Q There we go that should be recording. To simply start off do you mind just sharing kind of what made you interested in taking part in the research?

A Yeah. So my sort of background is I’ve got a brother who has got severe learning disabilities and autism, he’s also got a neurological condition which means that he uses a wheelchair quite frequently as well. And sort of growing up as a sibling of a, well young adult with special needs now, I know what a big impact that has on a lot of people; and I also know like when I was growing up there wasn’t an awful lot of support out there. And so when I saw it I did just sort of think it’s something that I really would like to help with to hope that people who were in my position when I was younger hopefully they will have a bit more support for them.

Q Yeah, brilliant, thank you. Do you mind then explaining a little bit about your situation and kind of what support you feel you didn’t have and things like that.

A Yeah of course. So my brother’s older than me so he’s always been in my life. He’s just turned 30 and I’m 26 so there’s not that big a difference between us but he’s always been a part of my life. So growing up we got on really well. I am a special needs teacher now and I’m doing that because of him basically. So growing up I’d like….we’d have all our teddies as a classroom, he’d be my teaching assistant, and all things like that. So growing up, obviously I knew he was different because he went to a special needs school and things like that. But it didn’t have that much of an impact on my life when I was younger, it was more when I started secondary school that as he was getting older and he became like a teenager and puberty hit and things like that, it just became more prevalent in my life that he was different to other people’s brothers and sisters. And the neurological condition he’s got which affects his hands and his feet, when I was younger we didn’t even really know he had it, it’s only as he got older because it’s a progressive condition, it’s only as he got older that things like using a wheelchair became part of our day to day life.

So that’s when I would say, I’d say when I was about 11 or 12 years old is when I would say it started having an impact on me in terms of my mental health. There were a few times in my childhood where kids in the playground would make comments about him and things like that, which did have an impact on me but I felt comfortable enough to go to my parents and speak to them. And I love my brother. I’m very lucky in the fact that yeah he’s got autism and learning disabilities but he’s not violent, he’s like a gentle giant, he’s a sweetheart. So I’m very lucky in that regard that I was never afraid of him, I never felt like he would hurt me or anything like that because he really is just a gentle giant.

Q Yeah lovely. And what then…so you say things started to change perhaps round when you were 11 or 12 and it started having an impact on your mental health. Can you kind of explain a bit more about that then please?

A Yeah. So when I started secondary school, at the same time my mum’s dad passed away and my mum struggled a lot with her mental health at that time, so it was at that point where I realised how much care my brother needed. So things like when he’d go to the toilet he’d need one of us to wipe his bum, but my mum wasn’t very well at the time so I would do it. I was never asked to do it, it was never expected that I’d do it but in the situation I felt like I had an obligation to do it, if that makes sense. Even though I was a child I still felt like it was down to me to do that.And then other things, like I remember when we first started doing our GCSEs we had this big assembly and it was all about ‘oh you’re at this age, you should start thinking about your future’ things like that. And I just remember breaking down in tears – so I would have been what, 15, 14 or 15 at the time – because all I could think about was that my brother would never do that. And it almost made me feel guilty because everything that I was getting to do he would never be able to do.

Time 4:40

And my mum as well at that point because her mental health was challenging for her, she’d see with my cousins who were younger than [brother] but older than me, starting to do things that….[brother]’s the first born child in our family of grandchildren so she’d start getting….I don’t mean this in a horrible way but she would be a bit bitter about her nieces and nephews, seeing them progress. And she wouldn’t explicitly say it in front of me but I’d catch wind of things that were being said. And it all started to become more apparent, the impact that [brother] – that’s my brother – the impact that [brother] had on us as a family unit. So that was sort of the first part of it, so it was when I first started having to do little things for him, making breakfast, making lunch, helping with his shaving, things like that and seeing the impact that him growing up was having on my parents.

So things like – I’ve just remembered – like when I was younger my mum didn’t like me to have friends round because she didn’t want him to sort of be stereotyped negatively. I mentioned a bit earlier when I was at primary school, I can remember it like it was yesterday, I had this friend, I was in Year 3 so I would have been 8-ish. And a girl came round to our house and mum, like I say, never let us have people round the house but she’d let this girl come round. And we were in the garden, and I can literally picture it like it was yesterday, and she just said to me ‘oh doesn’t it get annoying having a brother as stupid as [brother]?’ And in the moment I just didn’t know what to say. And I think I just said ‘no, he’s great’, something like that. But I told my mum about it once she’d gone home and my mum was really upset. Not at me, she was really like good with me. But a couple of weeks later the girls had said that I wasn’t her friend any more or something like that, and her mum had gone to my mum in the playground and sort of said ‘why isn’t she her friend any more?’ And my mum basically said ‘well because your daughter said this’. And it was a massive thing and the mum ended up coming to me and apologising. And a couple of years later the girl sort of, when we were at secondary school, came up to me and was like ‘oh it’s such a shame that we aren’t friends because I said that stupid thing about your brother’. And it was apparent that even years later she still remembered what had happened, which surprised me because it had never been mentioned since we were really little in primary school.

