Q There we go, that should be recording. And at the end of the interview, or once the interview has been transcribed, Martina will share a copy of that transcript with you so you do have the opportunity to kind of read through it if you want and redact anything or add in anything if you feel the need to, OK?

A Yeah of course, no worries, that’s fine.

Q First perhaps as a way of opening up and kind of beginning the interview would you mind just explaining why you were interested in the research and what kind of prompted you to take part?

A So obviously I’m a young carer. I’ve kind of always wanted to get involved with research and that sort of thing because I feel as though there’s not much for us really, so I think it would be a good thing to do, just to kind of get some sort of awareness, you know direct some sort of awareness and that sort of thing. It was kind of a while ago though so I can’t remember how I ???

Q No, no that’s fine. What are your experiences then as a young carer, what is your kind of situation?

A Yeah so when I was about 7 my brother was 3, and he was born completely neurotypical, absolutely normal and there was nothing wrong at all. And when my brother was 3 and I was 7 yeah, he had his first seizure. And then since then he’s developed a really complex form of epilepsy that’s not treatable really at all, we’ve tried pretty much everything at this point, he’s now 19. And it’s just got worse and worse and worse really. So he’s non-verbal, he needs 24/7 care. He’s very strong so that can be quite tricky sometimes, you know managing his care. His seizures are really unpredictable as well, so he can just drop to the floor at any point, so managing his safety can be quite tough. But yeah so it’s just kind of been….his abilities have just gone downhill really since his first seizure when he was 3.

So I played quite a big part in….I’m the older sister of 3 of us so I played quite a big part in the care and supporting my parents. My parents are divorced and I think partly because of all the stress and everything relating to [my brother’s] condition. But yeah so my mum’s kind of been doing physical care as well as managing emotional….you know parts of the condition in terms of you know how my mum’s dealt with things and all of that sort of….you know that kind of side of things as well.

Q Yeah. And how has that been for you then, what’s that like?

A It’s tricky. I think the thing that I find hardest about it is the fact that you just don’t feel at any point really like your peers can relate to you. I think that’s been quite tough and you can feel quite isolated I guess. Especially I guess when I was at school, also uni as well actually, it’s kind of no-one has any responsibilities – well this is my friends anyway – none of them had ??? responsibilities at all so they could be out as long as they wanted and they could do kind of whatever they wanted really, you know to some degree. But I’d always have to have it in the back of my mind like what else needed to be done and how I could relieve pressure from my parents, and also protect my little sister as well from kind of doing as much as I did. And it was quite a lot of managing whilst also trying to….well I’ve just completed my Masters and I’ve been working as well, so you know up to that point even it’s been quite a lot of juggling. But yeah I think that was probably the hardest part is the feeling really different from everyone else.

Q And that’s still the case now then, that’s still….

A It is yeah. I’m 24 now so I guess people have slightly more responsibilities, but I feel like ??? changed more recently to the point where all my friends, you know they might have responsibility to pay rent and, you know working and bits like that, but it’s all quite selfish – not in a horrible way, more just their needs are….everything they need to do is only because they need to do it, if that makes sense.

Q Yes, it’s choices they make, kind of things they want to do.

A Yeah. But I found studying and you know fitting everything else around that as well there’s always been other people to think about. And that’s not just [my brother]? that’s also everyone else in my family. So that’s…I think it’s changed but it’s not total freedom that all of my friends kind of have but it’s a different type of freedom where they can choose what they want to do, and although ??? their choice absolutely other than their work what they get up to. But I don’t really have that, and I haven’t really ever had that.

Time 5:20

Q Yeah. And where does that sense of responsibility I guess come from, is that something your parents have kind of requested or asked for at times? Or is it just something you have taken upon yourself?

