Q OK that should say ‘recording’, has that come up for you?

A Yeah.

Q Wow, it’s working. So first of all just to start with do you mind just sharing kind of what made you interested in taking part in the research?

A I had seen it advertised, I think it was Instagram or Facebook, it was one of the social media sites for the….oh gosh now you’re asking me what it’s called – is it [charity]?

Q [charity], yeah.

A And it just sounded like it would be quite an interesting project. I have done lots of research myself in the past so I know how difficult it can be to get volunteers. So if there is something that I think I can help with then I would normally volunteer to do it. I guess I’ve also been reflecting more recently on the impact that having a brother with Downs Syndrome has on my life compared to the impact that it would have had if he was neurotypical, if he’d been born without any kind of differences. And we don’t know what that would have been like but I suppose I’ve been reflecting more on it since we lost our mum three and a half years ago, so it’s been a huge adjustment for all of us. But when I often see photos, like just over Christmas and New Year I’ve seen photos of my friends having a lovely time with their siblings and their siblings’ families and things, and thinking it’s so different for me with my brother. Because we don’t really have that kind of relationship any more, I kind of tend to have more of a carer kind of….or more of the adult relationship there and where I’m kind of trying to help him to make good choices. I’m kind of doing a lot more of that kind of thing than I would have been when I was younger. So our relationship has definitely changed as we’ve got older, and especially since I’ve lost my mum.

Q What’s the current situation or the current set up then for you guys?

A So [brother] my brother lives in supported accommodation and he’s there pretty much all the time, he has one weekend a month with my dad. And since COVID and lockdown his day service has completely changed but he does now have a daily kind of routine. Like he sees my dad 4 days a week and they go to the cemetery on 3 of those days. I tend to see him on an ad hoc basis, but I get a lot of the kind of life admin that kind of goes with [brother] in terms of managing kind of his bank account and any kind of day to day issues that crop up. His bungalow is supported accommodation and they come to me. If he’s done anything that he shouldn’t have done then it kind of comes to me. I tend to be the big bad wolf and my dad is the kind of ‘oh…well….but you know….’ Like no that is not OK. So I think my dad’s relationship has changed with my brother as well recently. But dad is determined – my dad is 80, he’ll be 81 in April – so dad’s kind of relationship with him is much more of a kind of friendly kind of relationship and he’s trying to make sure [brother]’s happy all of the time. Whereas I’ve got one eye on his mental wellbeing at the moment but also one eye on thinking the longer term kind of implications of his daily routine and things.

So I don’t see him on a weekly basis, probably monthly, it varies depending on what we’ve got on. But they’re about 40 miles away from where I stay so it’s not that easy to nip up and see him just for a cup of tea.

Q Yeah. And have you always, you say things changed when your mum passed away. How did that dynamic change then or what….?

A So mum would have had control over his finances, mum would have signed all the medical things all of that kind of stuff. Mum was very tech savvy – well not tech savvy she still drove us mad with the computer, but she knew how to do all of that kind of stuff and she would have organized everything, whereas my dad never had to do any of that. I would have had – in fact when mum had died I had to phone the bungalow and I realised I didn’t actually have a phone number for the bungalow because I’d never had to do that, I would have always spoken to [brother] when he was at mum and dad’s.

So yeah it was quite a big change in terms of the kind of responsibility and stepping into the role. We already had Power of Attorney between myself and my mum and dad so it just needed to be altered so that it was just myself and my dad. But yeah it’s more the kind of admin side that has increased. And anything to do with DWP, I’m the one that has to deal with all of that and his allowances and things like that.

Time 5:00

Q Yeah. And had you kind of agreed that would be the case in advance, or has it kind of naturally just happened, or how….?

A It’s just naturally happened. I think we knew that dad wouldn’t be able to do it, and he’s got no interest in doing it. Because so many things are electronic nowadays it’s just not feasible to expect a man who has never used a computer in his life to all of a sudden get his head around internet banking. So I do all of that for [brother] and pay all of his invoices. But dad does the day to day withdrawal of money and gives him his money.

Q The nice bit.

A Yeah he gets the nice bit, yeah!

Q OK. And what then, can you explain a bit then about what impact it has had on you either recently or kind of being the sister of your brother kind of in the past as well?

