Q We are recording now. OK?

A Lovely.

Q So I’m going to ask you some questions but it’s not like a formal police interview! There are no right or wrong answers so I’m not going to be checking with other people, it’s not like Line of Duty style. So I have got some questions that I’ve got on my list but usually what happens is I just go with what people…you know kind of go with the flow. So I’ve just got a question to kick us off with really to ask why did you want to take part in the study?

A If I’m honest I’m hoping it makes a difference for people in the future, that’s my only real reason for it, yeah.

Q And so do you want to tell me about your experience as a carer?

A Well I suppose a little bit about my son [son], he’s 21 now. He has severe cerebral palsy, spastic quadriplegia, vision impaired, scoliosis. So he’s 24/7 care, hoisted from A to B. He’s not in and out of hospital as much as he used to, touch wood, thank you that will stay that way. But it’s constant, it is a constant from A to B, from C to D, the hoisting, the constantly looking after him. [son] is also verbal, he does have developmental delay so I would say it’s more like having a toddler around the house. And he’s very specific in everything. He likes a routine, he likes it to be the exact way every day and he can get quite cross from time to time if the routine comes out of kind of sync and everything. So it’s not just the physical side of [con], the looking after him physically, he also pushes you slightly mentally as well with his constant need for you to constantly be there helping him, doing things. Even just chatting, he’s very repetitive bless him and you can keep telling him but he needs to continuously ask and check and make sure everything’s going to happen that should be happening. So yeah he can be draining both physically and mentally.

But he’s also, and we say this because we are parents and we feel obviously we’ve just said something bad about our child so we feel the need we have to now say something nice, but he genuinely is also a pleasure to have around, he is funny and you know he does make us laugh. And when he’s in his good moods he’s absolutely brilliant to have around, and sometimes when he’s not here you almost kind of find yourself twiddling your fingers thinking ‘oh well what do I do now, I haven’t got [son] around to do the things that I’m so used to being having done every day’. But yeah that’s kind of the main jist I would say of mine and [son]’s little life going on.

Q Yeah. And what sort of support do you have around you?

A He goes to day services 5 days a week, which is brilliant. He’s being swapped over to one day service, every day the same one because we’ve realised that there’s one that’s able to cope better with his physical needs so he’s going to be doing 5 days a week there. He also gets 60 nights a year in respite, so that’s scattered throughout the months over the year. And carers, I have carers in the morning on a Monday to Friday and at teatime on a Monday to Friday as well.

Q So weekends are all you?

A Yeah, that’s more the choice of the household. Because [son] can get up at different times, so if he was to get up really early and I had the carers booked in for 8, I would do it anyway, I would get his pad changed, get him dressed and get him up because he wouldn’t want to stay in bed waiting for the carers. But I also couldn’t have the carers too early over the weekend because my partner likes to have his lie-ins over the weekend, so he would be a little irate if the carers come in and woke him up over his weekends.

Q Yeah. So you’ve just gone sort of through transition, so I’m wondering…

A Yes.

Q You’re sort of going ‘oh we’ve got this day centre’ and I’m thinking ‘hmm’. How easy was it to get all of that on board?

Time 04:42

A Transition was horrible, I hated transition. He was supposed to….it was all last minute. We hadn’t been given a social worker, an adult social worker until the last minute so we were thrown an adult social worker. He was supposed to go to a college that I was told would be able to cope with his needs but it turns out last minute they weren’t, they were going to just leave him behind in classrooms 95% of the time whilst the rest of the classes went out. So last minute I had to try and find him somewhere else to go. His social worker wasn’t that great, so obviously he left child respite and we didn’t have any adult respite. All of his medical side of things as well, no-one told you that you’ve got to self-refer them once you’ve left child. I just assumed he would be handed a new speech and language therapist, a new physio, a new OT, and then I was told ‘no, you have to contact your GP’. So it’s taken a long time to contact the GP to try and get hold of people into his life that he should have. Luckily we’re good, we’ve got a good OT and a postural specialist now and so they’ve been really good and made sure he’s set up properly in his day services that he goes to now.

But yeah the transition, nobody knew….and the strange thing is, I worked at the school that [son] went to, so I worked in a special needs school with all these people and I suppose I just assumed that when [son] swapped over to adults it would run smoothly. Because most of his childhood had run quite smoothly for me, I knew what I was doing, I understood what I was doing and I knew who I needed to speak to. But then you leave school and then it’s almost like ‘thank you very much, off you go, try and figure it all out yourself’. And that was quite tough. And if I’m honest it made me feel a little differently about the school because they should have been more supportive, they should have known when I asked them questions for example which day service should he go to on his day off of college, and they were like ‘oh there’s loads in the area, there’s loads for [son]’ that’s not true, there was only two that could cope with all of [son]’s needs.

So again I was left to be the one to go around and look at all these day services, try to figure out which one worked best. And it took up a lot of my time and most of them I needn’t have even bothered looking into because if I’d have known the full ins and outs of it I would have known not to have even gone and looked around these day service. So I felt a little let down should I say, I felt a little let down by the school, which actually I had formed this little family relationship with as well. So it felt quite…I felt quite sad about that if I’m honest because he’d spent his whole life in that area. I’d spent most of my life with them. I assumed that they were there to not just help you go through school but to help you transition through to this world of adulthood. But they weren’t.

