Q Perhaps we could start then by just you explaining what made you interested in taking part in the research?

A Well I think actually I’ve just got a really big interest in sort of helping facilitate these conversations. I think it was like 20…maybe lockdown was the time that I properly started exploring ‘oh…’ it just made me realise ‘oh my lockdown is different to other people’s lockdowns’. But also it just gave me time to think. And I’m trying to think of the timeframe now, whether it was January before lockdown or after. But basically I met for the first time, I met someone who also had a sibling – so my brother’s autistic, so also had a sibling who is autistic. And her sibling is non-verbal and her family are all in Northern Ireland. So like meeting her was the first time that I actually sort of realised ‘oh no, yeah we are carers’, like that was the first time that we actually said that and were like… Because you watch Children in Need and there’s like different levels of caring responsibilities, and I always thought ‘well you know he’s not in a wheelchair, he doesn’t need his nappy changing’, which I’ve got friends who their siblings do, but actually nonetheless you were still born into some sort of caring role because….but you’ve just never really realised that’s what it was because it’s all you’ve known. So then meeting someone else who had that experience, it was the first time we were like ‘oh no, yeah we are carers’. And so then I went on to write a show about my experience. So when I heard about this I was like ‘oh brilliant’ because I just think…. like the people I’ve met that came to see the show and the conversations I had in research for my show just made me realise how little is known about it and how little is spoken about the role of the sibling carer. And actually a lot of sibling stories is they don’t define themselves as a carer until you sit and reflect and you realise ‘oh no, but that is what I do’. Yeah.

Q What was that realization like for you then?

A To be honest it was just refreshing. I think because I was experiencing it in conversation with someone else and we had that connection. But then it was also tricky because I did battle with a lot of guilt with calling myself that for a while. Like I say because it’s like as far as things are concerned I actually had a really easy run of it, like it could have been a lot worse, do you know what I mean?

Q Yes, so you kind of felt you didn’t fully identify perhaps with that label, or there was something kind of not quite….yeah.

A Yeah. Because like in our household my mum was definitely the primary carer and we had a lot of like wider family support around us. So I was never forced in a position of like…like as a child I was never like ‘oh my word I am his sole responsibility’, it never felt like that. It was just that I’ve always been aware that I do have a caring responsibility towards him and that that will become bigger the older I get, and when my parents aren’t here I will become his primary carer. So it’s more in that sense I guess. Whereas again, like in research I met people that they really are their sibling’s primary carer because their parents work. So it was like a weird, it was like on one hand it was like ‘oh this makes so much sense and this helps me frame why I find things hard’, but then on the other hand I felt, what’s the phrase when you feel like you’re not good enough at something…. Imposter Syndrome.

Q Ah, OK yeah I get that the whole time.

A Yes. So I had a weird sort of Imposter Syndrome with the word ‘carer’, I think that’s…

Q OK that makes sense, yeah. OK. And what’s your current situation then? You said lockdown was very different for you, were you living at home, are you still living at home, or what is your….?

Time 5:00

A Yeah, so lockdown. So I’ve never lived further away than an hour from home, so I’ve always been within an hour’s distance. But in lockdown I moved back in with my parents and my brother. Yeah, and because obviously he didn’t know anything about it, all we knew is we got a letter from the doctor saying he was on the vulnerable list, and so….you know….yeah. And also just it was a big enough change for like neuro-typical people let alone like my brother, like it was….yeah. So it just meant the main thing was I realised I was taking it and having to take it a lot more seriously than a lot of other people my age and like friends that I had, and that actually the effect coming out of it I found it really difficult to like accept that it was back to normal. It took it me longer to accept that than a lot of my friends. And I think looking back I think that was because I was in such quite a ‘we need to take this seriously’ household. Yeah.

Q How did it kind of come about then you moving back, was that your decision to help your parents and your brother. Or what kind of prompted it I guess?

A The main thing was money. So I’m self-employed so I lost all my work and our landlord wasn’t going to lower the rent. But then there was also a part of it that was like I don’t know how long this is going to be. And I do have this thing where I sometimes worry if I spend too long away from [my brother], it makes it even more difficult to like interact with him. And we can’t communicate over Facetime and stuff, so that was definitely in there of ‘OK I just want to be at home because I don’t know how long this is going to be’. And the thought of that is quite scary. And in the end I’m glad I was because I think it would have been even harder for my mum because my dad was still working, so yeah.