A I was trying to think earlier on when our relationship really changed. Because growing up my brother was always just ‘my brother’, and I was trying to think when I first realised that he was different from anybody else. And I think it would have been about 9 or 10 I think and my cousin and I were at Sunday School and [brother] was there too. And somebody had said something to him and I was like ‘what!’ And I didn’t….it hadn’t really….I hadn’t twigged that there was something different. I knew he went to a different school, but it was just [brother] and I didn’t really appreciate that there was anything different.

And it probably wasn’t until I had my first child that things really started to change, because [brother] became quite jealous because mum was spending time with us and with her grandson and he didn’t really like that and it didn’t really go with his routine. And he found it hard to find where he fitted within all of that, to the extent that he reported my dad to the social worker and said that dad had hit him, so poor dad had to be interviewed by the police. So that has had a big impact on our relationship because we were all really angry with him. And we could see where it had come from, we could understand why he was feeling displaced, but he was still getting everything that he needed, and more.

And then he kind of recovered from that to an extent. His behaviour since mum has died has been quite challenging at times particularly towards one of the residents in the bungalow, but his behaviour in general has been quite difficult. And his health and wellbeing hasn’t been brilliant – well it’s more or less mental wellbeing really because he hadn’t had a routine for so long. So I was in quite frequent contact with the bungalow around about incidents that had been happening and what [brother] had been doing wrong and what needed to change, and that was quite difficult to kind of keep the positives in mind at the time. And I was [brother]’s advocate during all of that and saying ‘well you know it’s not his fault, he’s got all of these…he needs something to do, he needs entertainment, he needs to be kept busy’ and it’s taken us a long time to get to the place where the bungalow now have the right programme in place for him.

But I would say the mental toll that all of that took on me when I….if an email came in and it was from somebody from the bungalow I’d just be kind of ‘oh what’s he done now, what’s going on’. Or if I got a request ‘can you please phone’ then I would be dreading doing that. And it did feel like I was the responsible adult, or I was the one that was responsible for what he was kind of doing and how we would support him through a really tricky time.

So it’s been quite difficult, and it’s been very difficult trying to be [brother]’s advocate as I said through all of that and finding a way to make sure that his voice is heard. And it was really difficult around about the funeral and I had to phone the Mental Welfare Commission because [brother] wasn’t going to get to go to mum’s funeral, which just added extra stress at the time when I already trying to deal with….well we’re in the middle of a pandemic, well we were at the start of a pandemic, it wasn’t even that we knew a little bit about what was going on, it was right at the start. And trying to deal with all of that and then still fighting [brother]’s kind of corner to make sure that he still was allowed to come to the funeral and get the same kind of rights as everybody else was getting.

Time 10:00

There’s been a lot of reaching out to [charity] who are our local charity who have been really good and were really supportive with providing resources around bereavement that I could then share with the bungalow staff so that they could kind of try and understand. They’ve come to a couple of meetings as well which has been all off me kind of going and finding out what support we could access to kind of help him through things. So I don’t know if I’ve actually answered your question there, I’ve kind of gone off waffling on, but tell me if I haven’t.

Q No it’s all related, yeah talking about the impact on you kind of recently I guess and that change in dynamics, the changing role that you’ve taken on kind of and how that’s affected you.

A Yeah it’s definitely been an added stress. And I think when some of my friends have lost their parent they’ve had somebody to share that load with. And I almost got an extra load on top of that is how I sometimes feel. And I don’t want to feel like that because I don’t want to resent [brother]’s disability, that’s just who he is and that’s who he’s always been. But it has been that added pressure.

Q Yeah. So you had your mum passing away, the pandemic, and then having to manage your brother and the home on top. So a lot at the same time when, like you say, most people would only have one of those things to deal with.

A Yeah. And it’s definitely become less of an impact I would say as things have settled. And now that, as I said they’ve got a really good routine in place for him and he knows what is expected of him. There’s I wouldn’t say much fewer incidents, there are fewer incidents. There was one before Christmas time where he had accused dad of touching himself in front of [brother], and I automatically get phoned because of that. But thankfully because the bungalow staff know that he doesn’t always tell the truth 100% they didn’t go straight to the police this time and we had the opportunity to have a discussion with him about what he’d said and whether it was actually true. But that was a very stressful day and a bit of a sleepless night because I didn’t tell dad the night that I was told about it, we waited until the following morning because it was quite….yeah, I knew dad wouldn’t sleep if he knew what had happened. And we wanted to give [brother] a bit of time to stop and think about what he had said as well.

