Q There we go, that says recording now doesn’t it?

A Yeah well it said that. I can’t see it on the screen.

Q And so the last thing I should mention is, I’m working from home so if I mute myself it’s because there is background noise, the dog barking or something like that, it’s not because I’m not listening or paying attention.

A It’s also possible that my cat will come and interrupt ???

Q Great. If you don’t mind starting then just by explaining what made you interested in taking part in this study?

A Well….so I went to the event a couple of weeks ago run by [CHARITY], so like the adult sibling day. Me and my sister both went because we have two…well our two youngest siblings both have quite severe intellectual disabilities. And they are getting to kind of young adult stage now and they still live with my parents but there’s a lot of kind of questions about what happens next, my parents aren’t getting any younger. So I guess we’ve been quite anxious about the future and that’s one of the reasons we went to the adult [CHARITY] day just to kind of get some advice and kind of peer support. And that’s when I found out about this project. And I think my sister already has done it, she went and did it, and I was just like ‘yeah I feel like that might be quite cathartic’, there’s quite a lot of feelings and thoughts about this stuff.

Q OK, brilliant, thank you. Can you tell me about your experiences of being a carer then and about your younger siblings and your sister really?

A Yeah. It’s kind of a weird one because I feel like I don’t really think of myself as a carer a lot of the time because you know I don’t live with them and I don’t have any like responsibilities as such. But I guess like when I am with them I do kind of automatically go into a carer role, because you have to. So yeah I guess like I probably spend the most time with my brother and he’ll come and kind of stay with us sometimes. Which is really nice, like I love him and he’s great but it’s also so hard because it’s just like….you just always have to be ‘on’, like you can’t really like switch off at all because he just needs support all the time. And it’s the same with my sister as well but I only usually see her if I go home to my parents house. And yeah, it’s hard.

Q What was it like then, did you live together growing up?

A So only like not….so they’re both adopted and they were adopted when I was like in my….well when did [brother] come….must have been like late teens early 20s. So I never lived with him, either of them full time, but there have been like periods where – for example like my dad was really ill for a bit and I had to go home and live with them then. And just like really intense basically. Yeah I found that really, really, really hard. And I think partially because my dad was ill but also just like I don’t think I had quite realised until that point just how intense it was to care for both of them. And it was quite overwhelming actually.

Q I guess you’ve got the two things going on there, like you say your dad being ill and then stepping in to the carer role, so it’s a double kind of thing to manage.

Time 5:00

A Yeah absolutely. So he was out of action completely, he was in hospital. And then my mum was like trying to like visit him – well we were all trying to visit him but like….so I suppose like me and my sister especially kind of almost like took on maybe what my dad’s role would be in caring for my siblings in that instance. And yeah so we were doing like food and entertaining and personal care and, you know just kind of everything. Yeah it’s a lot.

Q And was it expected that you go home, or did you volunteer it, or how did that come about in that instance?

A I think that I volunteered it at the time. I mean I wanted to because it was like….we thought my dad was going to die basically so it was like, you know I wanted to be there. And we kind of almost needed all of us to be there. There are 6 of us in total so yeah we kind of needed to be there to almost take shifts to like get everything done to go and visit my dad and to care for [brother] and [sister] and just to generally run the house. So yeah it was….yeah.

Q How is your dad now, has he recovered?

A Yeah he has recovered, yeah he has. He made a full recovery against every expectation, so that was amazing.

Q Oh fantastic.

A I suppose it like demonstration like what the issue would be if either of my parents weren’t around in the context of looking after my siblings. And I think that’s probably been in our, at least mine and my sister’s mind ever since, it’s like what happens when they go, or like when they’re not able to care for my siblings any more. And I know that we both worry quite a lot about that. And yeah it’s like kind of considering the question of, you know how feasible, or like how much can we move from maybe just being that kind of a sibling who like dips in and out and does care when we’re there but doesn’t need to be there all the time, to like you know what role will we have later on.

Q And does that impact your mental health then, like those kind of thoughts and worries?

A Yeah.

Q Yeah. How does that play out for you?