Q OK. And what were your experiences then kind of as a carer? I know obviously the difficulties that are necessarily identifying with that but just for the sake of just using it here, kind of what were your experiences of your brother and growing up in your family, what was it like for you?

A Basically that, I don’t know on reflection, but everything in our house was catered towards him basically. So sometimes if you’re like in the frame of caring, sometimes our caring responsibility would be to like not be at home all week because he needed the space and my parents needed the space. So me and my other brother would go and stay with my grandparents during school weeks quite a lot. And in that way….it’s so weird, I think actually a lot of it on reflection is like helping my mum out more than anything. But yeah. And if they went out for meetings in the evening, my parents, then when I got to an age where I was responsible enough then it would be like ‘oh do you mind staying in because [my brother] can’t be left on his own’. Which was weird because [my brother]s older than me. So it’s stuff like that that you’re like ‘ah but really he should be the one staying in to look after me, but I’m the one staying in to look after him’. And because he really struggled with change, and like Saturday nights were like his sacred ‘we’re going to have a takeaway or fish and chips and we’re going to watch trash TV’, well what I think is trash TV, like you know things like X Factor and stuff like that. It would be if he was having a really rough day and had had quite a lot of meltdowns that day and I was going to go out to a party, I’d not go out to the party because I knew it would like make things worse.

Q Exasperate the situation.

A Yeah. So yes, so it’s like that weird, I didn’t ever have to do like hands-on when I was younger. Now I’m older I do, like I’ll teach him how to cook when I’m at home and take him, if he wants to go to the cinema I’ll go with him so he can go; and if he wants to go into [city] I’ll get the train with him. Stuff like that, like those sort of caring roles of helping him be more independent I guess.

Time 10:15

Q And has there been an impact do you think on your mental health?

A Oh yeah.

Q Yeah? OK.

A Yeah. Yeah. I started therapy in lockdown because of it, because it just…like moving back in. I think having….so I left home in 2015 to go to Drama School and then lived in [city] for a few years before lockdown. And like I say I was no more than an hour away so I’d be able to pop home. If mum was like ‘oh me and your dad want to go out and we can’t get a sitter’ like I’d pop home easily, but I never like lived with them since 2015. So 2020, moving back in, suddenly like realised how much I was walking on egg shells, how much actually…like I had quite a few moments of just being like ‘this just isn’t fair, like what if I want to do something tonight but actually just because that would upset him I can’t’. And it just felt…it just made it so apparent like how little….how much I just felt I couldn’t be myself in my own family home. And I think that’s….yeah. So realising that in lockdown spurred me to sign up for therapy.

Q And was that then because you’d had that break, you’d lived by yourself and then you kind of go back and you’re able to see it from I guess a bit like an outsider perspective?

A Yeah, yeah.

Q Were they similar feelings then that you did have growing up as well before you left home, do you think that was a similar kind of experience?

A Yeah definitely. I think I just wasn’t….so like I really struggled when I moved out, I really struggled at Drama School. Which I do now looking back I’m like ‘oh of course you did because of that environment’. But I don’t think I’d ever put two and two together like until I then went back home. But yeah it was definitely going back and being like ‘oh this is how it felt and I feel like I’m 15 again but I’m not’.

Q Yeah OK. So you started therapy. Was that helpful?

A Yeah really helpful. And I thought I’d like solved everything, but erm…. And recently, so I’m getting married in the New Year and I’m moving house.

Q Congratulations.

A Thank you. And moving cities, and it just brought up a lot of stuff again that has like ‘oh I thought I’d sort of like processed everything that growing up in that environment brought up’, but I’m just beginning to realise that actually it really does affect like every single aspect.

Q OK.

A Yeah. I think it’s just that feeling of responsibility, like it’s always in the back of your mind. And every decision you make, even if it’s sub-conscious like [my brother] is like in the back of my mind of, you know being factored into decision making. [my brother] and my mum. Yeah.

Q Where does that sense of responsibility come from? Has that been put on you to do you feel, or is it kind of coming from in you or…

A Yeah definitely not put on. Not knowingly put on me. Like my mum was always very, you know ‘we don’t want you to feel…’ like ‘while we’re alive we want you to be able to live your life and we know that when we’re not around things might change, but actually we want you to know that…. you know we don’t ever want you to feel you have to do things’. But then as much as they say that with the nicest will in the world, I just grew up knowing ‘well if I didn’t do that then it would be really difficult for them’. Yeah. Like I think I really felt like I was the one like holding everything together, I think. Because my other brother was quite…he reacted quite ‘I’m going to get out as soon as I can, I’m never really around, distance myself’. So because of that I then felt like I was sort of the glue keeping the peace.