Q Tricky.

A So there are still kind of peaks where it’s a bit of a ‘oh my goodness what are we doing here’, but then there are days and weeks go by where I don’t really have to worry about him, he seems to be settled and in his routine. I do worry what will happen when dad’s not able to take him out 4 times a week, and he is with my auntie one afternoon a week as well, so I always have that in the back of my mind. But I think we can’t worry about what’s in the….we can’t worry too much about what’s in the future because we don’t have any control over it.

Q Yeah. Do you have discussions about it then or not?

A I don’t know that we call them discussions. I usually kind of say to dad ‘that’s not going to be helpful because you’re not going to be able to do that for ever and then Auntie Laura and I are going to have to deal with it’. We don’t have sensible discussions. We don’t have measured discussions, that sort, we don’t have measured discussions we more often have disagreements about whether it’s right to do things the way that dad’s doing them. Because at the moment [brother] goes to the cemetery three times a week, and the cemetery is about 5 miles from where he lives, so there’s no way the carers could sustain that if dad wasn’t able to do it. And at the moment my dad’s very fit and healthy and is able to go and drive out and get him 4 times a week but I don’t know how long that will go on for. So yeah there’s a bit of a worry towards the future. But we do also have a lot of family who live in the area who I could call on if we really needed to.

Q OK. Are you the only two siblings though in the family?

A Yeah.

Q It’s just you and [brother], but then the wider family.

A Yeah. So my mum’s sister still sees him quite regularly, she takes him out on a Tuesday afternoon. And if we needed to I’m quite sure my cousin would help as well, and she’s just a year….she’s in between us age wise, there’s myself and then [name] and then [brother] a year apart. So she’s grown up with [brother] as well but doesn’t do anything at the moment, but if I needed to, I think if I needed her to I think she would, but at the moment she’s OK.

Time 15:00

Q Is that reassuring, knowing that you’ve kind of got that emergency backup or something, or….?

A I think so, yeah. Whether I would go to them or not I think is the question. I do tend to take all the responsibility on my own shoulders, but I know that there are there and they would do it if I needed them. And my mum always said that my children had to come first and I needed to remember that whatever my children needed [brother] would need to come second to that, so… And it’s hard to remember, but at the same time my kids are younger and [brother] has got a team of carers around about him, so yeah.

Q Yeah. And has there been an impact then on your children or your partner, if you have one?

A Yeah. I think in some ways my husband is more patient with my brother now than I am. But he gets angry at kind of the….not angry, is that the right….he gets worried I think about the impact that some of the kind of things that I have to deal with has on my mental health. There’s been a….has there been much of an impact on the kids? No. They just see [brother] as [brother], their Uncle [brother]. They know that he’s got Down’s Syndrome, we speak about it. They wear odd socks on World Down’s Syndrome Day. They know why they wear odd socks, it’s not just because they feel like it or it’s popular, they know why. They know about Uncle [brother]’s difference. There’s been other children in their school who had Down’s Syndrome, which I think has also been helpful for them to see it kind of normalized, it’s not just Uncle [brother] that has this. I mean it’s impacted them in terms of me not always being 100% available if, for example on that day when he’d made that horrible accusation about dad, I definitely wasn’t the best mummy I could be because I was stressed and I was worried and thinking ‘how are we going to deal with this’.

Q Yeah.

A But yeah they’re OK, their needs are always met. My husband is incredibly supportive and has known [brother]….we’ve been together since we were 17, so too many years, 25 years, yeah something like that. So he’s known [brother] most of our lives as well. So yeah I think he’s just accepted that this is the way it is just now. And he’s probably, as I said, more patient with [brother] than I can be at times, because I just get really angry with him sometimes. I also get angry when I know that he’s not doing the best that he could do. I think a lot of his independence skills have….he’s started to lose them as he’s got a bit older and I get frustrated that I think ‘but you used to be able to do that so why are you not doing that any more’. And it’s that constant keeping on top of things and saying ‘do we need to be starting to think about dementia assessments, should we be looking at that’, or ‘should we involve the speech and language therapist again’ because his stammer has got worse; and trying to kind of make sure I keep on top of all of the things that mum would have been advocating for previously.