A So I’m actually having some therapy at the moment, like I’ve been doing psychotherapy for like 2 years. And at the beginning of that I would never have really considered that this situation was something that impacted my mental health. It was just like ‘this is how our life is’ so you just kind of get used to it. But I suppose over the last couple of years I’ve been unpacking like what’s going on and how that has impacted me. And like you know I have had some quite significant mental health difficulties since I was a teenager, if not before, but I never really understood why, like I was always quite confused about….like I was just like well nothing bad has happened to me, like you know it doesn’t make any sense that I would be like super depressed or super anxious you know and have quite a lot of obsessive thoughts. And yeah you know it’s been quite a journey to get to the point where I’ve been able to like put that in context of like ‘actually this has been really difficult for me growing up’. And before we adopted [brother] and [sister] my parents also fostered children with learning disabilities, and that’s been since I was like 8 years old. So kind of gradually figuring out that like a lot of stuff, a lot of difficulty I’ve had with my mental health may have a link with that.

Q Yeah. So whilst you’re kind of used to it and it’s part of your family it still obviously has an impact on you, and it’s about picking that apart and working out kind of what’s going on.

A Yeah definitely.

Q And are you finding the therapy helpful?

Time 9:30

A Yeah it’s really helpful, yeah. It’s hard, like it’s really hard, and especially recently because it’s kind of like I’m exploring all this stuff in therapy but then it’s like getting to this kind of almost crunch point in the family where….you know. So my parents….so I always kind of like….my parents haven’t really communicated to me like what their plans are or whatever but a few years ago we all, like me and my sister and my other brother all signed some documentation which was basically like if my parents lose capacity then like we are…you know, what’s it called, we have Power of Attorney. And I’d kind of signed it at a time in my life where I was just like ‘yeah whatever, fine’ and didn’t think about it again. And then I think through the like course of discussions in therapy I was just like ‘hang on a second, what was that and what will it actually mean for me if something does happen to like either of you’.

And so I asked them, and it was like ‘I don’t even have a copy of this paperwork’, like ‘could I have one so I would know what it is’. And also ‘what are you plans about the future’. And it transpired that they were also like putting together some more paperwork for me and my other siblings, like non-disabled siblings, to sign but they’ve not spoke to us about it and I think there’s a bit of an assumption that we were going to take on some responsibility, deputyship is what they were thinking about, so we would literally then like have control of my siblings’ finances if they weren’t around. And yeah that’s been really hard, like because I was quite angry like that they’d not discussed it with us. And then I went to the sibling day and found out more about what that actually might involve, and I was even more angry because it’s not an insignificant thing to take on. And yeah.

Q And does that put you in a difficult position then with them, because if they are assuming it and you’re not necessarily sure about that?

A Yeah it does. It feels really difficult at the moment. Like I did say to them, like I’m not going to sign anything without knowing exactly what it is from start to end, like also I’m going to get some advice about this. So they knew like me and my sister were going to go to the sibling day and that we were going to be looking to find out some information. And yeah, but it does feel…. I mean it’s not like they’re like putting pressure on us or anything like that but it does feel difficult because it feels like, you know there is a bit of me that feels like I should be responsible in the event that something happens to my parents. But then there’s another bit of me that’s like ‘well what about me and my life’ and yeah it is tricky. And I think there’s a lot of kind of guilt for feeling like maybe this isn’t something that I really want to take on.

Q Yeah. How did your kind of….when you kind of put that to your parents how did they respond to that. You know when you say ‘hang on a minute I’m not sure I want to sign this’ or ‘I’m not sure I want this’, how do they respond to you?

A They were like OK, you know they didn’t really say much about it, like…no. Yeah it was kind of at the end of quite like a long and intense conversation that we had during the summer, and yeah they didn’t….they were just like ‘alright, OK, yeah’. You know my dad was like you know ‘I’m sorry that we haven’t communicated back with you’ and like ‘I’ll get you a copy of the other paperwork that you’ve kind of got’ and ‘we’ll talk more about it’. But we haven’t really to be honest. Yeah I feel a bit at the moment it’s me kind of trying to drive conversations and get like some….yeah like a proper conversation between everyone. I think there’s a lot of avoidance basically.

