Q Rewind that, let’s get to the…..so what made you….rewind….what made you interested in taking….you’re obviously very busy, what made you interested in taking part in the Spinning Plates project?

A So yes. I worked at a primary school for 15 years and I retired on ill health last year, and part of my role was a one-to-one support worker. So I worked with children who bang to a different drum. My daughter is now 24 and she has autism and a mild learning disability. I knew there was a problem when she was about 8 months old but the school were like ‘oh no she’s willful, she’s disobedient because she was bored’. And nobody, even though I was working there nobody believed. I had so much trouble trying to convince people that she was neuro-divergent and they just…. But I’ve been in a caring role for so many years that I just thought this was something that I really wanted to get involved in.

Q And does your daughter still live at home or has she moved?

A No, no, she’s part-time with me and part-time with her dad. I live in sheltered housing now so she lives most of the time predominantly with her dad because we’ve got a rescue cat, and the rescue cat lives with her dad, and he’s very much loved and part of the family, so yes.

Q So where she wants to be is guided by the cat is it?

A Oh yes. I mean we’re really proud of her because primary school were very like ‘oh bless’ you know, she’s got a learning disability and she’s got autism, so they didn’t believe in her so to speak. A lot of children, that’s how they viewed them. And of course I was on the other end altogether, and I was like two steps forward and one step back is still a step forward in my book so I was always encouraging all these children as well as my daughter that they’re not able to do it yet, the power of ‘yet’ is very, very powerful, you can’t do it today but tomorrow we’ll have another go and you might be able to do it. So I’m a very positive person, I like to be positive with the people that I work with. Now what was I saying about the school? Oh yes, but she got to O Levels, kerching.

Time 4:44

Q Kerching!

A And she went to college and she’s been on loads of internships, so I’m really, really proud of her, while she decided what she wanted to do. And now she’s got a volunteering job at the RSPCA. So her job now – and you’re going to be very jealous here [interviewer name], right – her job now is playing with kittens and cats from 1 o’clock to 5 o’clock every Thursday afternoon.

Q Kittens and cats. Does she do anything with dogs or is it just cats with her?

A No she did go round and look at the dogs. I went with her when she went for like an informal interview and she looked at the dogs. I mean some of the back stories are absolutely horrendous as you can imagine. And we saw the rabbits, they found 25 rabbits all stacked up in cages. Anyway they managed to save a lot of the rabbits. And then we saw the dogs, who were absolutely terrified, and so what they encouraged visitors and me and [daugther’s name] my daughter to do is to always give the dogs a biscuit because then they know humans can be good, we’re not all bad. And some of them were like tail between their legs, they were really nervous and very, very scared. But I think it’s really helping [daughter’s name] because she’s able to….because she’s always been a caring personality, even though she’s got autism she’s very, very caring and very loving, and she loves this job. And they want her to do another day so I’m hoping this might actually lead to a paid job eventually, which would be fab.

Q Oh that really is good isn’t it, that’s amazing. So what does she do with the cats then because I can’t imagine, she just strokes them does she?

A Well some of them have been….their back stories aren’t very good so some of them just stay really scared and up on one of the top levels and that, and she’ll just sit there with some cat treats and that and she’ll just be talking really calmly and quietly. And she gains their trust and she’s really….and they’ve given her this really positive feedback and said she’s a real natural, do you know what I mean, how she interacts and everything. And to be honest, animals are a lot more interactable than humans sometimes aren’t they?

Q Yeah. That’s such a positive story because….yeah it just isn’t it, to find, if that’s her strengths and she’s just got that ability to communicate and reassure animals that have been traumatized, that’s just great she’s doing that.

A It is.

Q So that’s cool. So you wanted to take part in this study because of your daughter basically and your experiences.

A Yes.

Q OK, that’s cool. So you’ve said you’re a glass half-full sort of person.

A Absolutely.

Q And you used that optimism and sort of positiveness from the moment you realised that your daughter may have some sort of difference than expected.

A No it was before that. Because I was brought up in care. I was abandoned at 8 months old and put into a children’s home. And I’ve always found….I suppose I’m a very positive person and whatever life throws at you I think there’s always somebody worse off, and that’s what keeps me positive. And I was fostered from the age of 2 to 10 by this couple, they’re both deceased now. And I know that my adopted mum never loved me. And she died just before Christmas and all these Pandora’s box I suppose, it all came to the surface then, because I was always made, growing up to believe ‘you’re not good enough, you’re not pretty enough, you’re not clever enough’ and all that. But as I’ve got older I’ve just decided that, you know I’m not defined by other people’s values and beliefs, I am my own person. And it’s taken a while to get to this point. So I’ve always been a very determined kind of person I guess.

Q So do you think having that background has sort of helped, or has made your experience as a parent easier?

A Yes, I do. I married my first husband when I was 21 and we had our son [son’s name], he’s 40 now. And I had a problem pregnancy, I had preeclampsia so he was….and back in the 80s of course it wasn’t like it is now so he nearly died and I nearly died and all that. And then [first husband’s name] his dad and I, he was bipolar, and because I was such a positive chirpy person – I’m telling me all my life story now, you don’t mind do you?

Q Not at all.

Time 10:00

A Because I’m such a positive person I just thought oh he gets moody or depressed, or he gets fed up sometimes, and I didn’t actually realise how serious it was. But to fast forward he took his own life at 49. And [son’s] my son was only 22 at that point and he had to cut his dad down from a hook.

