Q Right, we should see ‘aha’ recording. I have this just terrible feeling that one day I’m going to interview somebody and realise I didn’t press the button. So good to get that out of the way.

A I can empathise.

Q So I’m Katherine Runswick-Cole and I’m one of the researchers on the project working with Martina and some other people as well. And so I’m going to ask you some questions. But I got to the end of one interview and somebody said ‘did you ask me your questions?’, I think it was just because it was very much a conversation and very free flowing. And it’s very open, you can say what you want to say in the way that you want to say it but I have got some questions to kind of start us off. So my first question was, why did you want to take part in the study?

A Well I’ve been long term caring, unpaid caring for 32 years now and I’ve often said to my….I’ve got 5 daughters and I’ve often said to them and really anybody that will listen, that I really feel that there ought to be a study on the long term mental health effects of caring.

Q Yeah. Do you know it’s so interesting. I was telling someone else that when we applied to get the money to do this study it was actually a call from something called the National Institute for Health and Social Care and Research that was specifically focused on the experiences of carers of adults and older people, and it didn’t mention people with learning disabilities.

A Yeah I can imagine!

Q Yeah. But I think that’s one of the reasons why it was ??? because we said ‘there’s 1.5 million people with learning disability in the UK and you’ve mentioned them’.

A It’s a very hidden group.

Q Yeah, yeah I think we definitely agree with that. So can you tell me a little bit about your experiences?

A Sure. My daughter, she was the fourth of my daughters and we were out in [country]. And my mother had just died and about 3 months after that my daughter was born. And she was really very well when she was born, she scored the highest on the Apgar test, but in [country] she was a C-section and they took her away to a special nursery for observation where she had a breathing episode I learned later. And she came back and she was never the same again, she was floppy, I found it hard to breastfeed, all of that kind of thing. And about 3 months later after taking her to several pediatricians we finally found out – well the pediatrician rang me up and said ‘your daughter is going to be a vegetable’.

Q Oh!

A Yeah. So it was a traumatic time.

Q That happened in [country]?

A That was in [country]. My husband is [country]n and we met at university, so 4 out of 5 of our kids were born there. And she was very fragile. Once she reached the 18 month age she was incredibly fragile in terms of respiratory infections, they were just recurrent. So I was spending two weeks of every month at the hospital with her and away from the other kids pretty much for 6 months of the year on and off. And when we came here on sabbatical we found it was the first time in that year that [name] did not to go hospital and she seemed a lot stronger, which is strange, you don’t expect that you know leaving [country] to come to [town]. Anyway, when we went back to [country] she became ill again. So what I did was, I tucked the kids under my arm and brought them back. And my husband at the time was an Associate Professor and he was going to wait until he got a Chair here, so for three and a half years I looked after the kids myself here.

And she was doing really well but then she got whooping cough, because in [country] they didn’t vaccinate for that in case it sort of….they didn’t know….she was undiagnosed. We always knew it was post-birth brain damage, hypoxia. But they didn’t want to admit that, when I went looking for the medical records they suddenly disappeared. But because of that she was just termed ‘global developmental delay’. And….where was I?

Q You’ve come back, you’ve got 5 girls.

Time 4:36

A Come back, I’ve got 5 girls yeah. She got whooping cough. We ended up in ITU for 3 months, and then that was almost a legal battle because they told me she had a degenerative neurological condition. And I disagreed, I said it was respiratory, I could see signs of her improving. They wanted to switch off life support. I was threatened with being taken to the highest court in the land, blah-blah-blah. We managed to get a second opinion simply because, not for any other reason but my husband was able to show them through physics that they had got some sort of feeding tube angled incorrect. And all of a sudden when they realised ‘oh this guy’s an academic’ they suddenly allowed us to have a second opinion, because it was the Old Boys Club. So you can imagine my fury, because it didn’t seem to matter what evidence I threw at that, I even asked them to ring her consultant in [country] but they refused us that up until that point. The respiratory consultant came in, said ‘oh the mum’s right, it’s respiratory’. And [name] was fine eventually, she was on the ward for the next 2 years.

