember [name of person] hit his hundred and twentieth birthday. I was summoned to go and meet somebody. It was his mother.*

**Yeah.**

*Carer: So… but… you don’t forget these issues.* *And nor should you.*

**Yeah.**

*Carer: And some of the D-Day celebrations are actually about that sort of thing.*

**Yeah. So that… that’s what you mean by ‘resilience,’ really? It’s… it’s not ignoring it, and carrying on. But just…**

*Carer: Trying not to. You don’t forget them.* *As I say, of all the aircrew we had on that ship, the three I remember are sadly the ones that… who, who died.*

**Mm. Yeah.**

*Carer: And you can remember people from your nursing.*

Patient: I’m not sure that this is what we should be talking about.

*Carer: All right.*

**(Laughs) It’s okay, don’t worry.**

*Carer: I’m trying to explain where I’m coming from.*

**Okay… yeah. If that’s how… how you were sort of used to coping in the past, and** *(Mm)* **the kind of life experiences** *(Yeah)* **that… so in this context, then, when you say… sorry, what was it, ‘just bash on...’?**

*Carer: Thou shalt bash on.*

**Thou shalt bash on. (Laughs) Does that mean bash on with life, practical tasks, or…**

*Carer: I would say life.*

**...just any…**

*Carer: Yeah.*

**Okay. Do you have any other areas where you kind of just vent or distract yourself or something like that?**

*Carer: Mm. Interesting question. Grandchildren are quite a good distraction.*

**Okay.**

*Carer: I think, making sure we are enjoying life as we go along.*

Patient: Occasionally, [husband] will get an out of proportion irritation, and he’s on the roof.

**Okay.**

Patient: Like when your computer doesn’t work properly. So...

*Carer: But I don’t think that’s changed.*

Patient: (Laughter) I… I just wonder sometimes whether…

*Carer: Oh, I think you may well be right.*

**So where… where… what are the main sources, then of… well, both your support? In just coping with MND and things like that?**

Patient: I think… I think very… each other, it’d be humour. But certainly for me, because I’ve been seeing him for so long, it’s [name of psychotherapist]. The psycho- psychotherapist.

**Yeah.**

Patient: He… he’s been really a big part of my keeping it okay.

**Mm-hmm.**

Patient: Really helpful, and now we’re both going together. And [husband] came along because I wanted him to. Not that he wanted to. But I think you’ve been impressed, haven’t you, with…

*Carer: Yeah.*

Patient: Yeah. So… so [psychotherapist] is really important.

**Okay. Okay.**

Patient: Family are important. And we have an… we have an under-girding faith, and that’s keep… and that keeps us going.

**Yeah. Yeah. Yeah.**

Patient: I think that’s…

**Totally important.**

Patient: ...I think that’s the, one of the main parts that people see, but don’t understand.

**Mm. Okay.**

Patient: You know, because certainly a lot of people have a… a faith of sorts. But when push comes to shove, it’s difficult to hang in there.

**Okay. Okay. But you’ve found it supportive?**

Patient: My faith?

**Especially dealing with this condition? Yeah.**

Patient: I… it’s just really important to me, full stop. And if today’s MND today, well okay, get on with it. That’s what it is. Life is messy. We’re in the mess.

**(Laughs) Okay. Are there similar sources of support for you, as well? Yeah?**

*Carer: Yes. I would say family are a huge support. I think it’s the ability to make sure we still have fun. I mean, last weekend, was it, we went on a booze cruise to [name of city].*

**Yeah. (Laughs)**

*Carer: I mean…Three of our daughters, half a dozen grandchildren.*

Patient: There were twelve of us all, together.

*Carer: It’s about that, anyway. But...*

Patient: It was really lovely. Really lovely.

*Carer: I think we just had fun. We were silly.*

**Yeah.**

*Carer: And I think one of the things we’ve… we’re losing as a culture, is the enjoyment of silliness. Is that… a way of putting it?*

Patient: Yeah.

*Carer: As I say, that’s our life…*

Patient: Because we have seven grandchildren.

**Oh wow.**

Patient: From… from (Stutters) how old is [name of grandson] Nineteen, and this one is four.