Q Oh that’s horrible isn’t it.

A So that was really hard. And the hard fact was, I was working in a private nursery at that point and I used to look after a little girl with spina bifida. And we’d got all the team in, it was a really big meeting, we’d got the social workers, we’d got the MSK? team, we’d got the Speech and Language, we’d got a great big meeting about her progression from nursery to school, and so obviously I was not contactable because I’d got my phone off and blah, blah, blah. And [son] had tried ringing me and ringing me and ringing me and ringing me, and of course I didn’t answer, because he’d found his dad. And that’s always made me feel really guilty, do you know what I mean, that I wasn’t…. And I see signs of the bipolar in [son] which does alarm me sometimes.

Q Yeah.

A And my middle son – oh and then [first husband’s name] because they kept changing his medication, because I don’t know if you know much about bipolar but he was on Lithium, which is like a controlled drug for his chemical imbalance in his brain, and because they kept having to monitor it and change his dosage and everything he became violent. But it wasn’t his personality, it was just how it made him. And [son] was only little and I thought I don’t want [son] to think that it’s OK to hurt somebody if you’re ill or whatever, because it’s never OK. So we went to the doctor, he went to the psychiatrist, we went to RELATE as it was, marriage guidance RELATE, and because I believed in my vows I didn’t want to give up on him but it was just so, so hard. I couldn’t talk to my mother because she wasn’t bothered. I’d nobody to turn to. And because his mum and dad were so wonderful and lovely I thought I can’t go up to them and say ‘your son is hurting me’ because I had such a good relationship with them. So sadly we parted ways eventually but we still remained friends.

But then I met [new partner] and we had [second son] my second son, and I had gestation diabetes with him so I was on insulin three times a day, so again not a very good pregnancy as such. But then as soon as he was born my pancreas started working again but I was still glucose intolerant, so now I’m on Metformin twice a day because I’m still diabetic but I’m not on insulin, which is really good. He passed away from meningitis when he was 22 months and 3 days old, so that was another awful thing. And my adopted mother never really bothered about him when he was alive so she never bothered about him when he wasn’t here. So I’d got all that to deal with as well.

And then [daughter’s name] is an IVF baby because I was sterilized when I had Amil so then I realised I couldn’t have any more children. I didn’t want to go down the foster and adoptive route because it was so shit for me with mine. And we thought about sponsoring a child in a third world country, but then I thought you’d never get to see that child or you’d never know where your money went and blah, blah, blah. So the doctor said the only option open to you in IVF he said, but because of your health and because you’re nearly 40 he says it’s going to cost you money and I can only give you 7% success rate. And it was like ‘wow, what do I do with that’. Because I was sterilized at the same time as the section they couldn’t reverse my tubes or anything.

So to cut a long story short [daughter’s name] is a miracle baby. They put three eggs back and they knew I was pregnant straightaway. So there you go. So she’s got autism and a learning disability but she’s an absolute treasure, she’s so bright and funny and intelligent and happy – and a blessing. So you see now my cup is always half-full because whatever comes out of tragedy there’s always a blessing.

Q Good for you.

A Sorry, you weren’t expecting that were you?

Q I wasn’t expecting that, no. It’s always good to hear the unexpected as well, I like that.

A And that’s why I’m a writer, because I find it easier than talking to humans when I was in care and I wrote it down how I felt. And then always throughout my life, through the sad times, through the horrendous times, through the good times, I write it down. And that’s what I do, I’m a writer, a published writer as well.

Time 15:00

Q That’s brilliant. So is there a story about being a carer that stands out for you in relation to your mental health, or not?

A Yes, I think because when [daughter’s name] was born, because I knew that she had autism and I knew because of all the training I’d done and everything throughout my education, time as an educator, and nobody believed me, nobody…there was one teacher I think at the school who was on my wavelength so to speak. And she spent most of Year 2 on a naughty chair, which is absolutely horrendous. And she wasn’t invited to parties. She wasn’t….because she was fixated on meerkats. I don’t know if you ever watch Meerkat Manor, about all….do you remember that?

Q I really don’t. I mean I’ve heard of meerkats on the adverts.

A Oh no, no, no, there was a series called Meerkat Manor that Bill Nighy the actor used to narrate and it was absolutely fabulous. So it was all about the matriarchs and all that, and you got to know all the characters and all the personalities of the characters. Well [daughter’s name] used to love this and she used to watch it all the time. She had books with them in. And she used to go to school and on her break time she’d say ‘oh do you want to have a read about what Flower did’ or ‘what Shakespeare did’, he was one of the meerkats, and blah, blah, blah. ‘No, no we don’t’. And I used to stand in the playground, because as I say if I was on duty or whatever, and I had to wear the teacher hat not the mother hat, and watching her. But she wasn’t bothered because it was like ‘oh well I’ll just ask somebody else’. So that was hard. And I think from a mental health point of view I was angry because I thought ‘why have I been given such a hard life and I’m still….’