She had learning disability, she’s non-verbal, she’s tetraplegic, she has quite unstable epilepsy and a range of respiratory conditions that are quite similar in presentation to cystic fibrosis, even though she doesn’t have it but she has many of the same drugs and therapies that those patients have. So she has been in and out of hospital most of her life. As I said she is non-verbal but she understands everything around her and what we are saying. And she is, I have to say, the happiest of all my children, she’s a delight and a joy, and just lovely. And she communicates in very limited means, she has little wiggles and little flickers of the eyes and you have to know her for a very long time before you can begin to interpret for her.

So life carried on and the routine was intense, my husband did a lot of overseas lecturing and things. So as [name] got older she became kind of more fragile and she gets nebulised a lot and I was nebulising her for 20 minutes of every hour around the clock with no support whatsoever, apart from with my daughters, my daughters were fantastic, and when my husband was at home he was very good too, but you know it was kind of….

Anyway she then, at the point of transition I was fighting very strongly to get a 24/7 nursing team in situ in the house, I didn’t want her out of the family. Because we are a very big tight family and we want her here. And also we found that she wasn’t able to cope in respite, they weren’t able to cope with her, she’s too complex. Even if it was nursing care they didn’t have the one-to-one staffing, and it takes us about 6 to 8 weeks to train a nurse to be able to look after her conditions, even then it needs parental oversight, so it’s quite difficult. So we ended up fighting a legal case to get the nursing, which we have, but for the most part – it’s quite good now but for the most part it still left me working somewhere between 60 to 100 clinical hours per week and on top of that all the admin and everything else that goes with it. And I’ve been doing that half my life.

Q Yeah. I just want to go back to something that you said about your husband. They took him seriously because he was an academic. And I was thinking they don’t take me seriously and I’m an academic.

A Could be male.

Q That’s what I was wondering. That’s what I was wondering.

A Yeah. It used to irritate me, because I could articulate quite well. I grew up in a medical family, I grew up pretty much living in and out of hospitals and I could articulate very well, but it didn’t really matter what I said or how calm and collected I remained during any emergencies, it was the male presence.

Q That’s really familiar. So it’s also really interesting the way you tell the story because I think that we….you know ??? I would tell it in the same way. You sort of tell it in this kind of really ‘oh this happened and this happened’ and in that there’s a whole host of things that were happening. Like most people don’t have legal battles, you know they don’t have the fights, but we just go ‘oh yes, judicial review’, you know what it means, you know you know what it means. And I always find that really interesting. And then the fact that everybody just sort of tries to say ‘well that happened, that happened, that happened’. And of course we are talking about mental health and you said you think it’s really important that we do that. And you haven’t really spoken about your mental health as you’ve told me the story, so….

Time 10:00

A Yeah. I grew up with a very stoic mother, she came from a long line of northern women who worked in the mills for hundreds of years since the Industrial Revolution and she kind of worked her way up in the medical world. And she was great but she had very kind of ‘get on with it’ attitude and I was very much brought up in that way. And I am very strong, I’m very, very, strong emotionally and mentally and I think I probably off-set collapsing with fighting and being very aggressive with the authorities. But I think it came around my 60th birthday and I turned around and….I still think of myself as a young woman because I was 31 when [name] was born and very young for my age and I had a very sort of young outlook throughout. And then suddenly I turned around and actually I’m cracking on for being an old woman. And it was almost like a visual…which I feel very emotional about, you know that one minute I was a young woman and nothing’s changed except my age. Like it’s gone.

Q Yeah, and so much of that life’s been spent doing the care that you’ve loved doing and want to do but you would like to have done maybe not so much of.

A Not so much of. Not have it take so much toll. Not just on me but my husband and my children especially. You know they’re very much committed to whatever happens when my husband and I are gone they’re committed to taking over, not because I’ve asked them, I’ve talked to them very much about….you know. But they know what they’re taking on, they all live very close by, they’re all heading up for their….well one’s 40, my eldest is 40, the others are in their late 30’s except for my youngest who is 22. But they all know what they’re about. But I see in the one who is the most sort of responsible, she is already showing signs of mental shakiness, you know that she is aware of what this means and what the sacrifice on her life will be. And try as I might to dissuade her that’s not going to happen, but she has seen what’s happened with me. And I can’t say I’ve had a bad life, I’ve got the most amazing family. I love my girl, she is a joy and we manage to have a lot of fun and laughs along the way.