So yeah when [son] went over the adult services and left school it was very difficult and I actually had one of my worst mental health breakdowns I’ve ever had once he had gone into the whole transition into adulthood because I just couldn’t cope. I couldn’t cope with the fact that he was missing out of stuff. I was home with him more, I had to give up my job. So yeah it took its toll on me quite a lot when he swapped over. It’s calming down now and starting to sort itself out a bit now, but yeah it’s taken a long time to get us to this slightly better routine that we can be a bit more relaxed with.

Q If you don’t want to answer of the questions it’s absolutely fine.

A Oh yeah no.

Q But you said that was one of your worst mental health ??? Do you mind talking about…it’s going to be a tough conversation but when that kind of started I guess. Was it something that you’d experienced before you had kids, or…

A I’ve always suffered from mental health from a young age. When I was a teenager I started with anorexia and self-harming, from I would say….from around the age of 13 it started, and I kind of kept a lot of that to myself. Eventually, if I’m honest I was getting to the stage where I’d almost had enough and I was going to just end it, and then I found out I was pregnant with [son]. And the one thing I’ve always loved is the idea of being a mum. I love working with children as well, children is my thing, I love children, they just help you feel young again and you get to have so much fun with them. So when I found out I was pregnant that was an instant ‘no, this is it now, this is this person that you are in charge of looking after’.

Time 10:10

[son] was born at 24 weeks, so he was very prem. Again, really tough, I was depressed but having [son] there helped me in some ways push the depression out and he was my main focus. And most of my life actually [son] has been my main focus that has helped kind of draw me back from hitting too low, because I can’t allow myself to get low because that will affect him and that’s not what can happen. So yeah my depression up and down my whole life. My partner when he moved in with my step-daughter my depression took a hit then. My step-daughter had a lot of behavioural issues and she caused a lot of stress around the house when she first moved in, so there was another moment there.

But yeah when [son] swapped over to adult it was the first time I wasn’t able to control it. Literally my other h[son] came in one day and he’s always known I’ve suffered from depression but I’ve always kept a lot of it to myself, I’ve not really opened up that much in the past to him. I do now, I’m more open and honest with him now. But he came home and I was just on the floor, I couldn’t get up, I was crying, I couldn’t do anything, I was just stuck there I didn’t know how to get back up. So I went for my counselling, started speaking to someone. I managed to bring myself out of it again.

I think I’ve reached a point now where, I suppose as life has gone on especially with [son] I’ve been desperate for help whether it be from a family member or a friend, I just wanted someone to understand and want to just jump in and help me. But no-one ever has. But I think I’ve realised now that I can’t keep thinking that someone will magically come along and make it all better for me, the only person that can kind of make this life better is me really, almost an acceptance of what it is but also what isn’t working and what can I do to try and change that and make it better. Because it’s still my life as well not just [son]’s and I need to live the rest of it as happily as I can, rather than if I look back over the past 40 years actually most of it has been this hidden lie of depression. So yeah, kind of like a little moment where I’ve realised ‘yeah, it’s me, I’m the only one that can change it, nobody else’.

Q So when you accessed counselling how easy was that, to get that?

A I self-referred to [mental health service]. So I self-referred to [mental health service], sometimes it’s quite difficult because they phone you up and offer you these appointments and I say ‘I can’t do those days and I can’t do those times’ so it makes it quite difficult when you’re only giving a small window for them to be able to see you. So I did have to wait a little bit longer than the average person probably would do.

Q Did they know you were a carer, did they know why you were turning the slots down?

A Yeah, yeah. And actually the very first time, before I had my breakdown I had tried to go to [mental health service] for counselling then but I found myself getting quite stressed out because they kept phoning me up with these times and I kept saying ‘I’ve already explained I can only do these times’. And someone said to me ‘look, if you keep turning them down Miss [name] then we may have to drop you from our list’ and I said ‘but I was told before that it would be found to work around what I can do, I can’t just drop what I’m doing and come to you guys, I have no-one else to look after [son]’. And because obviously they were weekly slots it needed to be a time that I knew I could definitely make each slot, yeah.

Q That seems really bad, they should have made an adjustment because you were a carer.

A You would think. But I’ve realised as life has gone on that nobody does. Nobody adjusts to fit around you, you have to adjust to fit around them or you just don’t have it. That’s how it kind of goes. Which is wrong, but that is how the world is these days.

Q Yeah. And again I don’t want to pry too far but what we’re interested in is what is helpful. So I wonder if there was anything that was specifically helpful about the counselling. Because some people have accessed counselling and they haven’t found it helpful, and so what was it about it that helped?

Time 15:19

A Like I say it helped me with the realization that I had got so stuck in my mind that there was almost going to be…whether it be Prince Charming or a Fairy Godmother that would come and help make this so much better for me. The realization that there isn’t such a thing as Prince Charming or Fairy Godmother, it needs to be down to me. It needs to be that I stop and think ‘what do I need to do to make this better for me and easier for me’. It made me realise that I shouldn’t feel so much guilt towards any of those negative feelings that I had towards my life with [son]. You feel so bad when you have a day that you go ‘oh my gosh you are driving me mad right now’ and you feel awful that you are thinking these things. But actually it’s OK, it’s OK to say ‘do you know what, he’s really, really bugged me today and I’ve just had enough of him’, you know you don’t have to be a bad person to have said that. So it’s helped me to process a lot of the guilt feelings that I have.