And yet my sisters, I had two siblings who were adopted as well but we’re all from different parents so we’re not related, none of us are related, they came at 6 weeks old. So I’d gone to school, come home, I’d got a sister. Went to work, came home, I’d got a sister. So none of us are related but we’re all brought up as sisters. They’d had absolutely charmed lives, they’d had no problems with their pregnancies, they’ve had lovely lives, they’ve met wonderful people, they’ve never suffered anything at all. And I just think ‘and I’ve had everything’ everything. And then I think ‘but I’m happy’. And I’ve got a really good circle of friends and I’ve got wonderful children, it’s just….but I think it makes you more resilient.

So it has affected my mental health because of the unfairness of it all. And because in my adopted mother’s will she left a bank account and the house to ;either of my two daughters, Heather and Elaine’ and I wasn’t even classed as her daughter. Little things like that, do you know what I mean, and I was the eldest daughter. But when my dad left when I was 17 I was the one – I never saw him again, and I was really close to my dad so that was another horrendous loss – I was the one who had to pick up the pieces, get my sisters up for school, get them up, get them dressed, take them out, come home, do the dishes, go to work blah, blah, blah. She forgot all that, that I’d done all that for her.

And then when [daughter’s name] was born I think she came to the hospital once ‘she’s got disabilities’. So in her house she had one picture of….no sorry she had two pictures of Timothy my eldest, she had one picture of [second son] – because he’s dead – she had one picture of [daughter’s name] because she’s got disability. And yet the rest of her house and the walls were covered with my sisters and my sisters’ children. So yeah it was hard.

Q Have you spoken to your sisters about this, or not?

A Oh well they didn’t tell me my mother had been in hospital, they didn’t tell me that she’d died, it was an email I got from my niece saying ‘I regret to inform you that [mother’s name] has passed away. Her funeral is on Wednesday at half past 10’. And that was it. So I wasn’t involved in the funeral or the songs or the service, the order of service, I wasn’t involved in any of it, they didn’t involve me at all. And it was like meeting two strangers at the funeral, it was horrendous, it was awful. And the coffin was all chipped, so it was obviously like a reconditioned model or whatever. And it was one of these cheap funerals where after the service she goes into another hearse and gets driven away on her own, so we’re not even invited to the cemetery…not the cemetery the cremation, the Crematorium, so I don’t even know where she is. And they’ve blocked me completely on everything now so I’ve no idea how to get in touch with them. So I don’t know where she is to be honest – no.

Time 20:30

Q Oh golly that is tough isn’t it? So going back to when you said about your mental health and you felt it was really unfair, so it was just sort of like your life was unfair, or was it unfair about how [daughter’s name] was being treated, or….

A All of it.

Q All of it, yeah.

A All of it, all of it.

Q And did you sort of like try and get any help from the doctors or anything like that?

A I did. Because I think what it was is, because my health has deteriorated – apart from the osteoarthritis which you obviously know about now – I’ve got a heart condition; I’ve got pernicious anemia, I’ve got….I don’t absorb iron, I’ve got low Vitamin D, low Vitamin C so I’m on medication for that. I’ve got high blood pressure and high cholesterol so I’m on medication for that. I’ve got Dupuytren’s in my hands which means that, I don’t know if you can see there, eventually my hands will close up like this and I won’t be able to open them. And you can have an operation but in 90% of the cases it comes back, so I’m not going to bother, I’m just doing my exercises on my hands and hoping that…..but it means that I’m really weak, so I can’t open cans, I can’t chop vegetables properly. I’ve got all these adaptations where I have to use this thing for ring pulls, and if you get a tin without a ring pull I’ve got to ask somebody else to open it. Oh! But my cup’s always half full and I think there’s somebody always worse off. So my mobility’s not good, my hands aren’t good, my health’s not good. Oh and I’m diabetic, did I mention that, oh yes I did. Yeah, so…..

Q So in terms of your mental health, so did you speak to the GP about that?

A I did and they put me through for some counselling, which was….oh she was really, really good. It was on Zoom because it was at the tail end of COVID. And that was another big issue for me. Because I’m clinically vulnerable when I went into work, when I worked in COVID, we had small classrooms, it was the children who were vulnerable children and it was the children of key workers. So we only had children of about 10 in a class which was absolutely fabulous because you were still doing your work but you could do more fun activities. And everybody had masks on, everybody was washing their hands and being safe and everything.

And then all of a sudden everybody was told ‘oh it’s alright now you don’t need to wear masks, you don’t need to do anything’ and everybody came back into school, all the children, so we’d got 30 odd kids in a class. The parents were handed masks by the staff – didn’t want to wear them. I was still wearing a mask because I’m vulnerable. And it was like you went to staff meetings and you were told ‘what are you wearing a mask for, you don’t need to wear a mask we are having a staff meeting’. ‘Well yeah but look at all the staff in here, I think I am’. And I was ??? to the fact where I was the only person wearing a mask. And then I found it so difficult sitting on a chair for long periods with my knees; I couldn’t hand out loads of books because of my hands because I kept dropping them, which is really embarrassing. And so then it was just really, really hard and school were not supportive whatsoever, and that was difficult.

And so there was all sorts of accumulation of everything and I knew I couldn’t carry on doing the job I was doing. So I went to the doctors and told them and they gave me a sick note. And then occupational health were involved. And that was just an absolute nightmare. And then all the demons from the past came back, like horrendous things that had happened to me when I was growing up. And I thought they had all been put away, but then Pandora’s Box like I said, was opened up and released all these demons. So there’s all that ‘blurgh…’ just came out.