Q It’s a lot of responsibility isn’t it to have those….you know thinking about those questions and those kind of longer term implications.

A Yeah, and it’s a totally different role to if I had a neurotypical sibling, and I think that’s the kind of bit that sometimes does….I do resent it sometimes but at the same time these are the cards that we’ve been dealt and….I don’t know that…. Previously I would have said ‘oh I wouldn’t change [brother]’. And I remember mum saying ‘oh sometimes I just wish he’d been born without Down’s Syndrome and I think about what his life would have been like’. And I couldn’t understand that before, but now I kind of do see it from a different point of view. I think now that I’ve got a lot more of the responsibility I think ‘OK now I understand why you feel that way’. But even just being born into a different time, because there are so many more opportunities now for children with….sorry, an 8 year old Ninja just snuck into the room to give me a night-night cuddle….two seconds.

Q Aww. Is it bedtime?

A Yeah. He did have his night-night cuddle but clearly felt he needed to come and just check what was going on. He’s become more subtle. He walked in on training that I was doing to a heap of university teachers at one point and he was just like….straight up to the camera. Yeah I think things have moved on so much education-wise for children with Down’s Syndrome or learning difficulties now, they are so much more included, they’ve got so many more opportunities. Whereas when [brother] was born the expectation was ‘you will go to special school, he probably won’t be able to read or write so we probably won’t try that hard to teach you’. So I feel like he’s missed out on a lot that would be different nowadays as well. And definitely having [brother] definitely influenced my career path.

Time 20:22

Q Oh what was it you do?

A Because I wanted….I’m an Educational Psychologist.

Q Ah OK.

A So it was very heavily influenced by [brother]’s kind of experiences at school I think, in school, and wanting to make sure that things were as good as they could be. So that’s one positive that’s come out of it for sure.

Q Yeah, yeah definitely. What was it like growing up with [brother] then? Obviously we’ve spoken quite a bit about since your mum passed away and kind of your new role. What was it like growing up?

A To be honest I don’t think it was very different from any other kind of sibling relationships. I would have gone to my clubs, [brother] would have gone to his clubs, we would have done stuff jointly. There was a club that we used to go to together for families at his special school. He had his activities, I had my activities. We would always play family games together, we would have watched videos together. Where I learned to drive [brother] was very resentful that he wasn’t being able to learn to drive, and I think as we got older the differences in what we were able to do became more apparent. And I think that’s when he was starting to then question ‘well hold on a minute, why is she allowed to do all of these things and I’m not allowed to do all of these things, that’s not fair’.

I don’t think…. my mum was really careful to make sure that she was giving – and my dad – was giving both of us kind of equal amounts of attention and would always have been there to help if I needed something. I don’t know how she managed to do everything that she did. But yeah I mean my childhood was a very happy childhood with [brother] as part of it. There’s a couple of kind of incidents that stick out where [brother] had…there’s one where he got stuck at the top of a chute in a man….he wouldn’t go down. I think he was scared in hindsight. But I remember somebody really shouting at him and getting really angry with him, and that kind of sticks in my mind as kind of not knowing what to do in that situation.

And I also remember a time when somebody had come round to the house selling bags of candy floss and [brother] hadn’t realised they were selling it so he’d open the door ‘thank you very much I’ll have that’ and shut the door. And I remember mum being utterly mortified and running out and giving the candy floss back to the person ‘do you want to buy a candy floss?’ ‘No’. But other than that there’s nothing that really sticks out that was happy, sad, very different because of the kind of differences. It was more just that kind of later teenage stage where he realised that things were changing. And I mean he was left behind I suppose because I went and did….I went to university and my cousin went to college, she got married. And when she got married it was a bit of a rocky stage for him there. And then when I got married and had a baby, that was just….he really couldn’t cope, things really were changing around about him.

Q Yeah. Thank you. I was going to ask you something and it’s completely slipped my mind, which isn’t great when you’re an interviewer.

A That’s OK. It will come back to you when you are reading the transcription.

Q Yeah. Ah yeah exactly. But you mentioned like a couple of examples that stood out for you from your childhood, the candy floss and…. Is there anything which, is there a story which stands out kind of related to your current role I guess and your current situation with [brother] which kind of sums it up or kind of….