But you know my career was given up at the age of 31, it was a good career. At the time my husband was a young academic and I was the main breadwinner, I was an investigative research journalist for basically the [country] equivalent of Panorama, so I had a very promising career. And that’s gone. And I gave it up. My husband’s always been very good about sharing work and things but because I’m a severe asthmatic I was very, very good at picking up really subtle nuanced symptoms and very frustrated that he was unable to, so I was the one that gave up my job just because I had to keep her safe. But my mental health I think as I have got older, it suddenly dawned on me like I said around 60, actually my mental health isn’t as good. I pride myself on being very strong and just crack on with it, but I realised that so much of life has gone. So much of my girls’ lives were interfered with, I mean they did not have a holiday for so many…well all of their school years because I was at home looking after her, she was too fragile. And I had no help, I couldn’t take them out, our big treat was to go for a coffee or something like that you know, something totally pathetic you know.

And I find now that I am so enraged about what has happened, how much I have been lied to, how much we’ve had to fight. I mean there’s two of my daughters who were particularly adept at debate and arguing, and when we have meetings with the ICB and my husband’s there, it takes all four of us to get anywhere. And we often look around and say ‘how do just…’ you know most of them are single mums, how do they do this, how do they cope? It makes me distraught that they actually have to deal with this.

Time 15:00

I’m so enraged I sort of joke now and I say I don’t feel as if I’m civilized any more, I feel too savage, too angry to go out into society. Because I do live a very isolated life and I have done for many years now. You get to the point where you just stop telling people what is going on in your life because it sounds too dramatic, it’s too dramatic for a soap opera half the time, there is so much. And you can see people’s eyes looking and you think….and they’re wondering whether you are exaggerating. So you just gloss it over, you don’t speak about it, or you make it very casual.

And it’s just irritating to go out and try to explain to people this and then see them not being able to engage. So I just sort of cut people out of my life. I’ve got a few long term friends but most of those are in [country]. There was no real opportunity for socializing here, briefly I did join a theatre group, I love drama, but I had to give that up because my daughter was too fragile. But I find myself now sometimes talking to my husband about something that I feel quite strongly about and I realise that I’m almost arguing aggressively and I don’t realise I’m doing it. I don’t mean to do that but because I’m so used to…my days are spent firing off emails and having these meetings, and too annoyed to put up with the nonsense anymore. So yeah I used to be very friendly and very laid back and very full of fun – and now I’m just angry.

Q I recognise that. I feel like I’ve lost my filter and that now I just, much to my husband’s embarrassment … Yeah I come across I think as very aggressive – but I wasn’t, you know I wasn’t that, that’s not who I used to be.

A Nor me at all. I used to be quite retiring.

Q It’s quite difficult to know what to do with that anger isn’t it? I don’t quite know what to do with it.

A I don’t know. I joke that I’m going to get a punch bag in the garden – then I wonder what the neighbours would think of me flailing away.

Q Yeah I had to ring social services this morning because we haven’t seen hide nor hair of them in I don’t know how long. And I thought ‘right, I’ve got to find a way of dealing with this’. So I put my headphones on, because you have to hold, and I went for a walk because I thought I’m feeling so stressed about this that if I go for a walk before I actually speak to them I might be a little more ??? I try to come up with these strategies to manage my anger.

A Yes I do that. I try to phone somebody that I like who I have a quite amicable relationship with before I then….just so that I can be on an even keel.

Q Yeah. That’s so interesting isn’t it? We’ve been talking to people about what do they do to manage and it’s often little things like going for a walk, or just trying to find a time to have a cup of tea. So are the strategies….so ringing a nice person before ??? that’s a really good idea. Well you need these ideas, we need to share them around.

A We do, we do. I mean tangentially, about 4 years ago I was approaching yet another one of the dreaded assessments you know, and we are always living in fear of them either removing, continuing healthcare, or worse still putting her into residential care. And they never fail to let me know that this is a possibility, you know, which I find is emotionally terrorism because they have letters from every single doctor, GP, consultant, ex nurse and current nurse saying that it would actually endanger her life and the best possible situation is what she has now. And they refuse to evidence that on the assessment, which is a big thing for me. But facing yet another one of these, and I knew very much that this particular woman was pushing for my daughter to go into residential care, in the end I ended up having a stress-related asthma attack and ended up not breathing for 5 minutes and being intubated in ITU. It nearly did for me. And it was purely the stress of another assessment. And it absolutely floored me, I was very precarious for about 6 months, I think I had 3 admissions in 7 months flowing that. And I’m fine now thank God. But what I found was that if I take lots of ashwagandha and if I meditate for about 15 to 20 minutes a day, that has worked wonders. So they are my big go to.