Time 24:50

So I had this counselling which was really, really good but it was only for 10 weeks. So when it got to the ninth week she said to me ‘you do realise that next week is our last week’, and that was the week I’d got told that my mother’s funeral was going to be on the following week. And I said to her ‘I don’t know how I’m going to cope next week because it’s the funeral and I’m going to meet my sisters and I haven’t seen them for years’ and blah, blah, blah. ‘No but we can’t extend this service any more, we’re only 10 weeks. And next week I’ll see you on the Monday, the funeral is on the Wednesday’. And I was absolutely terrified and I thought what am I going to do, because it was like a safety net for me because I was able to just talk to somebody. And she really got me – do you know what I mean? She wasn’t like ‘oh I’ve got somebody else to see after you so you’ll have to hurry up’, and she really listened and she took time. I don’t know, I think for the first time I felt that I was being listened to, in all my years I was listened to, and that was priceless. And then she’d gone and it was like I didn’t have….I thought I can’t go back to my doctors and say ‘well that was really good but can I have some more please’ because, do you know what I mean? So I was just left high and dry really, so I just had to cope with it myself, all of it.

Q So has the doctor offered you ever like medication for your mental health or anything like that?

A Yeah he did do, and then that made me feel like a zombie, so that didn’t work. And then I got these….because I couldn’t sleep because of all these…. absolutely terrible, like you were saying about mental health, it’s not been a thing that I’ve ever, I’ve always managed to like, I think especially….with the experience of [first husband name] as well I always saw it as a negative, mental health is like ‘oh it’s something really frightening and whatever’. But the voices were just on me all the time. It was like ‘oh well how come you weren’t lovable, your dad wouldn’t have left when you were 17 if you were lovable. Your mother would have loved you if you were lovable, you’re obviously not. Your husband would have coped with life if you’d been more supportive, and obviously you weren’t. Your child wouldn’t have died if you’d have done this. Your daughter wouldn’t have had autism if you’d done this’. And it was horrendous, it was just constant, constant, constant all the time. And so I thought if I get these sleeping tablets I might be able to sleep.

Well then I got these sleeping tablets and then it said because….oh and I’ve got bloody cataracts and stuff as well with my eyes, and it said you can’t take this medication if you have this pressure in your eyes. So then I had to go back and say I can’t take this medication. And then….oh it was just….it’s been absolutely awful, it’s been terrible. But I’m in control now, and I’m in control, and I’m OK.

Q So you are in control without….you didn’t end up with medication at work?

A No.

Q Right, OK. So do you think, like because you were saying about the unfairness. I’m trying to understand like…so our project’s about the mental health of family carers when their daughter or son is growing into adulthood. I mean you’ve just dealt with massive stuff outside of that.

A I have, yeah.

Q So would you describe your mental health – I don’t know what you want to call them, challenges – as an outcome relating to like your family background?

A Definitely.

Q So it’s not about being a carer as such?

A I think I’ve been a carer from day one really, from my dad leaving when I was 17 and looking after my sisters, looking after my mother. And then when [first son] was born, because he was premature I was looking after him. And then [first husband name] being bipolar I was looking after him. So I think my role, I’ve always had to be strong, I’ve always had to be the one who…and I think you just wear that hat all the time. ‘I can deal with it, I’ve got broad shoulders, I’ll do it’. And I think it is a role that you take on, not necessarily you ask for it but I just think it’s a role that you take on. And I do believe that saying where it says ‘you’re never given more than you can deal with’, I have struggled with that sometimes I have to be honest. But I think on the whole I just get on with it.

Q So that saying, I’m just scribbling it down, ‘you never give them more than they can deal with’, is that right?

A Yeah, carers are never given more than they can deal with, they just get on with it.

Q Where did you hear that from?

A I don’t know, I just….I think it’s true isn’t it?

Time 30:00

Q Well I think it probably is. It shouldn’t be.

A No. It’s like….I don’t know, I don’t see it as a negative at all, I just see it as hard. And sometimes you think ‘tomorrow – oh’ you know. But I just think…I don’t even see it as a challenge now, I just see it as a way of life. And now when I talk to [daughter’s name] about the next stage in her life, about….because some of her friends, some of her peers have now moved into assisted living – and we’ve had this conversation with her and it’s like ‘yeah I need to be independent, I do yeah, yeah that’s what I need to do, I need to get my own place’. And then another time she’ll say ‘I love you and dad so much and I don’t know, and I want to stay with you as long as possible because you’re getting old’. It’s like, do you know what I mean, that is a really double edged sword. And if we have another conversation with her another day she’ll say ‘you just want to get rid of me don’t you, that’s what you want, you just want me out of your house’, ‘no it’s not that darling but we just….’ Because we are giving her all these skills to be independent, and she is very, very good, she’s an excellent reader. But even now at 24 sometimes she’s running with an idea and I have to stay ‘stop, look at this face, look at my face, is this face a happy face? [daughter’s name] look at my face’, and she has to stop and think. So she’s like a runaway train.

But because she’s really good at telling the time. She’s not good at money at all but she’ll count the change out now. Like if we send her to the shop, you know a coffee shop and we’ll say ‘you go to the counter and get two cappuccinos and whatever’ and we’ll give her a £10 note – we obviously don’t go to Costa. And we’ll give her a £10 note and she’ll go. And we say ‘get a receipt’. And she’ll get the receipt and she’ll come back. And I’ll say ‘right [daughter’s name], how much change have we got?’ ‘Well dad’s coffee was so and so, so and so; your coffee was so and so, so and so; so you’ve got £2.60 back’. ‘That’s right [daughter’s name]’. ‘So we’ve got £2.60 back, so is that right?’ ‘Yes that’s right’.