So that was the first time that I ever experienced anything negative and that’s when I started getting protective and feeling ‘this isn’t fair’, like ‘why am I OK’. so to speak. ‘and he’s not OK’, and ‘why do I get to do all these things and he doesn’t’. And then as I got older it then became a little….it was still always like that, like I’d never sort of resented [brother] but it sort of became when I wanted to do things my parents would be a bit more like ‘well why do you want to do that?’ Like I would want to spend time with friends and it would be like ‘well you spend a lot of time with your friends now and you don’t spend that much time at home’. And never did they say to me ‘you have to be here, you have to help with [brother], you have to do this’ but again it was me, rightly or wrongly, reading between the lines of their actions and the little comments they’d make. And it became this really heavy guilt on me that I felt like I had to be at home.

And fast forward a few years, my mum had a bit of a breakdown when I was in sixth form and it was all because of [brother]. It was like he’d got to that age where he’d finished special school and it was that issue of when they hit adulthood where do they go, what do they do. And the responsibility was on mum rather than the council sort of working it out for her. And it just was all too much. And my aunts and my uncles, they’re really nice people don’t get me wrong, but they don’t really make any effort to get to know [brother]. So it will always be a ‘hi, how are you’. And [brother] loves football, that’s his like obsession with his autism, and they’ll ask him a few questions about football but it will never go any further than that.

And it’s almost like it’s made my mum and my dad against the world when it comes to [brother], because as much as people aren’t rude and they try, they don’t get him. And they equally don’t understand the strain on my mum and dad especially and how having [brother] has – as horrible as it sounds – it’s frozen their lives, like they’ve got to look after him for ever now, And they won’t get that retirement where they can go travelling, and they won’t get to do the things that they’re seeing their brothers and sisters doing.

Time 10:00

And my mum basically got to the point where she was trying to get help from her sisters, she was internet rowing with them because they didn’t understand and she just had a complete breakdown basically. And I just remember at that point it was sort of my job to step up and look after [brother] and to try and protect [brother], and to try and like make dinner and do all things like that when I was studying for my A levels and GCSEs. It’s like you know in your heart that you’re like ‘this isn’t normal, I shouldn’t be doing this’ but at the same time it’s all I’d ever know so it just felt normal. And when that happened I remember I was sat in a lesson and it was all stressful exams, blah-blah-blah and I just broke down crying. And my head of sixth form sort of pulled me aside and I explained to her what the situation was at home. Because I think the school knew that I had a brother with special needs but they didn’t know any more than that, it wasn’t ever….like no-one would ever talk to me about it. And I remember….sorry I’m jumping forwards and backwards here.

Q No that’s OK, that’s fine.

A I remember in Year 5 we had to write a project about someone who we admired or someone who was inspirational to us, and I did mine about my brother. And it’s the sort of thing like people were always aware that I was in that situation but no-one wants ever, in terms of teachers, support staff, anyone, no-one would ever ask me ‘how are you’, like ‘what’s it like being in that situation’. And it’s only when I spoke to my head of sixth form – this was in 2015 – so it was only at that point in my whole childhood that anyone actually said to me ‘you do realise you are a young carer’, and ‘you do realise that what you’re doing is above what other children have to do’ and ‘it’s not normal’ and things like that.

And it was only at that point that I actually started to believe it. Because I’d watch things like Children in Need and I’d see the storylines where the daughter was looking after their mum and was cooking dinner every day, and I just always thought ‘well this isn’t that bad, this isn’t as bad as that’ so I never really made the connection that I was ever a carer until that point of my life. And my head of sixth form called my dad and basically said ‘we need to talk to you’, because my mum wasn’t very well at the time, but like ‘we need to talk to you about what’s going on’. And I remember being told, like ‘we don’t talk about this’, ‘we keep this between us’.

Q By your dad, or by your parents?

A Yeah. And like that’s something that I probably don’t want shared.

Q OK.

A But I just remember sitting in the car with him after having this massive conversation with my head of sixth form, and he just basically said ‘we can’t be talking about this because it’s me, you and mum, it’s us three, we’re the only ones that understand’ all that kind of stuff. But my dad’s very much like that, he’s a stereotypical man, he’s very much like you keep your stuff to yourself, deal with it with the people who understand and no-one else really needs to know unless they have to know. And it was just so….it was almost like that was a reality kick.