Time 15:00

Yeah. And I’m pretty sure from the moment I was born I just saw that ‘OK well if I cause a fuss it makes it even harder for my parents, so I just won’t cause a fuss’. And yeah I think that sense of responsibility to like keep the peace has always been there. And the responsibility of ‘well one day it is going to be my responsibility’ because my other brother – maybe he’ll surprise us and like step up to the plate, but he really struggles with depression and everything and I just don’t….like it’s always felt like it will fall on my shoulders.

Q What does that feel like?

A It’s weird, because there’s like a weird push and pull of ‘there’s like an honour in it’ because I love him and actually…you know, yeah there’s like a weird sense of like ‘oh I want to be that for him, I want to be able to be that for him’. But there is also a sense of frustration and I guess….it’s like a proper push and pull of like honour and resentment I think. Like just they’re both there in equal measures. Like it’s something I’m really proud of – like I wrote a show about it – but also at the same time in the show I showed a lot of resentment. Like both things are like really strong. Yeah.

Q Do you have conversations then with your parents about the future? Is that something you can talk about?

A More so now. Right, so until I’d written my show we’d never discussed anything as a family at all.

Q Oh wow, OK.

A And they all came to see the first read-through and my dad and my other brother sat at the back talking for about an hour after. My mum like apologized, and like it was a really big moment in our family, and since then…like I have a really strong memory of quite shortly after that – that was in October and then in the January we all went to Centre Parcs together and [my brother] had a meltdown in the swimming area. And mum managed to calm him down and was like ‘go get the ring and sit in the lazy river and space out for a bit’. So he went and sat in the lazy river. And when he went to do that, yeah we all just acknowledged it. And I think mum had said something like ‘I don’t know, what do you think went on there’ and we all just chatted about it briefly. And me and my other brother were like ‘that’s so refreshing, like we actually spoke about it’. Whereas in the past it would just happen and we’d just move on like nothing happened. So we’ve got better at talking about it. And mum has asked, like when I got engaged she did ask, she was like ‘and [partner] is OK with like all the future’ – [partner] is my partner. And I was like ‘yeah mum, he saw my show like a month into dating, he’s fine, he knows’. So she like….yeah acknowledges it in bits. But until then, like I signed Power of Attorney and we didn’t discuss it. I just came home from uni one day and they were like ‘oh we’ve been having a meeting with a lawyer and we’ve started doing our will because we’re just aware like if anything happened to us we didn’t know what would happen to [my brother]. So you won’t need to do anything until we’re gone but do you mind signing this form’.

Q Gosh.

A And I was like ‘OK’. Yeah. And I mention it in my show, and then after that they were like yeah I’m really sorry, that’s quite a big thing isn’t it, but we tried to play it off as not because we’re still thinking ‘well we’re around so it’s fine’.

Q Yeah, crikey.

Time 19:40

A Yeah, it was like oh who would be better at helping [my brother] out with health, and who would be better at helping him out with money. And we like joked about it of ‘well if it was health [my other brother] would be late, he’d arrive too late in the hospital’ and we like joked about it but never actually sat and discussed actually that’s quite a big deal.

Q Mmm, the implications yeah, yeah and what it means for you and your future I guess.

A Yeah.

Q Did you want to be able to talk to them before your show kind of?

A Yeah, I tried. I kept saying like ‘do you want to read a draft’. I think that was the way for me. Both me and my other brother, my other brother’s a musician and he’s recently written a whole album about….like he started therapy and he wrote an album and played it to my parents. And then I started therapy and wrote a play, like so it’s really weird.

Q They’re just going to want to stop listening and watching and seeing what you’ve produced then aren’t they?

A I know! Well mum joked, she was like ‘do you think we could be a normal family where we just discuss things rather you having to like make it public knowledge before we know’.

Q Oh funny, yeah.

A But we try and they can’t….I just think….you know like I offered ‘do you want to read it, do you want to discuss it’ and they kept being like ‘no, no, we just want to see the final product’. So I wish we could be definitely better at being more open now, like definitely. But then I think part of the difficulty is that, like yeah we’re looking out for [my brother] but also a lot of it is looking out for mum. Because like that’s the weird thing about being a sibling because you’re not just looking out for the sibling, you’re also looking out for the primary carer – who should be your primary carer too but can’t be.