Q From them kind of not wanting to think about the future?

A Yeah I mean I don’t know, like that might have been just my perception of it. But I’m sure they must talk about it between themselves, but like it doesn’t feel like we’re really included in the conversation very much, and I think that’s the difficult thing, yeah. So I don’t know. At the moment it’s quite like a weird point in time, there’s lots of uncertainty.

Q Yeah. And it sounds like you and your sister are kind of on similar wavelengths in terms of your thoughts around the future then and kind of uncertainty about it.

Time 15:00

A Yeah, I mean we definitely both think about it a lot and worry about it and we’re like, you know concerned for our siblings’ futures basically. She works in Disability Rights so she’s got a really clear idea of like what it is that is like (1) possible; and (2) you know what kind of should be happening, or what would be ideal. And you know I work in mental health and I’ve also worked in kind of institutional settings and stuff like that so I think that I also have a certain like amount of….I suppose like knowledge about maybe how this could potentially play out and like some of the stuff that could go wrong etc. So yeah I think both of our professional lives are informing like probably some of the anxiety around like wanting to get things kind of set up so that they are taken care of in the future in the best possible way. Yeah. And then we’ve got two other non-disabled brothers as well but they’re much less like involved in that way, like they….yeah don’t really get involved at all.

Q OK, why is that?

A So I think one of them just tapped out a long time ago because they found it too hard, that’s what I’ve like surmised because he’s not really a chatter. So like as much as I’ve kind of tried to like get him to chat about it he’s just not really up for it. And like he’s just had a baby in like the last year so he’s just kind of like doing that, which is absolutely fine.

Q I can understand that, yeah.

A And then my other brother, he’s quite young really, he’s only like….is he like 26? He still lives at home you know and he does help my parents, like he will kind of look after my siblings if they need to go out, or he does a lot of like driving around for them and stuff. But again he’s like not very…he’s not a chatter at all. And I don’t know, like he does have like mild learning disabilities as well and I think maybe discussing some of the more complex concepts involved in this is like a little bit….like I think he’s just like….I think he just taps out as well.

Q OK. What kind of support do you think you would benefit from, or what would make things easier for you as a sibling?

A Would have been to know about the [CHARITY] charity a long time ago. Like I feel quite pissed off really that like it feels like we….my parents have been involved in like fostering and adopting for so many years and like you know we’ve been in touch with countless social workers and like no-one’s ever asked like if it affects me.

Q Yeah, like ‘hang on a minute you’ve got other children, what’s the impact’ yeah.

A Yeah. I just feel like it just has been given no consideration at all. So to the point where I didn’t even think that it should be a consideration, if you see what I mean?

Q Yeah, just kind of been conditioned.

A Yeah exactly, like ‘that’s how it is and this is just how our life is’. So it’s only just recently you know from my own therapy, like which I’m paying for, to be like ‘actually what do I need’. And yeah I think that it’s kind of wild actually that social workers at no point have really asked that question to me or any of my other siblings. Yeah so to me it would be that, it would be early on like some kind of recognition anyway.

Q Yeah, and that didn’t even come up in the adoption process of them?

Time 19:40

A It did ??? ever run. But I don’t know. It’s kind of like….I don’t know. So [brother] is a bit of like an interesting kind of like anomaly almost because we didn’t….he’s from Thailand and we didn’t know how much disability he had at all. So like in all of the stuff for that it wouldn’t have even been like a consideration I think. With [sister], yeah I can’t remember actually, like they definitely spoke to me. But I think like I wasn’t really aware. Like maybe that was kind of, you know I was just like ‘oh yeah’, of course, more doctor and things.

Q Yeah, and if they’re looking at things from the perspective of [brother] and [sister] rather than the perspective of you guys then I guess it’s just….it gets lost, you get lost in it.

A I think so, yeah. I think it would be being specifically like someone saying that ‘it might be a thing that this affects you’ and be like ‘here are some support options’ or whatever. Yeah.

Q And your parents didn’t recognise that then either at the time?