Time 20:30

Q I think the point that you make about your mental health impacts your physical health.

A Very much.

Q Other people have spoken about those impacts. So it’s massive isn’t it that you can have, I think especially when you’ve been caring for a long time and you have the cumulative effects of that, it will have an impact on your mental and your physical health in the end. It certainly has for me.

A Yes, very much so, very much. I find that it takes me not very long at all to get cross or aggressive, always wanting to argue very, very strongly you know. And just not wanting to tolerate fools. And I’m actually a very kind person but I feel as if it’s led me to be too quick tempered, too unkind too quickly. And I don’t think a lot of people would say that that is what I am but it’s how I feel about myself, that I am no longer that gentle person that I used to be.

Q Yeah. In all of the caring that you are doing you are having to be patient and kind, and that’s where if you think of you, like your pool of patience and kindness, you are giving that to your daughter. And the people who are saying ‘we’re going to take your continuing healthcare away’, I’m not sure that they’re entitled to take from that pool.

A No they’re not, no. But I do worry that it seeps out of that circle into the wider world you know. I don’t think the reality is that it does, but it’s an overarching concern of mine.

Q Yeah I have been known to do that. I just can’t. I can’t be doing with it. I was visiting a friend who has retired to Portugal and met some ex pat. And I was talking about my children and I said ‘oh my son has a learning disability’. He went ‘oh I’m sorry’. And I said ‘oh don’t be sorry, he is fantastic. We’re sorry about the shit services, don’t be sorry about him’. So I just thought I’m not here for this. I’m not here for your pity. I’m really not here for this and I’m not going to be nice about it. And he looked at me as if I was some kind of crazy woman. And yeah I think I’m just not….no.

A I find myself saying that a lot ‘don’t pity me, I’m absolutely fine and my daughter has a lovely life’. But yeah.

Q If you want to help me you could do something about the services, you could get on board with campaigning, you could offer some practical support maybe ??? But you know what’s pity doing? I don’t need that.

A Nothing. It’s demeaning.

Q It really, really is. It really is. And you’ve talked about your daughters and I find that really moving because I have a daughter and our daughter says the same as your daughters, you know. And I think that I’m very proud of her for that but I’m also very sad.

A Yes, yeah I agree. I mean it’s wonderful and it’s a privilege. Because I’m also involved in sort of a parliamentary committee with John McDonnell who is trying to persuade the current Labour government – God help us – to adopt a manifesto for unpaid carers. And so many of those people are single parents and they are some of them older than me. And they are terrified as to what’s going to happen to their….

Q Is that the All Parliamentary Group for Carers?

A It’s not the All Parliamentary, it’s the….we haven’t actually got a title yet, it’s the Labour Unpaid Carers….something about a manifesto. We’re deciding on the title in the next couple of weeks.

Q Would you keep me in touch about that because I’d love to talk to them about what we are finding out.

Time 24:55

A They would probably be very glad to hear from you. I know that they are….ooh I’m trying to remember the lady’s name, [name]?

Q Oh yeah, she’s on Twitter I think.

A Yeah, she’s coming to talk to us in about 2 weeks time, they’re going to try to nail down an appointment. I mean I could put you in touch with John McDonnell’s secretary if you….

Q Yes please, yes please. One of the things that’s come up that’s very practical is somebody said that their sister is caring, does an overnight for their daughter and she is able to claim carers’ allowance. But once she turns 60 she won’t be able to.

A That’s correct, yeah.

Q And I think ‘what?’ I mean that sounds like a really practical thing that we could….I mean if we could change that….

A It would be huge, absolutely huge. Because you know I’m a bit more radical, I’m currently about to set on a lawsuit which also incorporates arguing for parents, or carers, unpaid carers, to be paid at the market rate equal to the skill that they’re replacing.

Q Absolutely.

A So we are doing nursing level care. In fact we have certain clinical skills that the district nurses and the hospital home team aren’t trained for, there isn’t anybody but us that can do these things. And like I said, I have given up my career to ???

Q And your pension.

A Yeah and my pension. And I will lose carer’s allowance the minute…well in 2 years time. But my work won’t reduce, in fact it could increase because it’s very difficult to keep a full time nursing team going.