So we’re getting her to do it bit by bit so she’s going to be independent. She can cook if it’s written down for her, if she’s got that, because she’s confident. But microwave meals and stuff there’s no problem, but we don’t use a lot of microwave meals, we try to encourage her to cook in the oven so she can put her eggs on. But her attention span is like a gnat. If somebody rings her and she’ll be ‘oh hello [name], yeah’, and her eggs are on for 3 minutes. ‘Yeah, yeah hang on, I’ll go in the other room where we can talk’. She’s forgotten her eggs, she’s forgotten her eggs, and then all of a sudden ‘[daughter’s name], check your eggs’. ‘Oh yeah, yeah, yeah’ straight in, pan’s nearly burnt to death – do you know what I mean? So it’s things like that, it’s like reassuring her all the time and, you know giving her little tasks to do.

Q Has there been a change because you’ve retired now, is there a change in your relationship with her or the time you spend with her, or is it just the same?

A No it’s lovely, because she’s finished college now as well. So it’s like when she was at college and I was at school it was like marrying up our days off or when she wasn’t at college and I wasn’t at work – because I was only working part-time towards the end. So that was really nice. And now that I’m not working at all, she meets her friends – because she can travel independently so she’ll go up to [place name] to meet her friends or she’ll go into town to meet them. She’s got her own money, she’s got her own card now, so we put her £50 on every month out of her account goes on her card. So when she meets her friends she’ll get a toastie and a coffee and a cake or whatever. And she’s independent, she’ll go out of here, get the bus, meet her friends, come back. So that’s really good.

I’ll sometimes say to her ‘[daughter’s name] I’ve got a course this morning do you want to meet me at 1 o’clock’, ‘oh yes mum I’ll meet you in town’. Or if I’m here and she’s still in bed I’ll say ‘right [daughter’s name] I’m getting the 10 o’clock bus, are you up yet?’ ‘Yeah I’m up’. ‘Right, come on then’. So her days are more structured now because I’m off. Then her dad’s obviously 74 so he’s retired obviously and she’ll go and meet him in town, or if she’s staying here at her dad’s then they’ll go to town and meet me or whatever.

Time 35:00

Q And what do you think needs to change for carers to feel well supported, family carers?

A I suppose I’m very lucky because I’m part of the Disability Partnership Board and [city] Carers and I’ve got…. And because of my role when I worked in education I used to help support parents who had got a new diagnosis with their children, and I used to work very closely with the parents of the children that I worked one-to-one with. So for example a little girl that I looked after had spina bifida so I used to change her catheter twice a day and I got really involved with the family. And I used to do bank nursing back in a previous life as well. And so I got really involved with the family so I could signpost them. So I said ‘don’t worry you’re not on your own, I know of an organisation that can help you, I know a telephone number you can support’. So because I’ve always been able to do that I’m quite good at getting support for other people, but asking for myself is not always easy. I’m the one that people come to, but when it comes to me asking for support and help I don’t find that easy.

Q So you went to the GP and told the GP. Have you spoken to anyone else about needing support or wanting support?

A Yeah well right at the beginning of my realising that I wasn’t able to work any more at school, which was going to be really hard because I love my job, I went to see the doctor. Now that was really hard going and asking for help because I’ve never done it. And he suggested….what’s that online one that you do? You know that other support. Oh I’ve forgotten what it’s called. They do it in America a lot.

Q Oh I don’t know, what like a support group?

A Yeah. Oh I’ve forgotten what it’s called, yeah. There was an online one. Oh I can’t flipping remember it now. Hang on a minute I’ve got it on here, I am with you, just two seconds and I’ll find out what it’s called. It will drive me mad now.

Q It’s driving me mad actually, I’m really interested.

A CBT.

Q Ah, OK.

A Cognitive Behavioural Therapy. That’s right. You’ve heard of it now haven’t you?

Q Yeah, yeah. So was that in relation to you stopping work, or life….

A That was in relation to anxiety. Because they put on my sick note ‘COVID related anxiety, COVID and work related anxiety’ because I didn’t tell him about all the stress that I was going through about the past, which I thought was dead and gone, I didn’t tell him about that because I thought he’s going to think I’m all sorts of things. So I just said I’m really anxious at work, which I was, and so that’s what he put on my sick note ‘COVID and anxiety related, COVID and work related anxiety’ sorry. And he suggested that I do CBT. So he gave me this number, I rung them up, and it was the worst thing I’d ever done. I did a 12 week online course. I’ve nothing against Americans before we start, I’ve been to America it’s a lovely country blah, blah, blah.