A Like kind of what I spoke about with dad and the accusations that he’d made against dad in the years. That’s probably what’s really had the biggest impact on [brother] and my relationship I think is that I find it really difficult to forgive and forget, even though I understand. And I have all the psychology behind me, I totally understand why he does it, but there’s that emotional component that is really hard to kind of move on from. And yeah, it’s probably the most significant thing that has shaped our relationship recently.

Time 25:00

But [brother] has come….I mean [brother]’s been included in everything that we do as a family, and always has been, we’ve been on family holidays. He always went with mum and dad, and then latterly with my mum and my dad and my auntie and my uncle. But then when mum passed away they’ve just started coming on our family holidays. So he’s always there with us, included. And thinking about the kind of impact on the boys of that, I guess I don’t relax as much when I’m on holiday with dad and my brother as well because I’m watching out for the 80 year old man who has got no idea what he’s doing in a foreign country, and my brother who will be quite happy to lead him down some kind of random path. But yeah we were in Florida Easter holidays last year and then in Turkey in the summer holidays, and they’re coming with us to Majorca this year, so we’re certainly….he’s milking the family holiday as well. While we’ve got dad that’s well enough to come, yeah.

Q Oh lovely though.

A But my boys like Uncle [brother] being there and they like to play with him in the pool. And they’re kind of at that age where they’re….Uncle [brother] still likes to go and do handstands at the bottom of the pool, whereas mummy and daddy not so much. But [brother] still has that unbridled joy of splashing. He was going down the water chutes and everything with my kids and he enjoyed that as well. So there’s definite positives to them having Uncle [brother] around as well.

Q Yeah, lovely. Have you reached….you mentioned kind of reaching out to the [charity] for various support. Have you had to reach out kind of anywhere else for support or have you actively sought any kind of help for the impact of mental health?

A We’ve had clinical psychology involvement in recent years. They’ve now discharged him now. But kind of around about the time when mum had passed, and the fact that he wasn’t moving on in the same way as they would have hoped I suppose at the bungalow and some of his behaviours were quite distressing for the other residents, we involved clinical psychology at that point with the LD team here and speech and language therapy. But other than that he has a social worker, but he’s had a social worker all his life. He’s had five….since mum passed away he’s had four social workers, four different people. The most recent one I’ve only met once and she’s probably been in post for about 6 years - 6 months, not 6 years sorry – 6 months, I’ll give her a bit more credit than that. But we had a super social worker when mum did pass, the lassie who had just newly taken over the role was really supportive and really good for [brother] as well.

But it’s a lot of professionals to kind of meet and get your head around things and get to know them and tell them the story all over again, and until they get to know [brother] it’s quite a challenge. Which gives me a different perspective. When I go to meet families in my own work I kind of have a different understanding of what that’s like. ‘Yes I am yet another educational psychologist for your child….I’m going to ask you some questions and I do apologise if you’ve told them before, but….’

Q Yeah, yeah that’s interesting, yeah. Is there anything that you can think of which would make your role easier?

A I don’t know if there are. I mean the [charity] charity, I only became aware of it because….is it Jo Wiley whose sister….

Q Yeah.

A And I only became aware of it because I’d happened to be following her on….it must be Instagram. And she’d shared something about her sister and had linked this charity. I do wonder whether it might be helpful for me to speak to other siblings to kind of have similar….who have the same kind of experience and the same challenges just as a bit of support I suppose. But other than that I don’t think there’s necessarily anything. I mean a lot of the other residents, all of their money is managed by the kind of care staff. But that was never something that my mum wanted, she always wanted to kind of have that responsibility, so I feel like I need to have that as well. But again it’s something that I’m aware I could reach out and I could relinquish some of the responsibilities, it’s just that guilt that goes with that or that feeling that ‘nobody is going to do it as well as I would’ or….yeah. They’re being paid to do it whereas I have that kind of emotional responsibility or that relationship to go with it.

Time 30:00

Q And do you feel then that you have to continue what your mum started as well, kind of doing it how your mum would have wanted it done?

A Yeah. And there would be none of that. If mum was here she would tell me not to be so silly and to hand it over if that was what I felt I needed to do. But I feel like she was doing that for a reason rather than….yeah. I think there was a little bit of distrust as well and wanting to make sure that there was always somebody external watching, or somebody from the family being careful with the money that he was spending and how he was spending his money I guess and making sure that he was never going to be short. Which is a danger because he’d quite happily buy a new deodorant and shower gel and a Toblerone every single week despite the fact he has a little stash of deodorants and shower gels and shaving foams and everything else in his wardrobe, just because that was part of his routine.