And then that was the point as well where I was applying for uni, because throughout my whole childhood I’d say from the age of 6, which is about when mum told me about [brother] – obviously not in scientific detail but she told me that… I remember the wording, she just said ‘your brother is special, he goes to a different school, he learns in a different way’, that kind of stuff, I’ve wanted to be a special needs teacher since then. And I knew, like in Year 6 we had to write an essay about what we wanted to be when we were older and I wrote ‘I want to be a special needs teacher’. And I knew because we had to research for that essay that I had to go to university for 3 years to be able to do that job. So I always knew it was something that I’d have to do. But it was something that absolutely terrified me because, again the guilt, I didn’t want to leave my parents, I didn’t want to leave [brother], like it just all felt wrong. It was just an immense guilt.

And then I went to university in [city] which was an hour away from where I am now, so it was really easy for me to get home. And I’d sort of spoken to [brother] about it and I was like ‘I’ll Facetime you every day, I’ll come home every 3 weeks’ and it was very clear what I would do for him and what not. But as sort of university went on, the guilt got worse and I ended up feeling really bad about myself. And that’s when….my mental health had been affected whilst I was at school, so I was seeing the school counsellor and I had been…well I had never been to a doctor when I was at school I’ll be honest because I was always worried my mum would find out, but I was talking to the school counsellor about how these things were feeling, and that’s predominantly because of what my head of sixth form did and said to me. Previous to that I had seen the school counsellor before as well but I didn’t really want to, so it didn’t really matter.

Time 15:30

So when I went to university and I was on my own and it all started hitting and my mental health did start to go down. And I went to the doctor for the first time when I was at uni and that’s when I first started having like CBT. And I have had anti-depressants and things like that. And it was something that previously, again similar to the caring thing, I never thought I was that bad that I needed to do things like that. Because again, in my life it was just the way it was, I didn’t really ever think much different to it. And since then I went to university, I did the 3 years. I had quite a few ups and downs with my mental health whilst I was at university, often due to the guilt of not being at home and feeling like no matter what I did nothing would ever make the situation easier for my parents. And it almost got to the point sometimes at uni where I’d think it would be better for my parents if they just had [brother] because they wouldn’t have to worry about me, they’d only have to look after him, and things like that . And that was really sad.

But I can also remember this, I wouldn’t say it was like mental health, but I remember when I was in Year 6, I can remember them so clearly it’s really like sad, but I remember like sitting upstairs once and I could hear my mum, dad and brother downstairs and they were laughing and they were so happy. And I remember thinking to myself, and I must have been 11, like ‘oh they’re so much happier when I’m not there’. And I look back on that now and I think, I was only 11 and I was looking at things in that way because I felt so guilty that I was OK and he wasn’t OK. And it was just….yeah it’s really sad when I look back on it.

But fast forward a few more years after university, whilst I was at university I really struggled in terms of trying to find a relationship because in my mind, and even now, [brother] is my priority. He’s not my child, but in however many years time – touch wood it won’t be for a while when my parents can’t care for him any more, he will basically be my child because I’ll be the one looking after him. And that again isn’t because anyone’s told me I have to do that but because I don’t want to risk him being put in a home or anything like that where he might get mistreated, I just couldn’t live with myself if that happened. So I do see him as important as anyone really, more important than anyone I think I’ll ever meet. Probably when I have kids it will be on par with that. But at present and for my whole life he’s been my person who I’ve always focused on.

So when I was at uni I really struggled to….I’ve never had an issue with friends in terms of making friendships, it’s just the social side of friendships that I’ve struggled with because I haven’t wanted to go for sleepovers and I haven’t wanted to go out for hours on end at the weekend because I want to be at home with my family. And they are my priority about everything. Like I know what my dad said at the time wasn’t the right thing to say to me as a child but in my mind those three people are my world and nothing else really comes close.

So when I was at uni and everyone was trying to find boyfriends and things like that, I talked to people but it’s almost like when it got to the point of not going on a couple of dates and then moving forwards I wouldn’t be able to, because either they’d say something about [brother] that’s insensitive, or I’d get a weird atmosphere from them that would make me think that they wouldn’t get on with [brother]. And it’s like because I knew that [brother] was always going to be a massive part of my life and I’d always be there for him and supporting my parents caring for him, I needed to make sure that whoever I chose to be with was going to be OK with [brother] 100% as well, if that makes sense.

Time 20:00

Q Yeah.