Q You know the thing about doing research projects is that we find out all this stuff and then, you know what are we going to change? And finding something that I think that…surely….who….well I know that….and then this Government wouldn’t care about that.

A No.

Q But I think saying to John McDonnell ‘here is something that you could do’ you know. I’m sure it’s even not that expensive.

A I don’t think it would be. And I don’t think he’s not in favour of it because it has been an issue that’s been brought up within the group probably I think because of the age group ???

Q But to get it in their manifesto would be….

A Yes, if they could. Of course John McDonnell is a very different kettle of fish to Starmer and the rest of them, so I don’t know how successful he is going to be. But definitely that’s the sort of thing we are pushing for. And also like NHS recognition, why can’t we get the same sorts of NHS discounts you know. And if we were key workers in lockdown why are we not considered key workers now? Why don’t we have the same ??? And why is not health and safety applied to us, you know all of that.

Q And the other thing people have suggested is carers’ health checks.

A Yeah.

Q So why do our children get them but we don’t?

A Yes.

Q So I think we need to be really strategic and think how can we…. I mean when people talk, obviously they talk about the system as a nightmare and of course we want to change the system. But I think we just need to find a few things that are very specific that we could get somebody to cost out for us and have a campaign around.

A Yes I think that’s an excellent idea. If you start with the smaller things it still will have a big impact.

Q Because I think there is a big frustration, certainly on my Twitter feed around people saying ‘make time for a cup of tea’, you know ‘time for a ???’ or you know the whole of like the carer’s badge and all of that kind of stuff. And I think no, no, no, it’s a bit like ‘no I haven’t got time for that’.

A And why are carers always represented as handing somebody a cup of tea and holding their hand, you know you never show them giving enemas or anything.

Q That’s a really good idea, that’s a really good idea. We have another part of the project which you can take part in, I’ll have to sort of roll back and explain this little bit. So we thought, and lots of us who are academics on the project we are carers too and we talked to other carers and we thought this is a good idea, we are going to get carers together and we will re-design, you know these questionnaires about being a carer, we’ll get the carers to write the questionnaire about being a carer. So we got them all together and they said ‘tick box, do you think a tick box is going to capture my mental health – jog on’. We’re like oh no. ‘And in fact filling in that form would do my mental health in’. Oh, OK we’ve got this wrong. And what they want is an online exhibition, which will be images and sounds and music and artwork and stuff. And it would be fantastic wouldn’t it?

A Yes.

Time 30:30

Q If you are doing those bits of caring.

A Yes, yeah. Because I mean to me it suggests that the Government wants the public to think of these carers as only doing these very menial unskilled tasks, because then we don’t have to consider the reality of their lives and just what value they are to society, how many of them there are. And what the harsh reality of their lives are, the skills that they have. I think it’s a deliberate tactic and I think a lot of the charities are in cahoots with the Government on that because they very much depend on certain amounts of their funding coming from that, you know it’s all very ???

Q There needs to be….I think that’s true for learning disabilities charities as well, that they need to sever their….I think SCOPE did that, so they stopped providing services, I think that they….or it’s very separate. And you see SCOPE being quite, they go for it quite a lot now. But you know MENCAP are providing services, MacIntyre are providing services, yeah so they are going to be commissioned aren’t they?

A Yeah.

Q Yes, that’s so interesting. So thank you so much for that and I’d like to stay in touch with you about that if that’s OK.

A Yeah very much so.

Q It would be fantastic if we could get something going.

A Something going. I’m all for that, very much so.

Q And all of us who are part of the project, we are all up for that. We have another project actually which some of us in this project are involved in where we are really going to spend some time looking at how to influence policy and to think about what it is that we need to be doing, so I’m going to take this back to that group as well. That’s extremely helpful.

A Oh good, I’m glad.

Q Oh gosh, everything you’ve said has been….you know it’s really resonated with me actually, but so powerful. And I think what you were saying as well about communication with your daughter and I think….my son speaks but that same thing about you need to learn, you need to watch him, you need to know the face changes and all of those things. And you are asking his support workers to do that on minimum wage. You know you’re asking people to do this really complicated job and keep them safe and….it’s scary.