**Okay. That’s quite…**

Patient: So they were… we have twelve grandchildren altogether.

**Oh okay.**

Patient: But there were seven with us in… in [name of country]. And it was just a lovely weekend, and everybody enjoyed it. Some were in the sea, some weren’t. It was great.

**Oh good. So you make sure you do little things like that to** (Yeah)**, to look forward to, even in the future? Yeah.**

Patient: Our youngest daughter, and I’m not sure how often you can be with your mum, where... if she’s even on this country. But…

*Carer: Is she here?*

**No, she is… but she’s in Europe somewhere, so close enough.**

Patient: Not too far.

**Not too far.**

Patient: But our youngest daughter needs to have in a diary when she’s going to meet us next.

**Okay.**

Patient: Because she can cope with that. If there’s nothing there, she goes quite down. She has three, you know, three little ones, are her’s, are four, six and eight. And they’re a handful. They’re absolutely gorgeous.

**Yeah.**

Patient: But they are a handful.

**Yeah.**

Patient: And so for us to have something in the diary on a regular-ish pace **(Okay)** is important.

**Okay. So both for you and for her, in a sense, yes?**

Patient: And for her.

*Carer: Yes. It’s a mutuality.*

**Yeah.**

Patient: And… and we have two daughters here in [name of city], which is lovely.

**Okay.**

Patient: We see them every week.

**Yeah.**

Patient: They… they keep an eye on the oldies. (Laughter) (Overtalk) We have lots of support.

**Okay.**

Patient: And I’m one of five in my family, and I keep up with them all, so… We have lots of support.

**Okay. Yeah. And I know you mentioned briefly as well about [name of psychotherapist]. But his… I’m just trying to see how he… how he supports you, basically, isn’t sort of giving you a space to think through issues, and plan ahead, is that cor-?**

Patient: Oh we, we see him about once every five weeks, and I can talk through – we can talk through – what’s happened in that month, and know he’s… he’s very person-centred, he doesn’t...he doesn’t give us directions or anything like that.

**Okay.**

Patient: But if we’re… what did we talk about last time? If we’re concerned or anything, we can… nothing’s off the table for him.

**Okay.**

Patient: It would be like going to see you, too, [name of researcher], and it would be **(Yeah)**, you know, this is what I want to talk about, and you’d listen, wouldn’t you?

**Yeah.**

Patient: And he’s the same.

**Okay.**

*Carer: It’s the art of talking though what you would otherwise bury. And we all do that a bit.*

**Yeah.**

*Carer: And I’ve seen it with parishioners, and when you start burying thing- you know, I suspect I don’t need to tell you this, is when they become harmful. And I don’t think, we’re fairly good at talking.*

Patient: You are quite open.

**That’s good.**

Patient: Mm.

**That’s good. Okay, so you have this sort of place where you can do that as well. In terms of professional support, also is there any other… like any MND or any other doctors or nurses or physiotherapists, I don’t know, that…**

Patient: Well there’s this unit in [name of city].

**Hmm mm.**

Patient: That is a community unit. And within that, they have a physiotherapist, an occupational therapist, a speech therapist, all of whom, if I need, I will ring and say “Help.”

**Okay.**

Patient: And I did a voice banking **(Oh, okay)** and the physiotherapist, the- (Stutters) speech therapist hadn’t done it before, so she came and we learned together how to do it. And the physiotherapist and the occupational therapist were here, just recently, because [care coordinator] actually contacted them, as it was out of my going to the respiratory clinic, and I was having trouble, getting, moving myself in bed. **(Okay)** So I now have a very super pillow that pushes me up.

**Oh, okay.**

Patient: And… and the thing on the side of the bed, that I can pull to turn myself over.

**Okay.**

Patient: And if I feel that I’m going down a bit more and want a bit more help, I can contact them and they will… they will come. So there’s that whole practical side.

**Oh, okay. Yeah. Yeah.**

Patient: And [psychotherapist’s] the psychological side and we have the support, so I’m…

**You’re well supported.**

Patient: This is the place for being, having MND. (Laughs)

**That is true.**

*Carer: I don’t think [name of county] does so much support by a long way.*

Patient: No.