Q Yeah, you’re caring for them as well, yeah.

A Yeah. So then it makes it a bit more difficult because you don’t want to like make them feel guilty by basically being like ‘oh I’d have actually appreciated like having the attention that [my brother] had growing up’. And yeah it just feels quite personal.

Q How did you feel kind of knowing they were watching your show then, kind of?

A I was so nervous.

Q Yeah.

A Yeah I was so nervous when they watched it. But then also I think it took me about 3 years to properly finish writing it, so a lot of thought and processing had gone through. So I was nervous but also everything in it was true and I thought needed to be said. So nervous but for a good reason I guess.

Q Yeah. And what was it, kind of I guess, the main thing that you wished or that you wanted to be able to talk to your parents about then? Kind of before the show I guess, what was it you wanted to say to them and, yeah what the show….

A I think acknowledging that it is a big deal, I think. Because again, because [my brother] is quite social….like so basically he can’t live independently at the moment, they’re working on trying to get that happen but he’ll still, even if he lives independently he’ll need someone popping in to help him know like when to eat and wash his clothes and stuff like that. But he is very social, so he works 3 days in a garden centre. So because he’s quite….yeah I think there was a lot of like comparison to people who have it worse I guess. I think what I wanted to talk to them about and to hear them say was just to acknowledge that it was difficult. And, you know even though he’s what some people would say ‘quite high functioning’ he’s still vulnerable and he still needs care, and actually that’s been the case our whole life. Like I just wanted that acknowledgement that….

Q Yeah OK.

A You know. And they’d keep brushing off the future as, ‘you know it will….’ But actually like that is a big thing, that is it you know. And hopefully my parents will live to a really old age, but if they don’t….what like…you know. Or even if they do, like I will still be around and [my brother] will still be around, so at some point the responsibility will fall on us. Yeah so I think just the acknowledgement of what it was like for us. Because it just felt like me and [name] my other brother had just been forgotten I think and just assumed that we were OK.

Time 30:00

Q Yeah, OK.

A So I think it was a bit of a call for like attention I guess.

Q Yes, just recognising the position you’re in, yeah.

A Yeah. And like I’ve really struggled with mental health things like my whole life. Like anxiety and really like quite severe things that I think, again, because they had someone else with greater needs, in comparison I don’t think it was ever properly thought about and it was just like ‘well you’re doing OK’. And then again I saw like in my other brother, you know I think yeah, there comes a point that you almost have like a cry for help of like ‘we’re not OK’.

Q Yeah. So do you think they could have perhaps handled or…what’s the word….kind of approached your mental health differently and your mental health needs ??? and done more to support you through that?

A Yeah, which again was like a big driving force behind why I wanted to write my show was to like, like I’d love like teachers and anyone who is like looking after children to see it and be aware of it. Because like I really struggled at school with bullying and stuff, which actually looking back I attribute a lot of the things that I was being bullied about to being a sibling carer. But it just wasn’t even thought of as ‘maybe actually that child needs a bit more support because of what’s going on at home’. Yeah.

Q OK, that makes sense. What else would have kind of helped you, and still kind of help you currently as a sibling carer then – and particularly thinking about mental health. Is there anything else that you may – obviously you mentioned therapy earlier and we discussed about being able to speak with your parents and them acknowledging and being able to support you, as well as I guess schools and people around paying attention to the impact of being a sibling carer. Is there anything else?

A Groups. I’d love to like be a part of a group of other siblings, especially at the moment like going through all these like big adult changes and like the different things that it brings up. Like I’d love to be able to talk to other sibling carers that are going through those things, or have. Yeah because it’s just quite easy for it to feel like ‘oh surely it can’t be….’ I keep joking with my partner about like every time something comes up in therapy it will somehow link back to growing up with [my brother], and I’m like ‘surely like everything can’t connect back to that’. But then actually a lot does. And you being to feel like a cliché. But actually if you had that community maybe you’d realise ‘OK yeah it does but also it’s OK that it does, it’s not like….’ Yeah that’s not a cliché.

Q Yeah that validation that it is what it is. Do you access, have you been to any kind of groups or sibling groups then?