A It’s really scary particularly in….you know I have no doubt that there are some wonderful paid carers out there but a lot of the ones that I also see are very poorly trained, not necessarily empathetic. It’s terrifying. I am lucky in that we do have nurses. But you know I rejected 14 nurses last year. I’d rather do the work myself if I didn’t feel that they were competent or interested enough. It’s terrifying what you are expected to accept. There’s a lot of pressure from the ICB for agencies to sort of foist anybody on you and it doesn’t matter how poor the training is. And you can’t relax when that’s the case, you know you’re on tenterhooks what’s going to happen.

Q And that’s then no break at all if you are….

A Yeah, or we don’t get respite. You know because we used to go to….we’re in [town], we used to go to [respite care]. And they eventually had to….they lied to us, they said that she could get one-to-one care. And eventually she was coming home sick or they’d be calling me out at 3 o’clock in the morning. And I did a spot check, they hadn’t fed or given her anything to drink for more than 24 hours, and hadn’t told me despite the fact that they had to tell me everything. And I took her out and said I’m not bringing her back. And they said ‘well to be honest we can’t cope with her, we don’t give one-to-one care’. So for very complex patients you often don’t get respite. And it would be actually too much of a stress to take respite because you don’t know what’s going on, the support just isn’t there.

Time 35:00

Q Just going back to mental health, has anyone ever offered you support for that?

A No. One of my daughters has a long history of depression and just watching her get nothing, you know go to GPs. Her son is autistic, one of my grandchildren, and you know the CAMHS system, what that’s done to her mental health. And there is nothing there. So I kind of feel well would I just be raising my stress levels, bashing my head against….

Q Another fight.

A Yes, to get nothing really. And my daughter has had you know quite serious suicidal thoughts but it still did nothing to get help. She’s had sessions on a talk like that sort of thing and that’s about it. You know you don’t really understand….I don’t know what the qualifications of the people are but they seem to be more sort of just sympathetic and nice people but not really offering anything tangible.

Q Yeah. I think the people we’ve spoken to, either they’ve been offered medication straightaway or they’ve been offered CBT, Cognitive Behavioural Therapy, which as people just keep saying ‘I can’t reframe caring 24 hours, that’s not going to help me, how do you reframe that’. Or ‘I was asked to put things on the worry tree’. Yeah, great, that will do the trick, thanks for that.

A It doesn’t appeal at all. If I actually thought it was going to do some help I might go seeking at some point but I have my meditation.

Q Yes that’s interesting, almost knowing that it’s rubbish and that it’s going to be a fight to get it is a barrier to going to get it.

A Very much so. If you haven’t got the time or the energy why are you going to take another thing.

Q If you are struggling with your mental health why would you take on another struggle that’s going to ??? you much.

A Yeah.

Q Yeah that’s important too. So I think Martina explained to you that there’s going to be a bit of the research around digital story making. And how did you feel about that? I think some of the people have been like ‘argh oh no’

A I did feel that, ‘oh my God what does that mean’ and do I have to come up with the theme or….

Q You do but not on your own. So I can talk about this with confidence because I’ve done it. And I went to a workshop where I was part of another project – I was a participant in that project – and I am not particularly good at that kind of thing in terms of the actual making the film. I didn’t actually have an idea. Some people arrived and they had like a script and I was like ‘oh God’. Some people were like ‘ah, this is the story I want to tell and this is how I want to tell it, I want these things and these things….’ And I was like....a bit…. And I think most people we have spoken to have not said that, they’ve been much more like ‘well I’m interested but I don’t really know how’. So you’re helped to think about what the story might be. And if you think about the story that you’ve told me today if you like there might be a bit of that story that you think ‘oh I could expand that story’. I spoke to somebody and I felt that they would almost like to make an information film, you know where they just told you this, this, this, this, do you know what I mean? I could imagine that person just speaking to camera because they’ve been a carer for a really long time and they had all of this knowledge and I just thought ‘well maybe you’ll do that’. And other people, I was talking to somebody about…and I feel this too, that idea that mental health is like you are holding books and that they put a book on and then they put another book on and another book on, and then someone takes one off, someone puts one back on until the point where you can’t hold them any more. And I think that would make a really lovely image wouldn’t it?

A Yes it would, that’s exactly….

Q And I was really trying to think about what the titles of the books would be.

A Oh yes.