There are still other things that come up, for example I’m kind of looking into the consideration of assisted living for [son], but at the moment that is a guilt that I can’t kind of cope with. I’m trying to process that through my mind. But yeah that is a guilt that is, you know how am I supposed to make that decision to tell my son ‘right, thank you very much but now you have to go and live somewhere else’ you know. So yeah. But again I’m able to process it better, I’m not going off and self-harming myself due to the stress that I feel, the anxiety I feel. I’m able to process my feelings, rather than going off and just hurting myself, ignoring those feelings and then carrying on with the rest of my day.

Q Yeah. Is there anything else that you find useful or that you have….I mean one of the things we’ve been talking to people about is the things like, you know people want to go for a walk and they know that will help but they don’t always have time.

A You don’t, you don’t have time. My other half says to me sometimes ‘why don’t you go out with your friends’. Well one, I don’t have very many friends, they’re all quite busy with their lives. And actually when I do go out, like the other week I met up with some people that I worked with and we all went out for lunch, I have to make sure that [son]’s up and dressed and ready, he’s settled somewhere. Dan needs to know the routine, I need to let Dan know this and that. And then I have to make sure I’m home in time for pad changing. So sometimes the whole process of going out is so draining that sometimes it’s like…. Or, I go out and I’m having an amazing time but I’m like ‘oh sorry guys I’ve got to go because I’ve got to get back and deal with [son]’.

And even when [son]’s in respite I don’t plan things with friends or anyone because that’s when Dan and I want to make sure we do stuff with our younger son, because obviously he misses out on doing things that he wants to do. And sometimes if I’m honest I’d like to sit down and do nothing – that would make me feel good if I could just sit on the sofa. I can’t remember the last time I had a day where I just went ‘do you know what, I’m going to sit and watch a load of Harry Potter films, as many as I can’, you know. In some ways that would be something that would be nice, to be able to just sit and do nothing for a little while, yeah.

Q So it’s just that lack of enough support to give….I mean it’s not much to ask for is it, a day on the sofa watching Harry Potter.

A It would be nice, yeah.

Q Yeah, I completely understand that. So when you spoke about you hoped that you’d have support from maybe family members or stuff, and they never asked. Did you ever ask them?

Time 19:34

A Yes, yes. I would ask, and whenever you would ask my parents for example ‘can you watch [son] next Saturday so I can go out for lunch, dinner with the girls’, ‘oh well hang on we have to think about it’. My family are ‘hang on let me think about it’ and then eventually they don’t get back to you. So then I would message again, and then in a bit ‘oh yeah sorry we can’t’ you know. So there was never a wanting to kind of do it. My parents aren’t just like it with [son] though, they were like it with a lot of their grandchildren – apart from the first. The first one was the one, you know. In fact my dad actually said to me once ‘look we’ve already done the grandchild thing before [granddaughter], we don’t want to start doing it all over again. I said ‘well that was that grandchild, you now have different grandchildren and it’s not a case of you do it once with one and ignore the rest’ you know. But that was kind of how they went.

Q It kind of makes me feel better that they did it with all of them.

A Well yeah, so I can’t say it was just [son], they literally have kind of…yeah.

Q It’s funny isn’t it that ‘oh great they did it with all of them’. Yeah OK. So I guess if we’re thinking about things that you’d like to change there’ll be stuff around….is it, I don’t know, what is it that if you could make….I know that there is no Prince Charming and there is no magic wand, but if there were what would you like to happen?

A What would I like to happen? In some ways I wish that I had someone in my personal life that was there that I could turn around and say ‘I am absolutely shattered today, do you mind doing [son]’s bedtime routine for me today’, or ‘[son] has been talking so much today that he’s given me a bit of a brain ache, do you mind being the person that sits there with him for a couple of hours and just chats to him for a couple of hours’. It’s kind of, you know that thing that when it all gets too much that you can have someone that you can just say ‘please just take over, I need to go and have 5 or 10 minutes to myself’. That would be nice to have something like that. But then that’s a big ask in some ways I think, you’re either lucky and you have that person in your life or you don’t. And I can’t force the people around me to want to do these things with [son].

Q Do you think they understand what your life is like?

A I have made sure that they know recently, in fact I’ve stopped speaking to my mum and dad over the past year or so because I have explained to them that I didn’t feel like they were there enough. I felt as though they left me to kind of deal. I felt as though we were this fake family that on the outside everybody thought we were the most amazing family but actually on the inside none of us were ever there for anyone, we were never honest with each other. We never discussed feelings, and when someone does try to discuss their feelings it’s ‘oh no, hang on we don’t….hang on what are you talking about that for….hang on let’s move on’. And I’ve explained to them that actually I need to be erm….I’m in a place now where I need to be around people where I can just be more open and honest and they can be more accepting of that open and honestness rather than it being too fake. So they know, they know that I’ve felt that they weren’t there enough. I’ve explained to my brother and sister as well that I felt that they left [son] out a lot more than they should have done.