A I’ve tried. So [charity], which I think is how I heard about this, they have groups dotted all over, but because I’m in the middle of moving it’s been hard to find one where I am. And because my job. So I’ve just been on a 7 month tour of evening shows, and they tend to meet in the evenings.

Q Oh frustrating, yeah.

A So yeah. So I’ve often found it quite hard to access those sort of groups because my schedule just isn’t your stereotypical 9 to 5.

Q Yeah, oh that’s frustrating.

A Yeah.

Q OK. Is there anything else as well, kind of supports or things you think could help?

Time 29:40

A Well I mean things like a magic pot of travel money for every time you had to like, or felt you needed to travel home. Because that is a thing, like it is, yeah.

Q Yeah that’s a really good point. And I guess something which kind of slips under the radar doesn’t it, people ??? you know having to go home and the impact on your life I guess of having to give up evenings or whatever it is, but actually the logistics and the costs and…yeah. And especially, I don’t know, if you’re down south and having to live within an hour, of paying for that expensive area as well.

A Yeah definitely. I think as well, like this probably comes in a support group because I think they do things like this, of like helping you understand things that….because it’s like you’re sort of expected to be born into knowing how to care for someone. But actually what if you don’t? And that’s OK. But like I think I’m lucky because I’m naturally quite good at that, but if you’re not then it must be quite daunting having that like feeling like you should be caring for them but you just don’t know how to. So whether like resources of like what is Power of Attorney and how does that….because again, like I’ve signed it but I’m like I don’t actually know if I’d know what to do when the time came. Yeah.

Q OK. Is there anything that you’ve tried or that you know doesn’t work and that you haven’t found helpful?

A Living at home! Yeah.

Q You know not to do that one again then.

A Yeah I know not to do that, which again I am very fortunate that I have the choice not to. Because I do just think…like if you’re then….like I remember when I lived in [city] I could have definitely lived at my parents and commuted in because they’re just outside. But then I would have ended up like picking [my brother] up from work every day, or falling back into those things of ‘oh it’s Saturday night, are you OK if I go out’, like because that is just what you know. And when you’re there you want to be as helpful as possible. So yeah. So I think probably that’s a really big thing actually for the sibling carers that can’t afford to live on their own, some sort of financial support to help them. Even if it’s just living down the road. Like just having that bit of distance so that you can live your own life and not fall back into habits that you had growing up I think. So yeah definitely living at home is something that doesn’t work.

Q Tried and tested!

A Tried and tested! Would not recommend!

Q Yeah. And kind of obviously your play, it sounds like that was kind of quite a big moment in your kind of experience. So maybe it’s that, or maybe it’s something else, but is there one story or theme kind of related to carers’ mental health and being a sibling carer that really stands out for you?

A Yeah. The theme of guilt.

Q Of guilt, OK.

A Yeah. It’s huge. Like I’ve not met a single sibling carer who doesn’t feel that. Like even in the guilt of calling yourself a sibling carer. You know like every single bit of it is like…yeah, because you’re like ‘well I’m just a sibling, and if I say sibling carer then am I just making them into their disability’. And you know there’s like so many layers of it. And yeah, yeah a lot of…. That first person that I went and had like a chat with in the café, that was basically what we just chatted about. And the main thing we took away from our conversation was being able to speak freely about how we felt without having to like caveat it with ‘they’re really wonderful, I love them, I wouldn’t change them’ because you are speaking to someone who got that.

Q Yeah, you’re not having to….

Time 34:50

A And they understood that….yeah. But yeah I think guilt would be the big theme. I’ve seen in like everyone I’ve met and in my life is like the big thing. Like even getting married and moving. Like I’m moving to Manchester, there’s like a layer of guilt in there of ‘am I stepping away from being a carer and am I forcing my mum to like be….’ you know, there’s so many… When actually all I’m doing is making a choice that I can make at the moment because…..yeah.

Q Yeah it’s interesting. Guilt very much comes through all the interviews we’ve been having. But what’s interesting is like how you say it kind of comes through in different ways and in different aspects of peoples’ lives. So yeah the guilt of leaving home, or like you say the guilt just of calling yourself a sibling carer, or the guilt….you know it just comes through in so many different ways.