A So I really struggled with that for a few years. And then I met my partner who I’m with now, [boyfriend]. I got introduced to him by mutual friends. And both of his parents are deaf. And when I heard that I remember looking up his Facebook profile before I met him and it said one of his languages would be SL. And I was like ‘ah, this one’s promising, he’s got some kind of understanding. And I know it’s not the same, like his parents don’t require him to care for them, they’re completely independent, they both work – they might need a bit of support with translation here and there. But I just sort of knew that because he’d grown up with that he had an understanding of having to prioritise people over yourself, if that makes sense. And he loves football as well. [brother] is a massive Arsenal fan, [boyfriend] is a massive Tottenham fan – not very helpful – and that was one of the only red flags when I met [boyfriend], I’ll be honest. But they met, I remember I think I’d been on about 3 dates with [boyfriend] and I said to him ‘I really want you to meet [brother]’ and then me, him and [brother] went and played snooker and air hockey at an arcade, and they just got on. And like he’d taken [brother] to the toilet when he needed to go to the toilet, and there wasn’t any awkwardness, it was just natural.

And to this day like [boyfriend] will phone him and talk to him on the phone. [boyfriend] bought him this magnetic premier league table where they put the teams in order and write their points down every week. And it sounds so small but he makes him feel like a person, if that makes sense, which none of my aunts, cousins, uncles, grandparents, no-one’s ever made him….like I’ve never seen [brother] be [brother], like 100% [brother], with anyone apart from me, mum and dad. So to see him be that with [boyfriend] was a massive big deal for me.

Q Yeah completely.

A And yeah. So that’s something that was also like a bit of a headache for me growing up, but like I say I’m very lucky now. Which takes me on to the next thing that happened. A timeline! So me and [boyfriend] have been together now for 4 years and we got to the point where we were like we want to move in together, we want to move out, and that threw up massive sort of similar to when I went to uni, but obviously now it’s real, it’s not for 3 years, I’m not coming back, I’m moving out. And that again, the process of moving out was so stressful because in the back of my head all the time, even though I knew it’s what I needed to do for me whenever we were looking at a house we wanted somewhere that had 2 bedrooms so [brother]’s got a room where he can stay when we look after him and things like that. But like [brother] would come to some of the house viewings and he’d like look and see things with us. But then when it came to the day where we actually moved out I was just a mess, which I know is normal like because you miss your family and things like that. But it’s like as the weeks went by, we moved out in May so it hasn’t been that long now….

Q Ah OK, May of this year?

A Yes, quite recent. And like [boyfriend] was getting to grips with it, he was happy, and I was a bit of a mess I’ll be honest – and I still am to a certain extent. Because like I ring my parents and [brother] every single day, we go round there for dinner once a week every week, and I usually go round there for a day at the weekends, or mum and dad will go out and [brother] will come here. And I don’t look after him as much as I used to, which again makes me feel quite guilty, but I do still look after him when I can, if that makes sense. And I am more than happy to do it, don’t get me wrong, but as I’m getting older and things like work and further study and cars and bills and all that malarkey, rubbish that I never used to have to worry about are happening, it’s so much harder for me to find the time. And like if I get to an evening and it’s like 8 o’clock and I have forgotten to call because I’ve been so busy all day, I just feel like the worst sister and the worst daughter in the world. Because they are – as much as I love [boyfriend] – those three are still my world. Like [boyfriend] is very close to it but those three people are the people who I will do anything and will prioritise over anyone no matter what.

Time 25:08

And I have like been in and out of therapy for years but I had to go back to therapy when we moved in here because I couldn’t…. it was almost like, the only way I can describe it, you know when you click off off a window on a computer and it like shakes, whenever I was trying to think about anything my head was just shaking. Because my brain was telling me ‘you need to do this, you need to do that’ but my heart was telling me ‘but you can’t, you need to go and see your mum’. Or like I’ll be driving home and I’m like ‘if I go down this road I can go home for half an hour and like make them feel happy’. And like I want to see them, don’t get me wrong, but like the amount of time that I feel I should be spending with them is way more than what I’m doing. And it’s almost like there’s this pull in me that when I think of doing something for me I can’t do that without thinking of them first. And that’s something that I think will probably always be with me growing up.

And it’s like when I see my mum and dad now, my mum always says she’s really happy that I’ve got my own place and she’s happy that I’m living my life, but she’s so unhappy at the same time. And like my dad as well, he’s always really happy to me but like me and my mum went out at the weekend and she was saying how he’s like so much grumpier now and he’s complaining a lot more about the fact that no-one else understands the pressure of having [brother] in their life and the restrictions that it has on them, particularly as a couple. Because whenever they want to do anything they have to get, as horrible as it sounds, a babysitter every time they want to do it. And nine times out of ten that will be me because I’m the only one who [brother] is comfortable enough around, if that makes sense.