I remember…I think it was more so a few years back, [son] had cancer. So [son] was always in and out of hospital with his normal situations, no-one ever come to visit. OK that’s fine [son]’s in and out of hospital, that’s just what he did. When he had cancer, that’s not an [son] problem, that’s a whole new situation, that’s got nothing to do with his disabilities, that is ‘oh my gosh this person has got cancer’. I barely saw any of them. There was no cards of Get Well Soon, there was no ‘let’s come and visit him in hospital’. And then when he got out of hospital my niece ended up poorly with a suspected lump on her neck as well, which is how they found [son]’s cancer, so there was this fear for a little while that she may have had it too. But I remember going to visit her and her room was smothered in cards and presents. And I remember thinking [son] had none of that, none of that. And that was my realization that [son] and myself, we were just ‘oh yeah, oh my God I’ve got this amazing daughter with this really poorly disabled grandson’, and ‘oh let’s feel sorry for the grandparents that have this person’. But it was all fake, they weren’t genuinely there to help me, they weren’t genuinely thinking about how I was suffering. And when I did mention it they were like ‘oh don’t be silly [granddaughter] you know we worry about….’

Time 25:25

So yeah I’ve kind of…yeah, as the years have gone on I’ve realised that I need to kind of step away from the family a bit more. Which was a tough decision because they’re your family and I’ve actually always been very family orientated. I would have them round for dinners, games nights. I always had them round, everyone would come to mine and I would obviously be the entertainer, the moniker of the family and have everyone round all the time. And then [son] started getting bigger and I couldn’t get him in people’s houses, they’ve all get steps to go into their houses. And then you just stop seeing them, unless you invite them round. And then I would stop inviting them round and then I would never see them. So it was kind of like well I’ve realised now that I was the one putting in all the effort and I wasn’t getting enough back in return, so I stopped putting in the effort I suppose.

Q That sounds really hurtful.

A Oh gosh, yeah, yeah, especially when you assume that they would be there for you no matter what. But I suppose I’ve kind of realised now that in some ways family, you assume because it’s family you should always be there. And that’s what I said to myself, if a friend – and friends have done this in the past – have treated me this way, I have then said to them how I felt, it’s ended up with them not accepting what I’m saying and we’ve ended up separating from our lives. I’ve done the same with my family, they’ve not accepted what I’ve said and so therefore we’ve separated from each other’s lives. So I suppose I’ve treated them in the same way that I would treat anyone that is making me feel this way.

Q Can we talk a little bit about the future again, I know it’s a difficult one but about supported living. [son] is only 21 so you know he’s still quite young isn’t he?

A Yeah.

Q And I think that it’s maybe a process. But in long run is that something that you would really like to happen for him?

A I think I need it to for me. I think I’ve put my life on hold to look after [son] since the day he was born. I left college, I left the prospect of becoming a teacher, which is something that I always wanted to do, and I’m having to….I’m living my life for [son]. And I suppose, like I say I always hoped that someone would come along who would make this life a bit easier for me but that hasn’t happened. And I know that I can’t continue the rest of my life living just for [son], I want to be able to go out and have a job and a career. I love working and I love working at schools and I miss it, and actually it is something that keeps me stable. I currently do work as like a catering staff member in a junior school, so I work a couple of hours a day, I go in and serve lunches and stuff. But it’s horrible, I hate it, I don’t like it at all but it’s the only thing that would fit in with the hours that I had with [son]. But yeah I want to have a life before I no longer have a life, if that makes sense. And if [son] stays with me for ever I will never get my own life, it will always be his life and I’m just that person that is there for him. My whole life would be just him and it wouldn’t be anything for me.

Q Has anybody had any conversations with you about that, ??? the answer, but you know like the social worker ???

A I have….the social workers are, in my eyes the social workers are useless, they don’t know much at all. I have spoken to our local carers centre, they don’t know much. They’ve asked around, they sent me a couple of emails of people who said that they would be willing to talk about their process of having their child go into assisted living. I emailed all of these people and no-one has emailed back. Yeah there’s no support I suppose. But you have like a carers centre, our local carers centre, and again all their groups are 11 o’clock in the morning or, you know h[son] 2. Now people work I suppose so you can’t even go in and have a chat with any of these people at the carers centre.

Time 30:21

So yeah there’s never anyone to really talk to in that sense that would be able to say ‘do you know what, I know, I went through it, I understand it, this is what happened’. Because if I know a bit more about it it will help me to process it a bit more, it will help me to be more prepared when the decision is made for [son] to move out. But yeah they just…yeah there’s never anyone around to talk to. And this is something that I’ve always said is that there’s never enough around, especially for parents with a child with PMLD. Children with autism and ADHD there’s a lot going on for those families at the moment, there really is. But for parents with PMLD I feel that the PMLD world seems to have taken a step back for a little while and there’s not really much out there or any access really for people.

Q Do you know about an organisation called PMLD Link?

A Yes, yeah I get their newsletter, yeah.

Q I just was thinking. I don’t know them very well, I just know of their existence. So I wonder if there’s a way that you could contact, whether they would have anyone.

A Yeah that’s true, yeah I haven’t thought about that, but yeah I could send them an email and they may be able to point me in a direction of someone.

Q They might be able to link you up with somebody who has done it.