But the lady who did it online was, if you can imagine the worst kind of American that you could ever come across (*in American accent*) ‘oh my God, well today we’re going to talk about anxiety because I know it affects all of you. Well today we’re going to talk about how else we can do it. So I’m going to put a series of questions up on here and you’ve got to tell me about this scenario on this video. And you’ll see this man [name] right, well he’s got this real problem’ oh, it was absolutely phew, phew. So you got this video of this guy called [name] right, and he’d got anxiety about work because his colleague had got this pay rise – this is the example – his colleague had got a pay rise but he hadn’t. And he was so frightened of his boss because his boss was a tyrant that he daren’t go in and see his boss and ask about the disparity ‘why haven’t I got a pay rise because X has got it’ blah, blah, blah. ‘So what you got to do now, right, you’ve got to look for this situation and you’ve got to think (a) should [name] do this, should [name] do that’. So you’d got all these scenarios what you should do, what [name] should do. And then you clicked on what you thought [name] should do, right. And then she’d say ‘ah, now you see that’s not what your fellow people would do. What I’ve got is that they’d do this’.

So you felt wrong, even though she kept saying there’s no wrong answers ‘there’s no wrong answers here, but it’s interesting that you’ve chosen that because of that. Everybody else has chosen….’ blah, blah, blah. So you felt wrong. So I came out of that thinking I’m hopeless, I don’t even know what to do. It was the worst thing I’ve ever done. If it had been somebody like, I don’t know, with a really nice voice – like Liam Neeson, or David Attenborough or somebody, anybody.

Time 40:30

Q Liam Neeson or who?

A Or David Attenborough even, or somebody with a really nice, calm voice I would have coped better. But every week I got more anxiety because I thought I’m going to get it wrong. You know and it was just….and it was always about these four people, it was their problems. And these are obviously actors so it wasn’t even like ‘poor Mrs [name] on flat 3’ it wasn’t, they were all actors. So every week it was the same four actors with a different scenario that you had to choose. And 9 times out of 10 I was wrong, I have to tell you that. And that did me no good at all. It was horrendous. So that’s why I went back and did the ordinary counselling route. It was so much better. I mean how would you have coped with something like that?

Q No I couldn’t do it. But why did you, when you said you didn’t tell the doctor about the other stuff, the Pandora’s Box because he’s going to think x, y or z, or she’s going to think that, what was your concern about not saying anything – about saying something sorry, not about not saying anything?

A I think it’s because I imagine that they’d say well how have you managed to get to 64 and not actually unload all this and compartmentalize it all and cope with it and stuff. I never took anything, I never…. I don’t know whether it’s a sign of weakness, I’m not….I don’t know. And I think because I’ve always thought of myself as strong and reliant and dependable and, you know as a friend, as the colleague, as a wife, as a mother, I’ve always….I don’t want to say that I’m bossy, I don’t mean that, but what I mean is, I’ll cope with it. Whatever it is, yeah I’ll cope with it, I’ll cope with it. And then I think I was scared of actually seeing the doctor and be saying ‘I’m really scared that sometimes I can’t cope with it’. Do you see what I mean? Because I didn’t want to….you know.

Q Is it that you didn’t want to get to a stage where you suddenly thought ‘I can’t cope with it’.

A Yeah.

Q Right OK.

A And I thought if you….it’s like when you’ve got a pressure cooker and you open it a little bit to let the steam out, right, it’s not quite done so you just let a little bit of the steam out, that’s what I imagined that Pandora’s Box of my life is going to be like. And I thought if I turn the key a little bit that’s OK, I can let a little bit out. But what is that key gets turned all the way and it’s like ‘whooosh’, what’s going to happen. And so I’ve kept the lid on it, I’ve kept it locked, do you know what I mean? And so, I don’t know. And like I’ve said you never give them more than they can deal with, so somebody somewhere must have thought ‘[name] can cope with this’, if [name]’s coped with that she can cope with this, she’s coped with that, she can cope with this. She’s coped with a shit life with her parents and abuse and God knows what else. She’s survived her husband dying, killing himself. She’s survived her son dying. She’s survived her daughter having autism and a learning disability. She’s survived having to leave her work which she loved because of her health. She’s survived it all, she’s alright, she can do it. She’s got all the skills, she’s got the toolbox to do it. Yeah I have. But you think if we’re supposed to have an equal measure of karma, where’s mine? Where’s mine? Do you know what I mean?

Q Your time. ‘Yet’. It’s the ‘yet’ isn’t it you mentioned.

A They power of yet. And I think for carers it’s the power of yet as well. Yes.

Q OK I’ve just got to keep an eye on my questions. So you haven’t really answered, you sort of answered obviously because you’ve given me a really good answer, but there’s nothing you think that needs to change for carers to be well supported because you’ve been motoring through it really yourself and managing?

Time 45:13

A Yeah. Like when we have a meeting for the Good Life Leaders or the Learning Disability Board or whatever, I’m the first who goes in ‘how is everybody’, gives everybody a hug, makes everybody a cup of tea. And very, very rarely it has to be said does anybody say to me ‘how have you been [name]’, because they know that I’ll be fine. Do you know what I mean? And so I’m not going to disillusion people by going in and saying ‘hi everyone, I’ve had a really tough week this week’ because I’m not sure how they’d take that. And so maybe a little bit of me is scared to do that, to actually admit. And I mean some weeks are really hard, and especially when the weather’s like this, that affects my joints more and I’m in pain more and, you know. But I don’t ever….you’ll never, ever hear me moan about it because I just think ‘oh my hands stiffen up when it’s bad’. And I shake, so if I’m having a cup of coffee I’m like this some days. But do you know what I mean I never mention it, I never say anything, I just….do you know what I mean, I’m just so used to coping and being there for everybody else. I’m making my doctor’s life easier by not putting all this on to him I suppose.