A No – or now even I don’t think. It doesn’t feel like….which to be honest might be like quite a bit of a problem in this situation. I feel like they’re quite like oblivious. I did like send them a…there was an article I think maybe in The Guardian not that long ago like specifically on this topic.

Q Oh right OK.

A And about how having a disabled sibling might impact other siblings’ mental health. And yeah I was just like ‘I would really like it if you could read this, I think it would be really helpful to help you understand like maybe how the rest of us feel’. And they just didn’t really respond. So yeah, I don’t know, I don’t know whether it’s a bit like generational and like not really that great about acknowledging feelings or mental health. Yeah.

Q That must have taken a lot of courage to send that article.

A Yeah it did scare me to be honest. Yeah. I think that I sent it and then just like threw my phone on the sofa and ??? without my phone, so I was just like ‘oh!’. Yeah.

Q Oh good for you for trying at least. What do you, if you could say anything to them then what would you say, I guess?

A I think it would like be….you know….you know you put so much like effort and care into caring for these kids, which like obviously you have to, but it does just feel like the rest of us just got lost along the way. And it would be nice to have the acknowledgement of that because it kind of feels like the relationship that like me and my sister anyway have with my, like especially my mum, is just like almost non-existent because she’s so consumed I think with caring for them.

Q Yeah. And you mentioned you pay for your therapy, is that private then?

A Yeah.

Q Have you been able to access any through the NHS?

A Yeah I have. I’m trying to think back now. Yeah I was on like a waiting list for ages and then it came through at the beginning of COVID I think. So it was online or like over the phone, and I just didn’t like it basically. And I just felt I couldn’t really make any connection with the therapist. And it just wasn’t the right time. You know I was having to like do the calls in my bedroom and I just wasn’t really like into that at all. So I just said like I didn’t think this was the right time for me to do this.

Time 24:50

And then, to be honest I don’t think that the NHS are going to be able to offer me the kind of therapy that I need. Working in it I know very well what is and isn’t available, and the therapy I’m having now it just wouldn’t be available at all. It’s open-ended, it’s really like psycho-dynamic, so it’s not just looking at thoughts, feelings, behaviours, it’s like what is actually underlying this process. And that’s what I have needed because I didn’t know what the hell was going on, and she’s like really helped me to see like maybe some of the kind of underlying causes of what goes on for me with my mental health. And that’s what I needed really.

Q What would be offered to you on the NHS then?

A I think it would be CBT.

Q Yeah. Which wouldn’t work?

A I mean I just don’t think it’s enough. And it would be 16 sessions, maybe 20 if I was lucky. And I’ve been seeing this therapist every week for 2 years now and I feel like we’re only just getting to actually what the issue is probably. And yeah I don’t think 20 sessions of CBT would have done that at all.

Q Yeah fair enough, that makes sense. Is there anything else you think would have been beneficial? So kind of knowing about [CHARITY] and support as a carer I guess, is there anything else alongside that that you feel?

A I mean I actually think that family therapy would probably have been amazing, be amazing, I don’t know. Like I think at the moment I really am like I just want to get everyone in a room and talk, but everyone feels so like avoidant of it that it seems like an impossible ask. And I wonder if like family therapy had been just like a standard offer for foster families, or families who are adopting, families who have got children with intellectual disabilities. Like would our relationship have been better if that had been available early on and just kind of offered as something that is probably quite useful because this is a difficult situation.

Q Yeah it’s interesting, something similar came up in another interview, not necessarily about therapy, but if something was just part of the process then the family would access it. That they wouldn’t necessarily go out of their way, the parents wouldn’t necessarily go out of their way to access it so then you kind of miss out on it. So it’s about having stuff embedded within the process, or social workers being like ‘this is what most families do’ or ‘this is what families access and take up’, real clear signposting.

A Yeah definitely. I mean I have so much respect and also empathy for social workers working within a system that is really, really stretched. But this is one of those things where I feel like if this was embedded in your processes for families then you would probably like save so much money down the line, or you know so much of your work time down the line because you would have kind of pre-empted some of the probably quite standard problems that arise when you have somebody who needs that much care in a family. Because you know that’s the thing that going to the [CHARITY] day showed me. Like we had a kind of taster, kind of support group kind of thing, and people were just saying stuff and I was going ‘oh my God, you read my mind’. Like everyone was having that experience. And it’s just like OK so this is really common to feel like this and it’s really helpful to know that. But like there’s no way you are going to know that unless you have contact with other people who have the experience or whatever. So yeah.