A That’s the thing is I want to speak to people that have actually done it, parents that actually understand. And what it is that made them decide to actually go ahead with it etc, the whole process. And whether their child is settled or not, because that’s the fear as well is he may move in somewhere and then what happens if it doesn’t work out. So I also want to speak to people where it hasn’t worked out, where they’ve put their child into a facility only to realise it’s not worked. Have they been able to get them out? Have they been able to move them or have they had to come back home with them? What happens if it doesn’t work? Because I don’t want him to go moving in somewhere and me absolutely hate it and know that they’re not looking after him, I couldn’t just leave him there, so what would happen then.

Q And so with the social worker, have you had any of these conversations with them? Because do they come? How often do they come?

A They don’t come out, they just wait for me to contact them. But she does turn up to his review at his day service. So every 6 months he has a review at his day service. And yeah I have spoken to her about this. She doesn’t know much about it either. Because I said to her ‘what’s in the area’ you know ‘what are these places like?’ And actually they say that you’re not even allowed to kind of go and have a look round any of these places unless you have your child on the list. So I think you should be allowed to be given the opportunity to go and see these places, what is it like. Because if there isn’t any assisted living in this area that I feel is sufficient for [son] I would know not to even bother starting the process. I don’t want to start a process of something only to go ‘no, no, no, no, no’, I’m not just wasting my time, I’m wasting everybody else’s time as well then aren’t I? And actually seeing these places, seeing one that may be the one that could be his forever home might actually help with the whole process of it. But yeah you’re not allowed to go and look round them, you’re not allowed to know anything about them. You just have to either make the decision to go for it or not, which I think is wrong as well because that’s not helping me to process ???

Q Sorry I just lost the end of that. Are you still there?

A Yeah I’m still here.

Q Oh you’re back. I just heard ‘are not able to process….’

A Yeah I just want to be able to process the possibility of where he could end up living. It helps me if I can kind of go through it in my mind, yeah, so it’s not so much of a massive change when it does happen or when I do start putting in the paperwork for it.

Time 35:00

Q Yeah. You know I think that they’re just, it’s like ‘there’s a space, do you want it’ isn’t it, not ‘is this the right space in the right place’ you know.

A Yeah and that seems to be how it will be. And that’s how I ended up getting the wrong college for him and ended up in this little running around tizzy all of a sudden trying to find him somewhere to go once he left school. Because I didn’t have the time to thoroughly look into it, to go in and to assess it and to understand whether it was or wasn’t something that would fit his needs, I just went by the word of people that work there. And that isn’t enough for parents, it’s not enough to just go in and have someone go ‘oh yes we’re amazing, we do this and we love doing that’. We all say those things but actually what they’re doing is they’re telling that one percent is amazing and they haven’t told you about the 99 percent that’s terrible, you know. So you need to go in, you need to see it for yourself, you really do.

Q Yeah. So the next stage of this is, so we’re interviewing people and then we want to work with people to make little digital films about their lives. And this sounds a bit scary but I promise you it’s not. And I’ve done this because I’m a carer as well, my son is 28 and I did it as part of another project that Patty who is doing this bit was running. And I didn’t have a clue when I arrived, I didn’t have a clue about what I was going to make a film about, what it was all….I just arrived. But some people arrived and they had like a story they wanted to tell and they’d written a script and I was like ‘oh my God’, and that was fine too but, you know that was not me, I was like ‘ooh I just don’t know’. So it’s a really hard question to answer and we’ll return to this when we actually start making the films but is there like one story or one message more than anything else? It’s a bit like you started with, you know why did you want to be involved with this ‘I don’t want anyone else to go through this’. So it’s like thinking about maybe that’s the hook, that is the message of the film. Do you know what I mean?

A Yeah.

Q So I think when we have the conversation at the beginning of the workshops and stuff we can all….if you can’t make a workshop that’s fine, we can do it at….because we will be flexible, unlike the counselling you can tell us the times that work for you and we can do things separately if that works better for you. So yes we’ll try and find something. And the reason why we do this is because the films can be really, really powerful because you can use images, you can use sounds, you can use music, you can use text, and you’ll get help to do that. Because the other thing is I don’t think I’m in that way a very creative person but in conversation with the facilitators who are like proper film makers and artists those things sort of start to come out. And the other thing I really liked about them was, I thought, because they are so brilliant and talented and have all of these amazing ideas, it would be really easy to go ‘why don’t you….’ and they never, ever do that. They just have a chat with you saying ‘well there is this and there’s this and there’s this’ you know ‘we can get images from here and we can do this with the music and we can use these sound effects’ and you get to choose how so it becomes yours. And then at the end of the….and the same with this interview as well, we’ll send you a transcript of the interview which I will anonymise, but you are absolutely….you can take stuff out, you can anonymise it further, you can decide ‘actually I know I said that but I don’t want anyone else to read that’, do you know what I mean?

A I don’t think I would though. I’ve reached a point now where I’m like if I say something and I read back on it and I go ‘ooh I can’t believe I said that’. But if I said it it’s true and actually people should hear it no matter how much it may be difficult for me to have said out loud sometimes people have got to hear the difficult, it’s the only way to ???, yeah.