Q Yeah, yeah, you go out and get your toiletries or….yeah.

A Yeah, even if you don’t need them you still do it.

Q Yeah I’ve seen that also. OK. So I’m just looking through the list as well. We spoke about kind of potentially reaching out more to [charity], but other than that obviously you kind of feel you don’t need anything else, any other, or you’re not sure what could be done differently. Is there any way you have accessed support in the past which has been helpful or not helpful?

A Just [charity] I think. And I mean at the time when mum passed away, the Mental Welfare Commission were amazing and really helpful in kind of dealing with the restrictions at that point.

Q Yeah OK.

A But I’ve got some friends who work in social work as well so I do sometimes kind of run things past them and go ‘is this OK, is this reasonable, is this what I should be expecting’ or ‘am I right to question this’. But no I don’t think there’s anything else.

Q So it’s more kind of practical support rather than emotional or anything like that?

A Yes. Another sibling to share the load with would be super. If I had somebody else just to kind of go ‘yeah’. And my husband is great as well and if I asked him to do anything for [brother] then he would do it in a heartbeat, he would step up. But it tends to be me that [brother] would see as his kind of….he will say ‘oh you’re the boss now [name], you’re the boss’. And if he’s doing something and the carers suspect that what he’s saying is untrue then they will say to him ‘well I’ll just go and get my phone and see if [name] is….’ and then quite often he will go ‘oh, well, well’ and backtrack a little bit. Which is not always a positive, I don’t like to be this big bad wolf all the time, but….

Q Yeah, they’re really kind of making that your role then aren’t they, or that’s becoming your role in that sense, yeah.

A Yeah. They try not to but it is also a way of finding out whether what he is saying is true or not. Because I would say the biggest issue that we have just now is saying things that are not true, which is going to land him in a lot of trouble if he does say something that is true and we don’t believe him. And that’s always kind of the risk.

Q Yeah. OK. Thank you. Is there anything else that kind of, or anything which springs to mind that we haven’t spoken about which….kind of with ??? stuff. But is there anything….

A The only thing that has struck me. Because I work for a local authority I’ve always said ‘well you shouldn’t have to fight for your children, don’t feel like you’re coming into battle’. But as now on the other side of it I suppose that’s how I do feel sometimes when I’m having to kind of go back and say ‘oh but…’ and as [brother]’s advocate kind of going back and saying ‘OK but from [brother]’s perspective what was happening in this situation was this, so how do we move forward with that’. I suppose that’s the only thing that I haven’t really touched on that much in the interview that does kind of have quite…. It’s impacted a lot on how I approach how I work as well and kind of acknowledging the fact that parents are, or carers often are the main advocates for their child an empathizing with them that that’s not always easy. Because it really isn’t.

Time 35:10

Because you don’t want to be having these difficult conversations, nobody wants to have difficult conversations. But I feel like as a carer of somebody with learning disabilities you really do have to have more difficult conversations in your lifetime than most people would otherwise. And I did feel, particularly trying to get his programme back in place after lockdown, like it really was a lot of back and forth and a lot of me going ‘no, still not good enough, that’s still not what he would be getting if he was a mainstream member of the community, he is still not accessing things’. So yeah it does put a lot of extra pressure on that way. But in some ways I hope it made me better at my job because I can now empathise when people are saying ‘oh I’m fighting, I’m having to fight really hard for this’ and I go ‘yeah that’s really hard, when you are feeling like that it is really hard, let’s see what we can do to make sure that you feel like I’m on your side’. Yeah. I hope I don’t come across as too big a nuisance to the social worker and the care staff but at the end of the day we’re all working together for [brother] and we have to put [brother] at the kind of centre of all the planning and the decision making.

Q Yeah. And he’s not….just to give the distance, is he in the same local authority that you work for?

A Yes he is.

Q Does that ever come into play in your mind in terms of….or are you completely separate?

A No it’s completely separate. And because I work with children and he is a vulnerable adult it is completely separate. Social work services as well, which I think has made it a lot easier. And I don’t know the social work systems as well for adults with learning disabilities as I do for children with learning disabilities, so I’ve had to do a bit of learning around about that as well. But as I said, I’ve got friends that I can reach out to and ask questions as well.