**Yeah. And it’s very different.**

Patient: And then you have these wonderful tea parties.

**Oh the coffee… yes. No that’s fine, glad I met you there.**

Patient: There’s normally more people than that.

**Yeah. But it established…**

Patient: But you can share ideas and discuss what’s happening and...they’re very nice.

**Oh good.**

*Carer: One particular day, not this last one, the one before, when we were down in [name of place]* (Yeah)*, I think it’s your, the lady you were talking about who, who lost the use of her legs. And they were talking about how they’d had to get a special car.*

**Mm-hmm.**

*Carer: And they were able to say which car it was and how it was adapted and how it catered, so that they could get out together.* *And I now know that the… that the company that do the conversions are in, not.. what’s the other one, beginning with ‘B’?*

Patient: Wherever.

*Carer: Wherever it was. And I know… the problem with a lot of things, and until you know the question to ask, you’ll never get the answer.*

**Okay. Yeah.**

*Carer: And just seeing that vehicle, that car, how it had been converted* (Yeah) *was very helpful.* **(Yeah)** *I now know the questions to ask.*

**Yeah. It… it helps being just prepared and knowing what…**

*Carer: Yeah. Yeah.*

**...what issues there might be. Yeah.**

Patient: Yeah.

**Yeah.**

Patient: Yeah.

*Carer: I mean, not that long ago, when I was first a vicar, people who were ill were just left in the corner. Seriously. They weren’t expected to want to go out.*

Patient: And the [hospital] is really amazing. We’re very lucky here.

**Yeah, that’s good.**

Patient: Yeah.

**And I think I’ve… I’ve asked most of my questions about like your experience and things like that, but everyone’s situation is quite different, so if there’s any bits I haven’t covered or anything I’m missing about… (Overtalk)**

Patient: I’m aware that the whole thing about your… your PhD is **(Yes)** online.

**Yes.**

Patient: Isn’t it?

**Yes.**

Patient: And for me, I don’t… I’m not sure that I would use that.

**Hmm mm.**

Patient: Because I need to have somebody to talk to.

**Face-to-face, yeah.**

Patient: So I don’t know what format it will take, I’ll be interested to know.

**Yeah. I guess… for… it’s more for… it’s not like we’re taking away from having the actual counselling or psychotherapy or** (Yeah, I appreciate that) **that… that kind of support. It’s just in case people may not be able to get to someone who provides that support. Or like you were saying, if… [name of place] has amazing support, but [name of another place] doesn’t. Then it’s sort of something in the meantime, until… until you get the support you need. Or there might be some people who may not want a whole session of therapy, say, but a few say tips and techniques, or something like that. It’s… it’s more person-led, so if… if you think you’d benefit from that, then you could use it. If you don’t think you would benefit from that, that’s absolutely fine as well.**

Patient: So what format does it take? **(So…)** Or were you hoping that it would take?

**Yeah, so it would work like… I’m glad you asked me this question, because I was going to ask you about your thoughts about it as well. Sort of like a… a website, or that kind of platform. I don’t know if you’ve done any kind of e-learning, or online modules, but it, it looks similar to that. It just… it’ll… so it’ll say things like ‘if you want to deal with anger or frustration or do you want to practice a bit of mindfulness?’ So… something like that, so it’s up to people to pick and choose what they want, and when.**

Patient: Right.

**Yeah. But…**

Patient: So you’ll give them, on that, on the website, there will be… there will be exercises for me to discharge my anger?

**In… it will be a lot of explaining, I think, about what… as you already know, I’m sure, you know, what anger is all about, and trying to identify what the source of the anger is, and working through those thoughts and feelings as well. So I guess, in a sense, it’s… it’s a two-way thing, it’s not just the computer telling you ‘this is what you have to do,’ but you taking some of that information and applying it to your life, and seeing if it’s relevant or not.**

Patient: It’s an enormous amount of work for you.

**(Laughs) Yes.**

Patient: A huge amount.

**Yeah. But I’m interested to see how… how people will react to it as well. Yeah.**

Patient: Well if it was there, **(hmm mm)** you’re obviously breaking ground here, if it’s there, I will certainly have a look at it.