Q I know that feeling

Time 40:00

A Yeah my other h[son] says that sometimes, he’s like ‘[name] I can’t believe you just told them that, you know you were so open and honest about some stuff that I didn’t think we should really be talking about to other people’. And I’m like I have to be open and honest otherwise no-one’s ever going to understand it or get it. Yeah it’s kind of….I also, like you say when you say almost like negative stuff about your child, you feel this instant guilt that you’ve just moaned about them and then you’re like ‘well actually no, because I moan about his little brother all the time and I don’t feel as guilty when I moan about his little brother’. It’s like as a parent I’m allowed to be honest and say ‘do you know what, it’s not all a bed of roses, no it’s not something that I had planned, and actually it is a lot tougher than we all pretend it is’.

Q Yeah. Well we have like a sort of system.

A Yeah, yeah and that’s true yeah.

Q And then that’s OK when we’ve kind of said it to each other and that makes us laugh and we’re all like ‘???’ I can’t believe ???

A And that’s the thing, is that for so long you almost feel bad if you turn around and say ‘oh my gosh they are really, really starting to grate on me right now, I seriously just want to shut the door on them so that I don’t have to hear them any longer’. And then you feel like people might go ‘oh that’s horrible, oh’. It’s not horrible, are you telling me you don’t want to walk out and leave your children sometimes? It’s the same feeling for us as anyone else.

Q Well I don’t know how many times….

A At the time it wasn’t.

Q Actually it was a bit funny because it sounded a bit like There Was an Old Woman Who Swallowed a Fly, do you know what I mean, the bat.

A Right, yeah, yeah.

Q Yeah, so I do believe it. Actually maybe we should have that as a film, like There Was A…de-de-de….

A Oh God yeah.

Q There was a social worker who ate the….I don’t know, the GP, I don’t know.

A Yeah!

Q It’s in the same sort of rhythm. But yeah. So if you can come to the workshops they start on the 7th of October and they are on Saturday afternoons for a month.

A Yeah I’m pretty sure, I’ve discussed with the other h[son], and he said….because they’re a couple of hours I think each aren’t they? So yeah the plan is like when I would normally go out with the girls. I will make sure [son] is settled, probably in front of the washing machine which is his favourite spot, and I have a wash load ready to go for him to sit and watch and everything, so the other h[son] will be able to keep an eye on him whilst I can do the Saturday ones. So that is the plan.

Q The other thing that we can do but everybody just goes ‘where am I going to get that person from’, we can pay somebody to do those 2 hours.

A Oh yeah, honest it’s not something that we would need. He’s not one to get hands-on in the sense that he’ll do his pad changing and dressing and stuff, but he knows if I’ve got him in front of the washing machine for a couple of hours he can keep an eye on him for me for that, yeah.

Q OK, so we’ll be doing that. And I think just trust in the…you know have a bit of faith in the way that Patty…she’s really experienced at doing it. So a lot of us on the team are university people, we’re also parents of disabled children so I think that means that, you know at least we know, sort of, we know something anyway, hopefully. So I guess the only other thing is, is there anything else that you wanted to ask me, anything else about the project or what we’re going to do with it I guess?

Time 45:00

A I suppose once it’s all kind of completed and stuff like that is it being used for…

Q Yes. So we really, really, really want to use it, you know that is why we are doing it. And we are conscious of the fact that it’s really difficult to make change but that doesn’t mean that we are going to not try. So we’re going to have these digital stories, we’ll have the interview data that people have given us. We’ll also have….we had a stage in the project where we were going to get carers to design a survey, and we got them together and they said ‘who wants another survey – that’s a waste of time’. We’re like ‘OK’. So we’re going to also have an online exhibition where people are going to be able to put images and stories and sounds, music or whatever on, and then we’ll use all of that to make some resources. And in the application we were a bit vague about who they were for, because we didn’t really know who they needed to be for because we didn’t know who people were accessing support from or who they wanted to access support from. And as we are talking to people I guess there were always going to be, the resources always have to be written for family carers themselves, that would be the first audience if you like. And we also think that we need to try and raise awareness amongst the general public and among wider families and all of that kind of stuff as well. So there’s that kind of audience.

And then in terms of professional audiences, the poor old social workers – well not really poor – they are ??? you know everybody is not….either they don’t know who their one is, they never see them, they’re not doing anything, so we need to do something for them. And kind of we’d like to have a conversation with them, if we could manage to in a kind way and say ‘look we have these stories, now can you tell us why you feel these stories are happening’ rather than just saying to them ‘you’re a load of old….’ you know. We need to do something with them. The other people that people talk about quite a lot is GPs, and we’ve had really mixed. So some people love their GP, and other people say ‘no they’ve been absolutely useless’.

A Yeah our GP is useless ??? Actually I’ve cried several times over having to speak to the GP, I hate it. If there’s something wrong with [son] I instantly feel the anxiety kick in because I know I’ve got to try and get hold of my GP. So yeah it’s not….

Q Also the loss of the pediatrician role, you know.

A Yeah that’s was so lovely, that’s what I said, it was so lovely. You would just speak to your pediatrician consultant and they would either know how to deal with it or they knew who to refer you to. Whereas with the GP they haven’t got a clue, they don’t know, you’re back and forth, you’re referred to this person that then says ‘no you’ve got to go to that person’ and it’s just all over the place. Even just calling up to ask for thrush cream when he gets thrush. Because I can buy it over the counter but he can’t have it at day services unless it’s prescribed and labelled, everything has to be prescribed and labelled. I can’t even get hold of them sometimes just to get him some thrush cream, which really bugs me because I can buy it for him but, you know then he can’t have it in respite or anything because everything has to be prescribed. So yeah GPs are a massive frustration.