Q Yeah but then it is their job isn’t it?

A That’s if you can get in to see them.

Q Well yeah that’s true. Is there anything like…when you said people come to you, you know you support people, is there anything you direct people to that’s mental health related in terms of…obviously the CBT is not a goer.

A Oh no I never actually suggest CBT believe it or not, no I don’t. No I will say mind mates is really good because I used to support people in the early days when they had issues with depression or anxiety and stuff, and I’ve got a lot of friends who’d suffered that from years ago and stuff and I used to find out and I used to say ‘oh yeah you need to ring this number, they sound really good’ and whatever. It’s like when I was working with the health visitors when I was pregnant with [middle son] my middle son. Part of my role as a health visitor assistant was ringing [Name] Children’s Hospice and saying ‘I have a family here who have got a seriously ill child, have you got room for the family to come’, or ‘I’ve got a family here whose child has sadly passed away, are they able to come’ and I used to book them in and do all that.

Then when Amil died the health visitors who I worked with had to do that for me. And they rung [hospice] up for me and Amil went there. I’m still doing fundraising for them. So through the sales of my book, my latest book which is poems that I’ve written for children over 50 years, illustrated by the children at school – so there’s ballerinas with moustaches and spiders with 5,000 legs and everything, I’ve raised over £1,000 for [hospice] through the sales and donations for my book. So even though he died in 1998, because they were invisible arms who held us when we faced the worst thing a parent can feel when you lose your child, I will never stop being grateful to them. And so I’ve done fundraising over the years for them all the time.

Oh by the way my mother never went to [hospice] to see him. When he was ill in hospital, the first time he had meningitis, that’s how he died. My last job when I was working with the health visitors was doing a big meningitis awareness campaign, giving all these cards out to parents and families, and my son died from it. So how can that be right? We had the pneumococcal, there was no rash, there was nothing, and yeah. So when he was in hospital with meningitis I’d asked my mum to come, and she came and she said ‘but I’m not going in’. I said it’s barrier nursing, you’ll have everything. She said no, she said I’m not risking passing it on to my niece – because my sister had had a baby at the same time ‘I’m not risking passing anything on, I’m not going in’. So she never saw him. She never touched him. She never had anything to do with him. No. So when he went to [hospice] she’d never go there either, ‘I’m not coming, I’m busy, I’m shopping’. And my sisters wouldn’t come ‘oh no they’re going out, they’re doing this’. No. So they weren’t there for me. Nobody was there for me.

Time 50:30

Q What about [daughter’s name]’s dad?

A He’s like my best friend, absolutely. I was friends with [first husband name] as well when we got divorced. He got married again after me and we remained friends right until he died, we were still friends.

Q So do you talk to…is it [daughetr’s dad] is it, her dad?

A Yeah.

Q So do you talk to him about any of this?

A Yeah some of it, some of it. I have best friends who know all my….who know about my demons, you know the kind of friends who you know you can ring at 2 o’clock in the morning and say ‘oh I can’t sleep’ blah, blah, blah. And they’ve stayed with me. They’re like my soul sisters. I know that sounds really weird but they are, they’re just….I know I can ring them any time any….and there’s three of them, the only three people who I know that I could call night or day and they’d be there for me. They know all my darkest secrets and demons.

Q Oh that’s good. So you’d count them as your support really.

A Yes.

Q And have you known them for a long time?

A Over 40 years.

Q Quite a long time! Well that’s good to know.

A And they can’t fall out with me because I know too much about them as well!

Q So that’s sort of all the questions I’ve got, apart from is there anything that we haven’t talked about in terms of mental health and caring that you wanted to add?

A I think mental health, it’s really, really hard for carers because I think a lot of them are in the same mindset as me is, ‘oh I just have to get on with it because, you know, that’s what I do’. And they don’t realise that sometimes you’ve got to stop spinning the plates, you can’t do it all the time, you can’t. You can’t put this hat on, take that off, put that hat one, take that off put that on. Because that’s what I feel I was doing at school all the time, taking that off and…. And I’m a volunteer, I’m a Trustee of 3 charities, I’m a Director of a charity. And so sometimes it’s just like a whirlwind of, do you know what I mean, doing stuff and supporting people and going here there and everywhere and whatever. And sometimes it is really hard to say ‘actually can I have some time out for me’, do you know what I mean?

Q Yeah. So I mean in some respects then has it helped you, retiring, because although you didn’t want to leave the school it’s taken one thing away hasn’t it?

A Yeah it has. Because they weren’t supportive at all. And that really hurt me because I thought I have given you 15 years of my life. Like for example the Year 6’s, when they were doing the big SATS, the Big Write, they’d be doing like about I don’t know the Fire of London or the War, or Anderson Shelters and stuff like that. And so they’d say to me ‘oh [name] our Year 6’s are doing…’ blah, blah, blah, and I’d say ‘oh yeah no problem’. So I’d go into their classroom and I’d do a narrative verse for example about whatever topic it was to help them with their Big Write. So that when they did the Big Write it wasn’t somebody stood at the front of a class saying ‘The Great Fire of London was in 1666, it started in Pudding Lane….’ do you know what I mean? Or it wasn’t about ‘oh the Germans invaded and then they captured all the Jews’ and blah, blah, blah. I made it come alive for them.