Time 39:30

Q Lying Bastard Professionals! You know, Judicial Review. So in conversation there will be ways of thinking about how to tell a story. So we always planned to do this bit of it but it goes back to what people have said about the tick box thing not capturing the complexity. And I think that one of the things that makes it….so we are doing this dance between I need to simplify the message so that I can tell John McDonnell ‘do this’ but at the same time I want to say to John McDonnell, ‘watch this film and how are you going to feel when you’ve watched that film’ because you’ll get a load more from watching that film than you would if we’re writing you like a policy brief. So we are trying to do both approaches. And the films that Patty who is based in Canada has made – did Martina send you a link to them?

A Yes I did look at….yes, yeah.

Q And there are some films that I’ve seen numerous times and I can’t watch without crying, there’s something about them that get you. And I think they are super powerful. And I use them a lot in my teaching actually and I think that’s really good for the Psychology students. And I teach on a teacher training course so I like to show them that and watch their mouths open a little bit, you know when they are watching it. And I think more than anything of all the things that I do probably that will stay with me. So that’s what we are hoping to do. And I don’t know what your availability is but we’ve got these four sessions in October but you don’t need to be at all of them, it would be lovely if you could make the first one because I think that’s when you would meet other people. But we’ll have somebody based in the UK who can help in between times and we’ll have people based in Canada who can help in between times as well. And at the end of it you, with their help, will have a story. And then at the end of it as well you can decide ‘do I want to share my story, do I not want to share my story’. If it involves other people we might have to get their permission to release the story. But you could decide that you were just going to make it entirely anonymous and no-one would be identified in it, you know. So we are very, very mindful of those sorts of questions and we’ll be talking to you about that as well.

A Thank you.

Q So we will be in touch about that. I’m going through my list of questions and I think that we have touched on a lot of them, especially in terms of those sort of very, very ‘we could do these things’, which is great. Is there anything that….you know when you knew you were going to be talking to me did you think there were any particular areas that I’d ask you about, or particular areas that you wanted to talk about?

A No I didn’t have any kind of preconceived ideas. I thought that you might ask me whether I’d tried to access any mental health help but that’s as far as I got really. I was just very keen to participate and explore what you were doing and see if I could contribute really.

Q Well I think you’ve already…I feel like….my mind’s buzzing now, I think it’s been fantastic to talk to you. And what you’ve said resonates with what other people have said and with my own experience but I think you’ve also brought things in to say ‘but you could do this’ and that’s been really, really helpful.

A Oh good, I’m glad. Well we all have our stories don’t we, but there is always a commonality of experience with unpaid carers but each of us has a different situation too.

Q Yeah I think that’s also really, really important that people don’t come with a one size fits all approach. And people understand their mental health really differently, you know some people have talked about always having a mental health struggle; some people feel that their mental health has been really challenged by their caring roles you know. So I think people need to understand that as well and that the perception – I’m sure that chap in Portugal thought ‘poor you’ because your child is causing you distress, I think that’s what the general public think.

A Yes it is. One point that I always make is that really we live with life and death here almost every day, we know that anything could happen tomorrow, and that’s always been the way for the last 30 years. And yes that brings its stresses but you come to an acceptance of that. And I wouldn’t say there’s no stress involved but that’s not the stress that I go to bed dreaming of or thinking of or the stuff that keeps me awake, it’s the machinations of the ICB that really bother me and you know who is going to encroach on our lives in a sort of bureaucratic sense. They’re the big enemies and fears for me, they’re the people that cause me stress.

Q Yeah. And I think it’s that thing of there are some things that you can’t change but there are some things that could be different. It’s the sort of manmade, human made system isn’t it that could be different, and that’s why it’s so infuriating. There are things about William that can’t be different and I don’t think I’ll ever want them to be different, but there are lots of things about the system I would like to be different.

A Yes, yes. I often wonder whether they psychologically profile the people they employ because they do seem to have some brutes.

Q Well we use the phrase ‘emotional terrorists’, they should have that on the recruitment ‘are you capable of emotional terrorism?’ I think that’s a brilliant phrase. OK well thank you so much. Unless there is something else that you want to say I think that’s about it for now, but I really look forward to staying in touch and to getting John McDonnell to change….he probably won’t be able to but we could maybe have a go.

A Yeah definitely, I’ll get straight on to that and send you his secretary’s email Katherine.

Q Thank you so much, that’s fantastic. Thank you. OK we’ll be in touch.

A It was lovely meeting you.

Q Thanks again, speak soon. Bye.