As much as my aunts will offer and things like that, my mum and me even to a certain extent we worry because, yeah they’re his family but like….it’s really hard to explain it….they’re his family but we don’t know 100% we can trust them with him. And it’s like, I don’t know, it’s so much harder to let other people in. And I think that’s why it does have such a strain on all three of us, because we do want to let people in and we do want to not be worrying about [brother] all the time but whenever we are in that position where someone else is looking after him it’s like constantly in the back of your brain, similar to like if you drop your kid at nursery for the first time you’re worried that whole day like ‘are they OK, are they looking after them properly, have they fed them, did they change their nappy’, things like that. But it’s like with him, he’s 30 and my mum still has that worry every single day because she can’t really trust anyone else with him, and it’s just….yeah it’s just really…..

Q Yeah and I guess were you expecting moving out of home to be so difficult in terms of the feelings it has evoked? Were you kind of prepared for that kind of mentally, or surprised?

A I think because I went to uni and I knew the impact that that had on me I did know that it was going to be really challenging and I do think that I was expecting it. But I don’t think I was expecting the anxiety side of things and my over-thinking and the constant worrying, I wasn’t expecting that to be as intense as it has been. Because every time like I’ve got a weekend I’m sort of in my head like ‘but when am I going to give mum and dad a break’, ‘when am I going to be able to spend enough time with [brother]’. And it’s like I was saying to [boyfriend] the other day, I sort of feel like my relationship with [brother] is drifting because I’m not there all the time. And like we still have conversations but they’re not flowing as comfortably as I….well as I’m telling myself they used to. And it’s just….yeah I’d say the worry side of it is a lot more intense than I was ever expecting it to be. OK.

Q Yeah. And it sounds like you’re not really in a position to be able to talk to your parents about your perspective on things and how it is for you.

Time 29:50

A I mean to a certain extent I can, but I just know that the fact that I’ve got some independence and I have got some freedom it’s nothing compared to what they’re going through, if that makes sense. So it’s constantly like in my mind, I do want to talk to them about it but I feel that if I do they’ll sort of be like ‘well you’ve got a house and you’ve got this and you’ve got that’. And it’s like whenever….because over the years there have been occasions where it has all got a bit too much for me and like me and mum will argue and me and dad will argue and it’s just always that line of ‘you don’t understand what it’s like to have a son with special needs’. And it’s true, I don’t understand what it’s like to have a son with special needs but I do understand what it’s like to have a brother with special needs.

Q And you’re not a parent so why should you understand what it’s like to have a son with special needs, you know you are not the parent.

A Yeah. So yeah. As much as we do talk about [brother] a lot we don’t really talk about me as much with regards to [brother], it’s always just generic as a couple if you know what I mean? Like it’s always like whenever my aunt and uncle go on holiday my mum gets upset because she’s like they can just decide at the drop of a hat, one day they can wake up in the morning and be like ‘we want to go to [town] for a night’ and they can just go, they can leave their son who is 21, who is like 9 years younger than [brother], at home and just go and do what they want to do. And like my other aunt’s a bit of a party animal and she’s got a daughter, granted she’s only 16 but she can go out and she can leave her 16 year old daughter and she’s completely fine. Whereas all my mum sees is, ‘I’ve got a 30 year old child and a 26 year old child, I should be able to do what I want to do now’.

And like my dad’s always said that before [brother] my mum was a completely different person. Like she’s only got 2 friends and she sees them about twice a year because none of her friends….she had a few friends who distanced themselves from her when [brother] was diagnosed and I think it’s put such a sting on her and a fear of like being rejected and misunderstood. Like mum will never talk to a counsellor because she just says ‘nobody understands, nobody will understand so there’s no point me saying anything’ because people just say you need to appreciate the good, which she does, but she says that doesn’t make it any easier to live day by day when you see people doing what you want to be doing. And it’s just….yeah it’s hard.

Q So a lot of that then falls to you to do the understanding and the….

A Yeah.

Q What supports, or what would make things easier for you then growing up and currently kind of?

A I think if when I was at school – and I’m not talking like when I was older I’m talking from when I was in like Reception – having someone there to just acknowledge the fact that I had a brother who had special needs. Like having someone, or a support group of some form. Like when I was at uni I volunteered at a Young Carers support group with kids. Like if there was something like that around…like I know there’s this charity [name] which is brilliant and like I’m on their email chain but I’m never brave enough to actually go to any of the meetings. But if something like that was around when I was younger and my school were aware of it and could have given my mum…like obviously she got a lot of advice from [brother]’s school about [brother], but I was always just ‘the other child’, I wasn’t sort of….no-one ever really worried about me and how these things bothered me. And I think just even having someone there to talk these things through with, I think growing up I wouldn’t have felt so confused and so scared and felt like I couldn’t talk to people.