A Yeah. I remember I had it quite strongly when I learnt to drive. I felt, because he’s older than me I suddenly was like ‘oh’. And like when you get to that age where you’re like ‘I just want my freedom’ and then suddenly be like ‘oh I feel really….’ like I know it’s OK to want that but I also feel guilty because you can’t have that. And yeah. And the guilt of when sometimes you’re like ‘oh I just wish I had an older brother’ like you know. And I know it’s OK to feel that sometimes but then you feel awful because you’re like ‘oh no but I’m really glad he is who he is and he’s made me the person I am today’ but sometimes that is a thought that pops into my head. Yeah.

Q And you say you’re moving to [northern city] So is that much further away from your parents or is that still within the one hour?

A No so that will be a 3 hour drive I think, yeah, 2 and a half to 3 hours I think. Yeah we grew up in Blackpool, so it’s like still near a home of sort but it’s not near them. Yeah because they’re down near [town].

Q OK. And what does that feel like that, intending to move and….

A Really exciting and it feels, yeah it feels really exciting to like just be doing something that is like a step towards making our own life. But also there’s been a lot of tears and there’s a lot of, I think grief would be the best way to describe it. Because, yeah I don’t know how that’s going to be. Like there’s an excitement for like ‘oh well we can have [my brother] to come to stay’ and like maybe he can even do a train journey on his own if he gets the support on the train, and like it could be a really nice chance for him to have some independence because he can come and stay with us. So it’s like really lovely that we can provide that. But then I am really worried about the effect it’s going to have on my mum not being able to just like nip in the car and be with me in an hour for a bit of respite. Yeah.

Q And have you spoken with her about that then?

A No.

Q No?

A No. I’ve spoken to [partner] my partner a lot about it, but yeah not…. Because it’s that thing of like I don’t want her to feel guilty. Because I think she’d feel mortified that I was worried about her that much. Yeah we’ve like briefly said ‘oh it will be really sad that we’re not able to watch Strictly’.

Q Mmm, you kind of acknowledge it but in a…like passing.

A So we’ve acknowledged it, yeah. Yeah that is the one thing I’m like really like ‘oh what’s that going to be like’. But I guess I’ve just got to trust that she will reach out to other people and….yeah.

Q Yeah OK. I’m just ticking through my kind of topics now to see if there’s anything we haven’t covered. Have you observed or experienced any kind of discrimination in mental health care, or any kind of….yeah?

A In the care that you get?

Time 40:00

Q In mental health care I guess related to learning disabilities and being a sibling carer, or… lack of understanding perhaps?

A Definitely when I was younger, yeah. I used to have quite….I think looking back I’d maybe class it as some sort of anxiety OCD of like having to go to bed at the same time every day and like having to do stuff. And that sort of sense of ‘oh if I don’t have everything perfect then there’s going to be absolute disaster’, which I think comes from growing up in quite a chaotic environment and feeling responsible. And yeah, and like I said earlier, like when I was younger there was just a lot of like ‘oh stop being a stress head’ or….it just wasn’t taken seriously. And like I struggled with attachment with my mum when I was like 11, but again I can totally see now is all related to that. But you just….yeah, was just not taken seriously at all basically. But now as an adult, actually if anything it feels like they sort of…a therapist feels like they’ve hit jackpot. Do you know what I mean? Like it’s like….yeah. It feels like it’s really taken seriously and actually any time I try and like bat it and be like ‘oh but it can’t be because of that’ they’ll be like ‘no but that is a really big deal you know’.

Q Yeah, yeah, like ??? kind of thing.

A Yeah.

Q Yeah funny. OK thank you. Is there anything else that we kind of haven’t discussed that you think is relevant that we haven’t perhaps covered?

A I think something that’s come up….I don’t know, a couple of things that I’ve been aware of and when I’ve like chatted to friends that have sibling caring responsibilities, like that romantic relationships and partnerships is quite interesting. Because again, like with a lot of things you are constantly viewing it – well in my experience anyway I’m constantly viewing it through a lens of ‘what will they be like with [my brother]’, like that is a big thing. Yeah. And the effect on like thinking about your future, things like children. Like you know would you want kids? And like I would love kids but at the same time I don’t want to jump straight back into like caring for someone. And yeah, and that’s a really difficult thing that I don’t think a lot of people have to consider and actually…. Because I don’t feel like I’ve….yeah I don’t feel like I had a completely free and easy childhood where I could just be a child. And I don’t feel like I had a free and easy teenage where I could just be a teenager and go to uni, and just go to uni.