Q Useful.

A Yeah. So I am fortunate. I’ve got kind of contacts and people that I can speak to. And I know a lot of people feel isolated.

Q Yeah. And I guess you’ve spoken about how caring for [brother] has affected you in your role and kind of had a positive influence. Had there been aspects of your role then and knowledge you’ve gained through your role that you have taken the other way into your caring for [brother]?

A Absolutely, yeah. Yeah because [brother] didn’t have an visual timetables or anything in place. Historically when he was in a work placement they were finding things were really difficult for him and he wasn’t following instructions, he wasn’t sticking to his routines, he was changing things, he was taking too long to have his lunch. And I remember just sitting in a meeting, and mum was still there at that point, and I said ‘but surely he has visual schedules in place’. ‘DIT!’ Sorry, ‘what’ would be the….that was the ??? the Scots version of ‘what’. And they didn’t have a clue what I was speaking about. So a speech and language therapist then got involved in kind of supporting them to put in place things that were necessary. So that’s one example. But I’ve had to go back to social stories. It was me that had said ‘we need a social story’.

In fact I wrote the social story around about mum’s passing to try and help him to understand the sequence of events. Because he was getting all muddled up, he couldn’t keep track of what had happened, when. He kept thinking mum would come back. So we were kind of trying to get some consistency around about the language. But since I’ve suggested the social story around about that there’s been quite a few more social stories that have come in place for [brother]. A lot of the kind of psychology around about his anxiety and his mental wellbeing I’ve been able to share with his carers. I just don’t think they always believe me, and I do keep kind of going ‘well I’ve got my psychologist’s hat on at the moment and I’m telling you this. And obviously as his sister I can understand that it’s really frustrating but with my psychology hat on this is why this is happening’.

And I think it’s a blessing, it’s more of a blessing than it is a curse. But I do kind of feel guilty at times because I think ‘oh you’ve just got really angry with him and you know why he’s done it – but you still got emotionally angry, why did you let that happen’. But it’s a typical sibling relationship I guess in many ways as well.

Q Yeah. And just going back to that point you said where the care staff might not necessarily believe you and so you kind of emphasise you are wearing your psychologist’s hat. Is that different do you think if you were going in as the psychologist, you know as a professional psychologist rather than as a family carer?

Time 40:13

A Yeah. I think whatever the clinical psychologist said they sucked it all up, they believed what she was saying ‘well right, well we need to do this’. But if [name] the speech and language therapist says ‘oh I think it would be really helpful if we looked at a social story for that’, ‘oh, right, OK’, or ‘he needs it structured’. It’s only because [name] the speech and language therapist has said ‘he needs to be entertained 24/7, we can’t have days with any downtown’ that they’ve made sure his timetable is so…it’s not got any gaps in it. Whereas I’ve been saying that to them since he moved in and that was, when did he move there….he was 39, no was he 38, he’s been there for about 6 years I think and I’ve been saying that for most of those 6 years but particularly since mum died.

Q How frustrating.

A It’s so frustrating.

Q Yeah. And especially like, you know you are an expert as a family carer but additionally you do have that psychology background as well, which is what those professionals are bringing to the table.

A It varies depending on the member of staff as well I am speaking to. And there’s some staff who have been carers for year; there’s some staff who have been carers for weeks; and it doesn’t seem….that doesn’t necessarily have an impact on whether they will listen to you or not. I think a lot of it comes down to personality, and some people think they know best and they’re not changing how they’re doing things. In much the same way as I have conversations with teachers who don’t want to change how they are doing things – but they need to in order to teach this child. It’s exactly the same for [brother], we need to…. But as a sibling I’m much less patient with the carer who is not listening to me than I am as a psychologist speaking to a teacher, because it’s my brother, it’s my…..yeah I have to stand up and kind of say ‘but you need to do it this way’.

But it is very frustrating when [name] comes in and goes ‘oh but this is what needs to happen’ and I’m thinking ‘that’s what I’ve just been saying’, I’ve been saying that for the last 3 years [name] but nobody will listen to me. But I guess the difference is as well they are then able to come in and model it and show them and give them the resources to be able to use. Because when I wrote the social story for mum I had it all put together, I printed it off, I laminated it and I gave it to them and then they used it. Whereas I think if I’d just….well in fact when I did say ‘we need a social story for him’ it was kind of like ‘oh, oh well…I don’t really know what to do with that’.