And I also think that my parents then would have had the support to support me as well, because as much as [brother] went to a special school he was on transport and mum and dad never got the opportunity to meet any other parents in similar positions. And because of that I do think that’s a reason why we became so on our own, because mum was scared, and dad was scared, to let anyone else in. But I feel like if there were things like support groups for me which were recommended by say [brother]’s school for example, or even like my mainstream school, there would have been way more than just me in that school who were in a similar position and who would have benefitted from stuff.

Time 35:00

Like I remember when I was in, I think Year 4, there was a boy in my class who had special needs and there was like this club for him communication and they wanted kids who were in the class to support him. And I like signed up for that and he had a one-to-one. And I remember talking to her about [brother], and it was the first time anyone really showed any understanding. And I remember in my school report it said ‘Sophie’s really good at supporting our lower functioning children’ and things like that. And like me being a teacher now, I like to think that with like the safeguarding training and things like that that we get, if a child was to say that now I’d hope that the teacher would pick up on it and they’d want to learn more and they’d want to support that child, rather than just thinking ‘oh they’ve got a brother or sister with special needs, that’s nice’, if you know what I mean.

Q Yeah, so understanding that impact of being a young carer and having others around you recognise that and respond to that.

A And I think going back to the Children in Need thing that I mentioned, so many people are aware that if a child looks after their parents they are a young carer but there isn’t a lot of understanding…. like even now, again this is a bit of a ramble, but [boyfriend] went to a football game a couple of weekends ago and [brother] was staying here for the first time. And [boyfriend] kept saying to his friends ‘I need to go because [brother]’s staying, I need to get back before he goes to bed’ and all of his friends were just taking the Mick and were basically just saying ‘oh it’s not my problem that you’ve got that responsibility, just stay for one more drink’. And like when [boyfriend] got back, granted he listened to them which was very annoying and of course a big argument, but anyway, but when he got in he completely broke down and was crying and he was like ‘they don’t understand the responsibility of [brother], they just don’t get it’. And I was like ‘welcome to my life’. Like this has been my life for a very long time.

Like the amount of friends that I’ve had who are like ‘why doesn’t your mum let you come out’, ‘why doesn’t your mum do this…’ and it’s just….it was just really heartbreaking for me to hear him say that. Because I was like I don’t want to have to put someone in that position where they feel that they can’t do what they want to do, even though I know that’s what my reality has been for ever I really hate – and this is why when I was at uni I didn’t get involved with boys because I’d never want anyone to feel like…as dramatic as it sounds….the pain that I feel because of [brother]. So seeing him like that – granted he’d had a few beers so he was a bit drunk – but seeing him like that, I said to him in the moment, I was like this is like the most hurtful thing I think I’ve seen for quite a long time. Because I hated that I’d made him feel like that. Like it was because I’d put the pressure on him that [brother] was here and that I’m the one who said ‘you need to get back before he goes to sleep’ and that was all me. And that sort of….it made me feel like I was my mum because I was making him feel bad for enjoying himself. And it was really horrible.

But yeah, no it’s just…I do feel like….I don’t know if this is a bit dramatic but even, you know like when they do PSHE at school and they talk about different families and this, that and the other, let the other kids in the school know that there are families who have children who aren’t well and that there are families who have to do more. And like not just single out those young carers and take them out of their classroom and let them talk and then put them back in as if nothing’s happened, like give them a chance to have a voice and to let people know the reality so that when they grow up their friends….I’m not saying everyone will because I know that’s not going to happen, but there might be one person in their friendship group who listened when they did that lesson and bought into what they’d said. I just think things like that would be really handy to help just like generic understanding.

Q Yeah, so that the friends that you’re making today as well have that understanding and that kind of care and consideration I guess for different peoples’ situations.

A Yeah definitely.

Q OK thank you. Are you OK for time?

A Yeah, yeah completely fine.

Q Sorry I’m just looking at the list of things. Just to say a question, because this has come up in a few interviews about carers accessing CBT and how useful or not useful it is. Just out of interest do you find it useful, CBT for your situation?