Q We need to talk to GPs. I also think we need to try and do something about the access to psychological therapy. So I think what you were talking about is part of a wider thing called Instant Access to Psychological Therapy. So for example we need to tell them that if you’re a carer they need to make an adjustment. And also some people have not found them very helpful because they’ve been offered….

Time 49:50

A They don’t understand it, they don’t. I had a therapist a few years back when I was younger, [son] was about 4 at the time. And over the summer holidays obviously I had to go for these appointments so I had to get [son] round to my sister’s to be able to get to my appointment. And I was forever running late. I was forever…. I remember one time, he suffered from projectile vomiting so he would projectile vomit all over him and I’d have to stop the car, pull it over, change him, put him back in his car seat. I remember another time he decided to projectile poop as I was leaving the house. And she constantly ‘so why are you late again [granddaughter]?’ And I’d explain to her and she was like ‘well how are you supposed to resolve this constantly being late for everything [granddaughter]?’

And then summer holidays finished and I went for a doctor’s appointment, and no word of a lie the fire alarm went off, so I had to leave and wait for the fire engine to come. I had an appointment with her as well. I was so panicked I was taking pictures of the fire engine to prove to her. Because obviously she knew [son] was back at school so what would have been my excuse for being late again? In the end after that one I stopped going because I was so anxious about going and in such a panic to get [son] ready and round my sister’s quick enough to be able to get, so I stopped. That was my very first experience actually with therapy and it took me years before I decided to ever go back because she just made me feel like I was in trouble for being late all the time. And I was like you genuinely don’t understand, I can’t help it if he projectile vomits everywhere. And it would be on a regular basis, this boy would vomit constantly. You had a bag of spare clothes in the car because it was constant with him, you know. So yeah she got me in a bit of a panic and made me feel really anxious about going that I just couldn’t go any more. And it took me years before I plucked up the confidence to try and go back again.

Q Yeah. And I think people are also not very happy with like a one size fits all approach. So lots of people have been really critical of CBT, like ‘put it on a ???’

A Yeah. I don’t like it. I’ve done quite a few of those courses. And I was actually there with another lady who I recognised when I was there and obviously I started chatting. She was a head of another specialist school in the area and obviously she has a son as well that has disabilities, so she was there as well. And we both said we know the process of this CBT but it’s so hard to be able to stick to all of these exercises when it’s something like ‘go for a walk’. When I first went to the doctor about my self-harming, ‘well you need to distract yourself Miss [Name], if you feel yourself needing to self-harm go for a walk, read a book, do this, do that’. Right so I can’t do that. I can’t just pick up a book and read because [son] is still there. I can’t go for a walk because [son] is still there.

So yeah the whole….I mean I believe in the whole process of you know trying to calm the mind, breathe it, really try to count it down and see if you can calm yourself, but when you live in this life sometimes you don’t have the ability to be able to calm it down. You’re trying to breathe through it but then it just seems to be more and more and more, and before you know it that’s how it ends up with you exploding because the breathing isn’t enough. So you can’t just go for a walk and you can’t just walk away from the situation and come back once you’ve calmed down.

Q No. And it feels to me like actually people know what they need to do, they just aren’t able to do it.

A Yeah. And my other half doesn’t understand that either. Because he’s gone through therapy himself, he’s suffered from PTSD from his childhood and eventually he went to therapy and it has done wonders for him. He’s learnt to empathise with people, he didn’t have empathy at all for anyone, he didn’t understand emotions. He’s learnt emotions, he’s learnt ways of calming himself down rather than just reacting, and he has done brilliantly with it. And then when I have my bad days he’s like ‘well why don’t you do this’ and ‘why don’t you do that’. And he’s one of those as well, it’s like I have done that, I have done this, what it is is it’s just become too much, there’s so much. And sometimes no matter how much breathing I do or no matter how much music I try and listen to, it’s not enough, it’s just too much. So sometimes it almost is that you just want to maybe cry, and just shout out ‘argh….I hate this life’, you just want to shout it out. It doesn’t mean you actually really hate this life, it doesn’t mean you actually really want to do anything or you’re going to do anything, you just want to shout and scream.

Time 54:55

But in some ways I don’t think you can because then people think that you’re wrong for doing that, you’re wrong for shouting ‘oh my gosh I hate this’ or ‘oh my gosh I’m going crazy’ or just screaming and crying. You’ve almost got to be calm all the time or, you know ‘breathe your way through it [name]’, it’s like ‘well actually I wanted to just cry, scream, I wanted a hug and then I want to just move on from it’. Whereas if you react in that way sometimes the people around you see you react that way and then they want to over analyse it, and it’s like just don’t over analyse it, I was just having a scream from a mountain moment so I could let it out – and now I’ve breathed and now I can carry on. But yeah it’s a very different process and it’s very hard for people to understand that, you know not everything works for everyone, we’re not all the same.