Q Yeah it’s that extra level of input to kind of come through.

A Yeah. But again it’s kind of mind boggling to me because social stories are so much part of what children with autism I guess in our schools would be getting as standard, we expect that in our schools. So for it not to be standard in the same local authority but with the adult population is quite shocking.

Q Yeah. Oh I’m sorry!

A No that’s OK.

Q It’s been a long day! Yeah it’s just frustrating to see the differences between as well children and adults in such a way.

A Yeah. And I would hope the adult will catch up in the same way that changes are being made in education, changes will eventually be made in adult services. But they’ve kind of got the rough end of both sticks at the moment I think. But things are much more positive, we are moving in a better direction I think. But it kind of depends on which carers are on duty as to whether [brother] can have a good day as well, which is hard.

Q You said he’s been there about 6 years, so is he relatively settled? Obviously you know there’s good days and bad days and things like that, but overall it’s relatively….the accommodation and care, kind of that side of things, is relatively….

A If you ask him he’ll say that he would want to stay with dad. And initially he didn’t want to move and then he really did want to move and he was excited and he was going to go and choose all of his furniture and his bedding and everything for his new house when he was moving. And then he was really settled to start with, and then there were ups and downs. But before….just about lockdown period actually he was probably the most settled that he had been, so that had taken about 3 years to get to that point I think.

Time 45:00

Q And then everything kind of….

A And then everything changed. And then they were all together 24/7 with different carers coming in and out. But none of the activities, nothing to kind of….so that did unsettle them, in the same way that it unsettled everybody but then [brother] had the added stress of leaving mum within it as well. Yeah. But he is relatively settled, we’re not moving him. At one point, I think it was maybe about 2 years ago the social worker report needed to do an updated assessment and they recommended that the placement could no longer meet [brother]’s needs. And I kind of said ‘well that’s not OK, we need to think about what needs to happen in the placement so that it can meet [brother]’s needs because this is [brother]’s home, this is where he’s staying, he’s not moving’. So again that was kind of me going ‘oh really, we’re gearing up for battle again’. But I think a change of manager to the setting really helped to resolve that and a new manager who was able to listen and take on board the kind of information from different agencies and supports as well. So yeah it definitely depends on the staff as to how well the care setting works for [brother] I think, and for the other residents.

Q Yeah. But it does sound like you have to keep quite a close eye on things then in how it’s running.

A Yeah. And the manager who was there when the recommendation was made that the placement couldn’t meet his needs went off on long term sick and came back quite….maybe about 6 months ago. And there was that level of fear, I was like ‘oh no please don’t go downhill’ because things had got to a better place. But the man who had kind of been the interim manager was staying on in a post of sorts, so he is now line managing that lady so it’s like ‘OK I’m going to lay it all there’ ??? getting too ??? Goodness knows what that will look like in a transcript. Yes I said ‘I’m just going to be honest with you, this is my experience previously’ and he just agreed he was going to keep an eye on it. And because we had that trusting relationship I trusted that he would still.

But if I email [name], the kind of day to day manager, I will always copy [name] in as well as her line manager because I still don’t have that level of trust that she has [brother]’s best interests at heart, or that she wants him. And I guess that’s the kind of key thing is that you want your sibling or you want your child to feel like they are wanted within their home. So yeah.

Q Yeah. A lot then isn’t it, not just being able to relax and just trust it will all be OK. You are constantly, you know down to who….thinking about you know down to who you copy into the email and….

A Yeah.

Q Thank you. I think if there isn’t anything else I think we’ve kind of covered everything which I was hoping to, which has been really great, thank you.

A Super. Sorry I hope I haven’t waffled on too much.

Q No not at all it’s all been really, really helpful. Did you see in the information the stuff about the digital story?

A Yeah, I definitely will not have time to do that.

Q That’s definitely a ‘no’, OK that’s fine.

A No sorry. I would love to, in a different lifetime without two small children, but yeah.

Q No that’s absolutely fine. Sorry if you’ve already said that to [name].

A No, no that’s OK.

Q Brilliant. Do you have….actually I’ll just stop the recording.