Time 40:00

A I’ll be 100% honest – not really. So whenever I’ve been through it they’ll give you tools to cope in that moment. But being like a carer, as much as your responsibilities are the same no day is the same. And it’s almost like you get given all these tools to help you, which in an ideal world you will use and on the good days you can use, when like a spanner in the works is thrown in you can’t think about those, you don’t have the time to do your breathing exercises, to do your mindfulness, to challenge any negative thoughts. You don’t have a spare second to do it. And by the time you’ve been through those situations, say for example like my brother sometimes struggles with toileting. If he’s like had an accident and in that moment you’ve got to clean it up but you’ve got people round and it’s just all over the place. Until you stop and your energy has gone because it’s been so dramatic having to get everything fixed, you’re worrying about what other people are thinking and things like that, you can’t really use them.

And I feel like what I’ve struggled with is, I’ll do a therapy and then a couple of weeks will go by and I’m like ‘I need it again, I need more, I need some help’. And it’s like unless you can afford to pay for private therapy that is constant and you can see them twice a month and get out what you need to say, and it’s always something that you know is there and you can go and rant it out and it’s gone, if you can’t afford to do things like that you’re stuck in this six week cycle of therapy that gives you some things that you already know but you know that in reality they’re not really going to help unless everything’s fine. And I’m not saying it doesn’t help at all because it does have some benefits, but overall I haven’t had much help from them in regards to [brother] related worries.

Q And I guess it doesn’t change the situation ultimately does it, the practical side of stuff you are still going to be split between caring for [brother] and leading your life being a teacher. That physical kind of caring role doesn’t change does it and CBT doesn’t change that.

A And I know that that’s what my mum says because she tried counselling once and she was basically just told ‘you can’t change it, all you can do is try and think more positively’. And she’s like well if I can’t change the situation my emotions aren’t going to change. And that is the…if you put it black and white, it really is, no matter what therapy you go through it’s short term and it’s not going to change anything. So yeah.

Q No it’s interesting because that has very much come out in our interviews as well. And kind of part of the research is looking at how things can be improved, and I think it’s very clear that people want other people outside of your immediate bubbles to have more of an understanding of the situation, so like we were just talking about. And actually counselors and therapists come into that bracket as well to understand the realities of caring and why CBT isn’t this kind of one ???

A ???

Q Yeah exactly. Interesting, thank you.

A That’s OK.

Q I guess we’ve talked a fair bit about your parents, again thinking about what you’d like other people to know is there anything particular you would like to say to your parents if you could, or what you would like them to know ???

A I’d want them to know that I want to know what’s going to happen when they can’t look after [brother] any more.

Q OK.

A Because it’s something that’s always been brushed over, never sat down and properly come up with a plan. So I’ve always said that I will look after [brother] when they can’t look after him any more, whether that’s when they pass away or whether that’s when they’re so frail they can’t any more because he’s quite a big boy. So I would love them to….I’d love to just have that conversation with them. And I have tried to have that conversation a few times but there’s, again similar to when [brother] became an adult and there wasn’t a lot of support out there, there’s not a lot out there to support us as a group in terms of what will happen, if that makes sense. So I definitely want that.

Time 44:55

And I’d also want to say to them, because like I say my parents have never, ever, ever said to me ‘you can’t do this’, like they’ve never said ‘you can’t go to your own home’, ‘you can’t go to uni’, they’ve never said that to me. But I would like them to sort of know how some of the comments they make sometimes impact me. So like the little remarks when I was growing up, like ‘oh you don’t need to see your friends that much’ or ‘your friends aren’t that important, we’re the only ones you need to worry about’, little things like that that I know they wouldn’t have meant in a horrible way, I know they didn’t, but because of the way my brain has taught itself to cope with these things every little comment or every little glance or look or like tut, everything they say affected me growing up – and even now it still affects me. But it’s so hard to say that in a way without making them feel that I don’t want to look after [brother], if that makes sense, because I do want to look after him, I want to be a part of his life.

But at the same time, because of [brother] – and I feel horrible saying this – I’ve missed out on quite a lot in terms of….particularly me being confident in myself and having my own opinions and having my own voice because I’ve always felt that what my parents said was the way it was and if I ever disagreed with that there would be a blazing argument where I would be called selfish and things like that and I’d then feel like ‘oh hold on a minute, I can’t have this opinion’. And it’s just, yeah, I’d like them to know that I do want more from my life. And I don’t blame them for that at all because like I said they’ve never explicitly told me you can’t do anything. And I know that all of those little things that I’ve described they would never have meant it in a horrible way. But I do wish that – I say at the time I was a child – but like I do wish that I had the confidence to talk to them in a way without it being met with ‘how dare you say that’ if you know what I mean.

Q Yeah, and not become that competition of who has it worse or who is struggling the most.

A Yeah definitely.