So for example, can I give you an example? They were doing about the First World War and they were doing about Hitler, and they had to write a letter as if they were a soldier on the front line, writing a letter home to the wife or the family or whatever so that they could try and get into what it must have been like in the trenches and stuff like that. And then they were doing about concentration camps and stuff. So I went into the classroom and I said ‘right guys, you’ve got to imagine now that you’re an 8 year old boy and you’re living in Poland and your life is you’ve got school and you’ve got parks, just like you have here in Leeds’. I said ‘just think that you are living over there, life is going on as normal’ right.

Time 55:21

“I remember the days of the tanks and the guns when the uniform men came to town,

We were children of Israel, hard working Jews and they turned out whole world upside down. Well they entered our shops and they took what they liked, they were loud and sadistic and cruel,

Judan forebode? and they screamed in our ears, ‘no more shops, no more trams, no more school.

I remember the days when the bricklayers came and they built a huge wall across town,

A ghetto for vermin that’s what they said and they started to shut our world down.

They read out our names from a list that they had and they rounded us up in the square,

We didn’t have time to pack everything up, but the uniformed men didn’t care.

Joseph Branislav a neighbour of ours was quite elderly, slow on his feet,

He couldn’t keep up as they herded us on and they shot him out there on the street.

Well they herded us through those ghetto gates, nine of us in one place,

And they rationed us with food and drink, no privacy, no space.

To us it was simply survival and we sneaked through a hole in the wall,

We begged for bread and we stole the fruit, hunger made thieves of us all.”

So the children when they did the Big Write, they knew how it felt. So that’s the kind of thing I did. And so when I had my leaving do, which only half the staff bothered to turn up, the Headteacher didn’t for example blah, blah, blah, they said ‘oh we’re so grateful for everything you’ve done Mrs Ugati, you’ve looked after all the children with disabilities and you’ve always helped our Year 6 children when they’ve been doing their Big Writes with your narrative verse. And when teachers have left you’ve always done a verse for them – I used to do that as well. And we’re really going to miss you. And that was it.

Q Oh dear.

A Yes. So I believe in giving something back.

Q Mmm, you do. Is there anything else you want to say? The dog’s just answered that!

A I think that’s carers. Hiya darling. I think that’s carers. We just need to know that there’s somebody who is willing to listen, do you know what I mean, and that we don’t have to have broad shoulders all the time. I’m the biggest culprit of this, do you know what I mean? And sometimes you don’t want to cope with everything but it would be nice if, you know yeah. And I think mental health goes hand in hand with caring because you just sometimes get overwhelmed with people asking for support. And sometimes you just don’t always have the answers. But then you always say ‘I’ll find out, I’m not sure but I’ll find out’. So then it’s more pressure on you because then you’ve said you’re going to find out, because then you’ve got to find out.

Q Well yeah.

A Do you see what I mean?

Q Yeah. Oh dear. OK well I think that was absolutely brilliant [name] and thank you for sharing.

A Oh thank you, I know you weren’t expecting all that [interviewer name], but thank you very much for putting up with it.

Q Not at all and I thoroughly appreciate you sharing it all with us, it was absolutely brilliant and really powerful. And you’ve said a lot of things that we will be thinking about in the analysis and stuff. So [name]’s going to get in touch with you about various bits and pieces and some admin bits, and also we’re doing some digital story telling workshops which she will share the details of. It’s quite interesting because some of the workshops have started and it’s around sort of family carers, well not writing a story, telling a story, but then it’s made into a film. We’ve got some professional film makers based in Canada working on it. You’ve actually sort of said, you’ve told so many stories today you seem to already have stories, but if you want to take part in that then [name] will be asking you about that as well.

A Yeah definitely, yeah.

Q OK.

A Because you’ve got to give something back, and if whatever you say, if they just take a nugget of that it’s got to be worth it hasn’t it?

Time 1:00:04

Q Oh I so agree, yeah I completely agree. Well it’s lovely to meet you.

A Oh just changing the subject very slightly, I’m an environmentalist as well and just before COVID, right, I was asked to perform on the stage in [city] in front of hundreds of people about the environment. And on the back of that I wrote to David Attenborough to tell him what I was doing and I got a handwritten letter back.

Q Oh wow.

A From Sir David. ‘Dear [name] U, I want to thank you for everything you do for the environment and everything’. So that is up on my wall. So how wonderful is that.

Q Oh that is amazing, yeah good for you, and good for him.

A I just wanted to share that as well. But how lovely that he didn’t pass it on to a secretary.

Q Yeah absolutely.

A What a wonderful man he is. If I could choose what to do I would love to meet him and…I mean he’s 95 now, I would love to like shake his hand. Because my foster dad who I got on really well with, he loved David Attenborough, so that was one of the most pleasurable parts of my childhood, that we could sit there and watch it together, David Attenborough.

Q That’s a lovely story. Well I hope you get to meet him, because there is always that ‘yet’, you haven’t met him ‘yet’.

A No but I will I’m sure.

Q Well thank you very much and we will be in touch.

A Oh it’s a pleasure. It’s been lovely chatting to you [name]

Q Oh good, I’m glad.

A Yes, thank you.

Q So yeah.

A So I’ll hear back from Martina.

Q Yeah definitely, in the next day or so.

A That’s good. Hope I haven’t bored you too much, but thank you very much.

Q Not at all, don’t be silly. See you.

A OK thank you, bye.