Q Yeah OK. What did that feel like then, going to that day then and being around other siblings and sharing those kind of stories in common?

Time 29:50

A It was amazing, like it was really like….it was so….it blew my mind. It was really emotional. There was lots of kind of like people being like ‘blugh….’ like just talking to each other and sharing their experiences and then like realising ‘oh I’m not the only one who feels like this’. And there were so many commonalities in what people were saying that it was really like reassuring. Because I think there’s so much guilt attached in like these situations, it’s like ‘oh I want to make sure that my siblings are OK and I want to help my parents etc, but then I also find it really, really difficult and it is like disruptive to my life or to our family life’. And it’s like hard to like disentangle those things and like just being about to talk to people about the really difficult aspects of this was so helpful. And yeah, and then just to learn about all of the stuff that we kind of had questions about as well was great, really good.

Q Are you going to keep going, like do they have online support groups and stuff that you’re going to stay on?

A Yeah they do. They’ve got them all over the country. So I’ve signed up. So that’s good, I’m really looking forward to actually going to that because I just think it’s going to be really helpful.

Q Brilliant.

A Yeah. And they do work with younger children as well. And actually my mum’s sister adopted a child with severe disabilities as well and then he’s got a sister who, she’s also adopted but she’s not disabled. And I just sent the information to my auntie and was like ‘please tell [cousin] about this because like she will need that support as well’. She’s 11 and I just think if she can get that now, like….

Q Yeah, tap into it early.

A Yeah definitely. I think if social workers also knew about [CHARITY] and could just give that information to families when they see them that would also be really helpful I think.

Q Yeah. Obviously you don’t have to answer if you don’t want to, but do you have a partner or does it impact, kind of conversations about the future impact on relationships or anything like that. Because obviously it’s a big thing for you what will happen in the future.

A Yeah it does. And yes so I have a partner, we’ve been together for 6 or 7 years now. And when we met I was just like ‘I don’t want children’ and so did he, and we were like ‘great, cool, this works’. And yeah and he….you know he met my family and is very like great with my siblings and has been like very accommodating when my brother’s come to stay and like I’m really grateful for that. But I think he also was the first person that really like witnessed how hard it was and kind of reflected that to me, I think. And I was just like ‘oh, OK, maybe this is really hard’. And yeah so I mean I don’t think it directly affects our relationship as such but I think my mental health difficulties have done, definitely. And that’s like because a lot of the stuff that happens for me is like obsessive thoughts about the relationship, which I never understood until quite recently really. It’s like I think due to relational trauma as a result of my kind of family dynamics. And I think essentially I’m terrified of getting close to anyone, and that’s especially amplified in like a romantic relationship. So that’s the thing that we’ve been trying to unpick in the therapy really.

But before I was really like able to understand that it like really impacted, because I would just think it was to do with him and that like I would feel like I needed to end the relationship all the time, or be like nit-picking about his like behaviours or loads of different stuff. And it did have really a negative impact. But like through a good few years of kind of figuring it out and doing the therapy and stuff, now it’s much, much better. And yeah we have been talking recently about the future, especially like with my sister and her partner as well, like we’ve….

Time 35:10

Q Oh you’ve just frozen….

A ….had discussions before. Oh! Have I?

Q Sorry you’ve just unfrozen again.

A OK.

Q So I got up to with your sister and her partner you’ve had discussions with them?

A Yeah so we’ve had discussions among the four of us about like what will happen and like, you know kind of be like I feel like we’re going to end up looking after [brother] and [sister]. And they don’t have any kids either and like, you know I don’t think that they’re sure that they do. And I think at one point we were kind of like just kind of accepted like ‘oh maybe this is what will happen’. But then like more recently, like maybe in the last like year or so I’ve been like ‘OK I think I actually do want kids’, so me and my partner have been talking about that. And like, you know actually if we have kids then it’s going to….you know our capacity to be really involved in [brother] and [sister]’s care would be a lot less. And yeah. So yeah it does kind of impact the conversation. But I suppose like I’m gradually trying to figure out what it is that I want and go with that, rather than be like feeling like I have to, or like become responsible for them at some point. But I think my sister still feels like she will and she wants to do that.