Q So like you said, them having some training or support around siblings and young carers, is that you know sibling carers and how to manage that and the impact of that on you. Yeah.

A I remember when [brother] was at his special school there was a youth club every Saturday and you could take your siblings with you to the youth club, and I went with him there. And I was just sort of thinking like it would be such a good idea to use something like that as an opportunity to give parents either a space to talk about how they’re feeling, or give them a space to talk about how to support not only their children but to support their other children as well. And my mum particularly doesn’t do ‘people’ very much. She doesn’t really like mix in with people or things like that but I do feel like if right from the start when [brother] was first diagnosed if that was just the norm that as a parent of someone with special needs the expectation is you come to these groups once a month, if that was in place right from the start I do think she would have done it. Because she would have met people who ‘got it’ to a certain extent, they obviously wouldn’t understand how it was to be with [brother] because no-one else is like [brother], but they would have been more aware.

And it’s like when I went to uni and I had like a lecture on autism, my dad was asking me about it because he didn’t know a lot of the stuff about autism. Like he didn’t know the need for routine and the need for sensory regulation and things like that. And I didn’t know that. And it’s like if they’d have known that at the time when they first found out [brother] had autism then maybe it would have helped them to understand [brother] a bit more, which could then have been passed on to family and things like that. There’s something else that I’d want to tell them, I’d want to tell them to let more people in. Because I do think a lot of the reason why my mum in particular is so alone really is because she’s too afraid of letting people in. So that’s something else I’d want to tell them.

Time 49:50

Q And I guess if really more people were let in then it would reduce the responsibility on you as well, it would have that knock-on impact.

A Yeah.

Q This is all really, really helpful. Thank you so much for sharing and being so open.

A Sorry if I’ve rambled a bit.

Q No not at all, not at all. And this is why we record it because I think possibly….do you know what I mean, I might not remember everything though.

A Exactly.

Q Have you ever….sorry I’m just flicking again through the things. Have you ever had any….has there kind of been positive support? So obviously we’ve talked about where you think support would have benefitted you and your mental health, has there been any positive things what have helped your mental health kind of which you’ve experienced?

A So with regards to [brother] – again this sounds really silly, but when I was at primary school, I’m talking I think I was in Year 1, I was really, really little but I can still remember this, my school opened early so that siblings could have a school photo together.

Q Oh we’ve got that tomorrow at my son’s school.

A Oh that’s so cute. But like me and [brother] would never have got a school photo together because we were at different schools. And because this one school….and it was….I left this school a year later and my new school didn’t do it, but we’ve got this one photo of me and [brother] in our school uniforms together. And it’s so simple but it’s just a little thing that the school did that I can still remember now and I’m still grateful for now where he was included and he was acknowledged, if that makes sense.

Q Yeah, yeah.

A So something as minor as that. And similarly that youth club, it was so nice that I was allowed to go to it and I was able to meet his friends and like talk to the TAs, mainly from like wanting to be a special needs teacher, but like also talk to people who knew him on a different level. So that’s something that was really beneficial. And then because of that I met some other siblings, and when I went to uni I met a few people who had brothers or sisters with some form of special needs. And that is something that I really was grateful for because it made me feel less on my own. And also, I’ve just remembered, my mum bought me a book when I was….I can’t remember how old I was but I was primary school age, she bought me a book called ‘The Views From Our Shoes’ and it’s literally just a book about siblings writing about their siblings who have got special needs. And again that was really nice to have because it was good to see people….and I’ve just thought of another thing, I’m sorry. The film ‘Wander’ it’s based on a book. They obviously show the boy’s perspective and he’s not got like cognitive needs….

Q No, it’s facial isn’t it and….

A Yeah facial disfigurement, but they show it from his sister’s perspective as well, the film. And I remember watching that film and just being like ‘oh my God they’ve acknowledged the sibling’. And again it was something so minor but it just makes you feel a bit more like the rest of the world is going to watch this and they’re going to maybe start to see things from the sibling’s perspective as well as the parent and as well as the child. So little things like that just….I know it sounds so minor, but just where you are acknowledged.

Q Yeah and your role is acknowledged.

A Yeah.

Q I know. Yeah I can completely understand that. And given the kind of impact that those things have, you know the fact that you can remember them….say that photo in Year 1….it’s had that lasting impact, it shows it’s not minor at all doesn’t it? They might be small kind of instances but the impact of them really isn’t that minor at all.

A Yeah.

Q Thank you. Is there anything else which we haven’t kind of discussed, particularly in relation to kind of your experience of caring and mental health? Is there anything?

A I don’t think so to be honest, I think I’ve said everything.

Q Brilliant, thank you. I’ll just stop the recording there.