And as much as we….like I did psychology at college, I’ve done a few courses throughout my life as well, because I love the idea of psychology. And that’s what I said to my other h[son], I said I do know, I said I do know but sometimes it just becomes too much and I just have to let myself break down. I have to. I have to just break down so that I can then get it out and then pick myself back up and then carry on, yeah.

Q And I think it’s important, you know really important for somebody who is supposed to be supporting you to understand that you’re not late because of some, I don’t know, counselling avoidance. That was not counselling avoidance, it’s not something you needed to get to the bottom of about why you were avoiding counselling, late because those things happened and ???

A Yeah, and that’s the thing, I think some people don’t….because they don’t understand it, they don’t live it, they don’t know it. Hence the reason people lose friends, because you keep cancelling on people because it’s either that your child’s not very well, or I’ve been honest in the past and gone ‘I’m sorry but I’m going to have to cancel, I’m just too tired, I’m so tired I don’t want to get dressed up, I don’t want to go out, I want to just get my jama’s on’. And there are some people that can’t understand that and they feel that you’re being rude and dismissive towards them. But what you are doing is, you’re just being honest and saying ‘I’m burnt out, I can’t make it’. So you lose a lot of people in your life because nobody can really fully understand.

And I think that’s the thing is, it’s quite lonely because in your life there is isn’t a single person that can fully 100% understand what it is you’re going through. Even with friends that have children roughly the same as your child, which I do have friends, in fact we’re out for dinner with the kids this Friday, so we meet up and go for dinner every couple of months. Again, their home life is different, their children’s needs are different. Some of them are able to wait there, some of them have partners that are full on, ‘yeah I’ll do it, I’ll do it, I’ll do it’. Some of them don’t. So some of them have families that help out. So even with the world of having a child with special needs or disabilities there’s still never that full 100% understanding because it is different for everybody.

But I suppose the one thing is we do understand is if someone turns around and says ‘I’m sorry I can’t come today’ it doesn’t mean that we can’t stay friends, it doesn’t mean that I’m being disrespectful to you, it just means that, as you understand, life has been difficult this week and I’m too tired to come out. And that is the one good thing about having friends with children with disabilities and special needs is they understand that when you say ‘I’m burnt out’ it is that you are generally just burnt out, you’re not being rude.

Q Yeah. And then there is one thing that I didn’t know and I just think it seemed so ridiculous. Do you know that you can’t claim carers allowance post 60?

A No.

Q Didn’t you?

A No I didn’t.

Q So I’ve got a colleague who does numbers, so he’s going to do a calculation to find out what it would cost if you paid people carers allowance, pittance as it is, til 67. Because that must be something historical about women retiring at 60 mustn’t it?

Time 59:55

A Yeah, yeah. And also no matter a person’s age, if you’re caring for someone you’ve got the right to get carers allowance. I mean carers allowance is a touchy subject anyway because you find it with if you work too many hours, or if you go over a certain amount of hours you lose your carer’s allowance but yet actually you are still doing the exact same amount of care. Like with [son], when he goes into his full-time day service I shall go back to full-time work, but my care for him is the same as what it is anyway, it’s getting up every morning with him; it’s putting him to bed every night; it’s giving him dinner; it’s looking after him over the weekends; it’s showering him; it’s shaving his hair; it’s getting up with him in the night and trying to re-sort him when he’s got himself into a bit of a painful situation in bed and stuff. So you know the amount of care I do with him, whether I work full-time or work part-time or don’t work at all, what I do with [son] will always remain the same.

So I don’t understand how…in fact you’re pushing people to not work with people with disabilities in some ways. You’re making it very difficult for them to work. And actually I know some people are OK with not working, and that’s fine. But there are other people that that’s almost like a lifeline to having some other kind of life. I like to go to work because that way I have some other form of life that’s for me and it’s not just [son], housework, shopping, cooking, you know which are all the things that I still do whether I’m working or not, but work gives you something for you, You get to go, you get to chat with your colleagues and have a laugh and it gives you the social life that you can’t have in other ways. I don’t get to go out and I don’t get to have friends and things like that, but when I work I create friends at work, I look forward to going to work and having adult conversation with people, you know. So in some ways work is my social life, so being forced sometimes to not be able to work can have an impact on a person’s mental health as well.

Q Yeah, that’s a really important point. Yeah so that’s what we’re going to…at the moment from what people have told us I think those are the things that we are going to try and focus on.

A Yeah.

Q So is there anything else that you wanted to ask?

A No. I just wanted to say that if there was ever anything that you guys felt that you were doing that I could be helpful with in the future, you have my email and obviously feel free to get in contact.

Q ??? with the transcript and with some more information about the workshops, I think that will come out on Monday.

A Yeah, lovely.

Q So I’ll see you again at the workshop.

A Yes, yes you will indeed, yeah. And then one day I’ll have this amazing video that I’ve made.

Q Yeah. Thank you so much for talking and, you know thank you for….I know you’ve shared some really difficult stuff and I really appreciate it and we’ll….you know.

A You’re welcome.

Q We’ll do our best with it, we really will do our best.

A Yeah. I believe that at some point it will get better. It takes slow time to change things but hopefully the little changes will one day make a big difference, and that’s the plan.

Q I hope so too. Thank you so much.

A Lovely. Thank you so much. Nice talking to you.

Q You too. OK, bye.

A Take care. Bye.