Q Yeah, so finding your own voice and your own kind of path I guess outside of what’s expected or assumed or….yeah OK, thank you. Is there one story in particular that you can think of – don’t worry if there isn’t anything – but if there is one story in particular which springs to mind which kind of sums up your experience of being a carer, or having siblings with disabilities and how it impacts on your well-being?

A Yeah I think it’s probably…there’s always like a kind of scene that comes to mind of like the time when I was living at home and my dad was unwell. And you know always like want to make sure that they’re having a nice time basically and we took them out to the park and, you know it was a really nice day and stuff and like it should have been nice. But like [sister] was just….she’s extremely repetitive in the way that she talks especially when she’s anxious, and she was really anxious, my dad was in the hospital like and she didn’t understand. And she just like was going on and on and on I think asking where he was, because she like just couldn’t settle really.

And I don’t think that I shouted at her but I remember being like so frustrated and like just feeling horrible. Because I was kind of like it’s not her fault, and like she’s anxious and this is a horrible situation, but like I feel shit and then I feel like I was like not being very nice to her and not very accepting of her. And it’s just like for me that kind of encapsulates that kind of like horrible quandary of like this is really difficult but like it’s not your fault. I want the best for you but also it’s really difficult to spend time with you, and that really impacts how I’m feeling, and then that kind of impacts you. It’s like this kind of cycle.

Q OK thank you, yeah that makes sense. Sorry I’m just looking at the topics roughly that we’ve got to cover just to see if there’s anything else. A bit of a tricky question maybe but have you observed or experienced discrimination in mental health care, or kind of….

A I don’t think so.

Time 40:00

Q No. Is your therapist understanding of having siblings with learning disabilities, or learning disabilities, do they get it?

A Yeah I think she does, but I also think that she’s like super focused on me, which is like the most helpful thing. Because I think that like if she wasn’t I would just let it be about them probably. Yeah.

Q Yeah, which is what you need in therapy isn’t it, about you.

A Definitely.

Q Yeah, having that space.

A Yeah. And yeah she is very much like focused on like interpersonal stuff and she just does kind of keep everything on that and like how the situation must like impact on the relationships and like the feelings within the family. I haven’t really like….other mental health professionals that I’ve been in contact with I don’t think I’ve really spoke to about it honestly. Yeah.

Q I was just going to ask what was your experience of mental health care when you were younger then and kind of growing up?

A I didn’t have any experience of it.

Q Non-existent, yeah.

A Yeah. I mean I didn’t even know until like I left home I think that how I felt wasn’t normal. Like I remember realising that I was depressed and having previously had no words for that, like just thinking that like that was just how I felt, that’s just what I knew.

Q It was just you.

A Yeah exactly. And I mean I don’t think that mental health was ever discussed at home. Like my mum especially is quite phobic to like feelings, so it just wasn’t ever like a discussion basically.

Q And nothing was picked up in school or university or anything like that, if you went?

A So when I went to university that’s when I realised that this wasn’t normal. And I did go to university counselling, that’s probably the first bit of like support that I ever got – I think. Apart from I did go to the GP and they just gave me anti-depressants.

Q Oh right OK.

A So that was my first experience was going to the GP saying that I feel really low and crying I think in the GPs office. So I would have been 18 I think then. And him just giving me anti-depressants.

Q God.

A Yeah. So that was my first experience of like sharing how I felt with someone was that.

Q Take a pill and then off you go.

A Yeah exactly. And I think that I took them for like 3 days and I was like ‘no, I want to deal with this myself’. But I didn’t know how to do that or what the options were. But yeah then I went to the university counsellor at some point, and yeah because it was really affecting my relationship at the time having these like intrusive thoughts. And they gave me like a couple of strategies I think to help manage the thoughts, which were probably quite helpful. And I did get to go to like a managing low mood course at the university, which was also really helpful. It was just teaching like CBT strategies essentially. And you know I really struggled with insomnia before that, but that really improved after I had been on that.