And I feel like I’m now at a stage where maybe I could like move to [northern city] and enjoy doing that, but then it will still be in my mind. So then the thought of having a child where you potentially have to give up your whole life… And because my experience was, my mum had to give up her work and she had to give up everything after [my brother]’s diagnosis because what else was she going to do like, you know? So that’s always in my head, I’m like ‘well I have to be prepared, like what if I do have a child who is autistic’, I feel like I need to be in a position in my life where I’m prepared to give up everything. So yeah I think that would be an interesting thing to like explore is the effect of thinking of the future because that…. Again I think it’s probably because I’m stepping into that next stage of life. But that’s a really big thing that I didn’t even think was in there.

Time 45:00

Q Yeah all these ripple effects I guess and how ???

A Yeah.

Q And you said then about kind of when you’re dating or looking for partners ??? So it was an extra consideration as well that ??? And I guess you mentioned that he saw your show early on, but did you then have to have then big conversations quite early on?

A Yeah, yeah definitely. And there have been situations as well where I’ve dated people that have then met [my brother] and they’ve… like just seeing the way they’ve interacted with them, even if I was still interested I was like ‘no’ and like shut it down. Because I was like it’s just not going to work, you know that is just such a big…. I think because you’re aware it just such a big part of your future. And yeah actually, interestingly, we’re taking [my brother] to Paris, to Disneyland Paris, it was his 30th birthday present from me. And I had a whole big thing of, I don’t know I just wonder if it’s an interesting analogy because it’s happening right now, but where in my head I was like ‘oh it’s a lovely sibling thing to do, I’ll be a great sister, that’s great’ and then actually had to acknowledge that ‘oh I don’t want to go on my own with him because actually that won’t be fun’. And that was a really hard thing to acknowledge. But then I’m blessed to have [partner] so he’s going to come with me. But that was like a big thing that [partner] and I had to discuss of being like I think I’d sort of assumed he’d understand that that’s something I needed, because I think part of…I don’t know, I also wonder whether part of it is that as a sibling carer you’re like looking for someone that could help share the load.

Q Yeah OK.

A So actually if they’re rubbish with your sibling or….

Q Yeah, they’re used to…

A And it sounds awful but I do think that is part of it, or having your person in your corner. Because you feel like you’ve lacked that and so you’re sort of looking for the person that’s going to be in your corner with you. So I wonder if that’s part of why we’re extra fussy, it’s because we’re looking for that. Yeah.

Q Interesting. Thank you.

A No it’s alright.

Q Yeah that’s lots to think about so thank you. Is there anything else?

A I don’t think so. I mean there is, we could like chat for hours but….yeah.

Q Yeah it’s always that things crop up afterwards don’t they, it’s like ‘should I have talked about that’ or ‘I should have said about that’.

A Yeah. I think it’s definitely interesting just, I think just reiterating like how it literally just….like [my brother] literally is in every single part of…like even in planning the wedding. Yeah. And that’s something that should be our day, and it is, but even then I’m thinking ‘oh how can I plan in a way that is helpful to [my brother]’.

Q Yeah, thinking ??? I’m really intrigued, is there a recording of your show anywhere?

A Yeah I can share it if you want.

Q Yeah I’d really, really love that if that was possible.

A Yeah absolutely. Because actually that will probably be much more eloquent than I have been today.

Q I’ll be like ‘oh I should have asked you about that, and that, and that’. Oh yeah I’d really love to see it if possible.

A Yeah definitely, I’ll send you the link in an email.

Q Thank you. Yeah I loved how just you and your brother have both had to kind of go down creative routes in terms of….yeah share things with your family, your parents. It is interesting.

A Yeah but also that’s how we communicated with [my brother] when he was non-verbal when he was younger. It was like he could write, so he would like write scripts for us to perform.

Q Oh, OK.

A So I think creativity has been such a big part of the way we communicate, yeah.

Q And I guess it does kind of just take that, I don’t know, an outlet for you but then it also takes the pressure off doesn’t it of, you know sitting down and having that conversation. It’s a different way in I guess isn’t it?

A Yeah.

Q Are your parents creative then as well?

A I guess in their own way, yeah. Like mum….well I think mum, if she could do it all again she would do what I’m doing, I think she’d like going into performing. And my dad’s a vicar so that’s kind of performing every Sunday.

Q Yeah, you’re doing your sermon aren’t you, having to ???

A Yeah, so they are. And they both play instruments and everything.

Q OK, yeah. I’ll stop the recording now.