**Oh, I would… I would love to hear your opinion about it. (Laughs) But even in terms of say your… your journey with MND as well, did you… did you always feel comfortable accessing information about psychological support and things like that? Or do you think maybe there were certain points where you wouldn’t want to…?**

Patient: Sometimes… have you seen their magazine?

**Yes, I think so.**

Patient: Sometimes they have people who have written some poetry. And I find that, ‘oh, I can’t read that, put that down’. So just… it’s like being… grieving.

**Mm-hmm.**

Patient: It catches you when you’re not expecting it. And you think you’ve got **(Oh, okay)** a good day. I’m fine today. And all of a sudden there will be a smell, it… whoever used to wear it…

**Yeah.**

Patient: You know, and it just… oh, it just catches you. So I would be very happy to have a look at these things.

**Yeah.**

Patient: But sometimes I might think, ‘oh no, I can’t. I can’t go there.’ Our, one of our daughters doesn’t read that magazine that they put out, because it’s too upsetting for her.

**Mm.**

Patient: So… but I usually read it. By the time the next one comes, I’ve finished the one before. It takes me a bit of time, but…

**Yeah. But that’s useful for me to know, as well, when and how people access information and support and things like that.**

*Carer: Yeah.*

Patient: Yeah.

**Especially if you’re providing it in an online way as well. Did… did you both…** *(very interesting you asking this question at the moment)* **do a lot of Googling about MND?**

*Carer: If I… one of the things I do, I’m a sort of chaplain with a naval reserve at the moment.*

**Okay.**

*Carer: And they’re just exploring the use of exactly this. And the latest idea… I, where did I read this? It doesn’t matter. But instead of having to use… you’ve heard of, you know what I mean by a simulator for an aircraft, for pilots?*

**Okay.**

*Carer: Taking it much further than that, if you imagine a simulator for a whole ship activity.* *And they’re just exploring that, will this be cheaper than having to have a whole ship tied up doing it?*

**Okay.**

*Carer: So there’s a lot of other work going on.* *And I think modern simulators, I know they’re an awful lot better than in my day. Probably very much better. But at the end of the day, you’ve still got to get… if you… (Stutters) coming from aviation, you’ve got to get into an aircraft and get it airborne. Before you can actually feel it. That doesn’t mean that what you do on the ground* ***(I see, okay)*** *is vapid without value. Because it’s actually extremely cheap* **(Yeah)** *to not use an aircraft for an awful lot of the basic procedural and the ordinary.*

**Yeah.**

*Carer: But there needs to be a safety net, I suspect.*  *For… it’s both ended is what I’m saying…*

**Yeah, it’s a combination.**

*Carer: Yeah.*

**Of all kinds of stuff.**

*Carer: I mean, look… what have you, we haven’t had time to say, I was trying to do… I wanted to do some safeguarding for [name of organization], and I tried to get onto their website this afternoon, when you were with whoever, and the wretched thing wouldn’t open.*

Patient: Yeah.

**Yeah, it’s those sorts of issues as well, and especially if you’re trying to access something for psychological support, and you get an error message, or… Yeah.**

*Carer: Well something like safeguarding will always have a psychological dimension.*

**Yeah.**

*Carer: When I do get on, I might be better educated. But I was just frustrated the wretched thing didn’t work.*

Patient: So have you got… have you got titles for the emotions that you want to put on?

**No. So they’re going to come from whatever you two tell me, and what the rest** (Right) **of my participants also tell me. So that’s… that’s the whole procedure. I can chat about it more, but if… I’m just wondering if I should stop the recording and then talk about it, ‘cause…**

*Carer: Okay.*

Patient: Have you finished all your questions…

**I… I’ve finished my questions.**

*Carer: You got what you wanted.*

Patient: Have we given you what you want? (Overtalk)

**But if there’s anything… yeah, yes, you have.**

Patient: Good.

**Is there anything else you wanted to add, just while that’s on?**

Patient: Em… I thought of something just now, and forgot it, so that was no good. No, I don’t think…

**Is it about the online thing, or…? Just something entirely different? No?**

Patient: It’ll come probably when you switch it off.

**Okay. That’s fine, I can turn it back on.**

(Background noise)

(END OF RECORDING)