Q Oh right.

A So that was good definitely. But yeah. And then I’m just trying to think after that. I don’t know what would have happened next really, I think I just spent quite a lot of years drinking a lot to try and cope before I realised that I needed to do something else.

Q Yeah. And obviously I guess you’ve got to be in a financial position to be able to pay for your own therapy and ongoing, it’s not cheap is it?

A No, no it’s not and I think, you know I probably couldn’t have done this before now honestly. Like there’s a few things that have conspired to mean that it’s the right time, and like one is money and the other is I’m in like a really flexible work position so, you know I can just go to my therapy session when I need to and I can work what I need to do around that. Yeah, so previously I think it would have been really, really difficult with my other jobs, so yeah.

Time 45:13

Q OK thank you. Is there anything else kind of about kind of being a carer, your experience and particularly in relation to kind of your well-being and mental health that we haven’t touched on that you feel is important or you can think to share?

A I mean I think I feel like I’ve talked a lot about the negatives, but you know there are positives and like you know my relationship with [brother] especially is really good. And as much like it’s hard work to look after him, like he’s so funny and he’s so lovely and like he’s actually like way more emotionally expressive than ??? my parents. And so like it’s actually like a massive like mental health benefit when I spend some time with him, you know. It’s like you can’t really be too sad in the company of [brother] because he’s just like so funny. So yeah I don’t want to just say it’s all doom and gloom.

Q No, that’s really nice to hear. I think the danger with this type of thing, because obviously we are exploring and I’m picking like mental health so there is a tendency isn’t there just to go for the negative stuff because that’s the nature I guess of what we are discussing. But within that then the fun and that sense of joy does get lost in those conversations doesn’t it because we are focusing on kind of negative stuff.

A Yeah absolutely. And like, you know I do think it teaches you lots of like skills that are transferable. I mean like I’m sure that I probably wouldn’t have been doing the job that I’ve been doing had it not been for growing up as a foster sibling and then as an adopted sibling of children with learning disabilities. You know you do learn patience and kind of tolerance of challenging behaviours, and for me it’s like kind of understanding what actually someone is trying to communicate, rather than like just seeing it as like a naughty behaviour or whatever. And you know that has stood me in very good stead for what I do, and it probably is why I do what I do.

Q And sorry if you don’t mind me asking, what is it that you do exactly?

A So I’m trained as a mental health nurse and for a long time I worked in a children’s in-patient unit. And then like I’ve moved from that into a more research role and now I’m doing my PhD which is looking into peoples’ mental health services.

Q Oh OK. What stage in your PhD are you at?

A Second year, just started the second year. So yeah I’m just in the process of trying to get responses to a survey that I’m doing nationally, so that’s fun!

Q Good luck, it’s such a slog. I finished mine 2 years ago and, yeah I can empathise.

A I’ve got really demotivated recently, it’s like the first year I was like ‘yeah this is great’. And like the last few weeks I’ve just been like ‘oh my God’. But I’ve heard that’s normal for year 2.

Q Yeah. I just found the whole thing I think just a bit of a roller coaster. Like I’d be in love with it and absolutely love what I was doing and everything; and then other times just like, yeah completely despondent about it and just like ‘oh this is awful’ you know, and just have such highs and lows throughout the whole process. And even from day to day, like you have one good meeting or a good….you know you get loads of responses to a survey, to your recruitment and stuff like that and so you are on a role, and then a day later you get a negative response or something and it’s just like….

A Yeah, yeah.

Q Oh good luck with it.

A Thank you.

Q Sorry, digressing. So you’re talking about how thinking about the fun and the humour and stuff as well, and the joy that they do bring to your life and they can bring to your life, yeah.

A For sure.

Q Yeah, lovely OK. Is there anything else before we finish up?

A I don’t think so. No I feel like that’s covered quite a lot of stuff, yeah.

Q I’ll just stop the recording then.