A Well…yeah it’s tricky. I think as the oldest sibling, that kind of capacity. I think also my mum has always kind of relied on me and spoken to me a lot about how she’s felt about things and all of that stuff, so I think it kind of came naturally from there. But also my mum has never wanted to have any sort of carers or anything like that, so we’ve never had that. And because of that I think I was kind of the default, if that makes sense.

Q Yeah. That must be tough then, kind of choices, she’s making that choice not to have carers.

A Yeah. I’ve always found that a bit difficult to deal with because….especially now as well because I’m an adult so ??? I should be consulted now on these things really, but it’s just kind of a status quo I guess.

Q Yeah. Can you talk to your mum about how you’re feeling, or have you been able to in the past?

A Yeah, yeah. My mum feels quite a lot of grief and she feels as though she’s lost her son. Although I can speak to her she really does struggle with things like that so I’m quite conscious not to put an extra kind of emotional burden on her because she’s already got a lot that she’s dealing with herself. But even though I could, yeah I could and she’d want me to, I’m quite mindful not to really, yeah.

Q OK, yeah. And do you live at home now or have you moved out after uni and things?

A No. So I went to uni in [city], I chose [city] because I’m in [town]and it’s really easy to go to and to come back home to look after [my brother] and, you know all that sort of thing, and just to be near enough. But I then moved back afterwards pretty much because of the situation, yeah.

Q OK so you’re still at home now?

A Back home after uni, yeah.

Q And is that where you kind of….do you want to be there now, or would you….kind of do you think about moving out or towards the future?

A Yes I am thinking about it, I just worry about how my mum ??? things, yeah. But my sister finished uni, she’s up in [city] at the moment and she finishes uni, she’s in her third year now so she will be back in kind of May/June time, which is when I’ll probably consider making my next ??? as well because then mum would have support here. Yeah.

Q OK. And are you able to talk to your sister, do you kind of have a…..yeah what’s your relationship like with your younger sister?

A Yeah it’s tricky. She is….her and my mum don’t get on brilliantly at all and so I’m kind of the peace maker in the situation. Which is….she doesn’t ever really understand where I’m coming from because she can’t empathise with how my mum feels and like thinks that sometimes mum might not deal with it in the best way. So kind of maybe if mum’s stressed it might come across as anger, and I’m very aware of that, my sister maybe isn’t so much so then she’ll respond with anger, which doesn’t make….you know makes things worse. So maybe not the best person to speak to. I’m more of a peace maker really in the situation.

Q Yeah. And you said as well that kind of when you were all at home together you were kind of trying to do some of the caring for your younger sister as well, to kind of take on some of that role.

A Yes.

Q So you’ve had different experiences growing up as well then I guess.

A Absolutely, yeah. I tried to shield her kind of from especially elements of my brother’s personal care, so things like showering and that sort of thing, or you know taking him to the toilet and bits like that, I’d try to make sure that I would be doing all of that so that she could kind of maintain kind of elements of being a child, if that makes sense I guess, so protecting her a little bit from that. Yeah.

Q So you’ve been kind of caring not just for your brother but for your mum and your younger sister then as well, you’ve kind of taken on everyone.

A Yeah I think so.

Q And like obviously you said about not being able to relate to peers, but has there been an impact on your mental health, and if so….

Time 10:00

A Yeah. I think I’m quite an anxious person at times because I really feel the stress around me, I can’t separate it from my own, if that makes sense. So if my mum’s stressed for example I’ll take that on and absorb it a bit, which is bad and I need to kind of think about ways to manage that. But I haven’t found that really counselling or anything like that has helped massively because it doesn’t really get to the root of the issue and they’re more worried about….well I’ve done CBT and that just didn’t really help because it was more kind of focused on thought patterns, and I found that with me the problem was the situation as opposed to how I was thinking about the situation. So yeah it definitely has had a toll on my mental health, definitely. And even things like going on holiday, I find it quite hard to not feel guilty about not being at home. So that kind of takes a bit of time, yeah.

Q Yeah, it is interesting, the kind of CBT and it’s about changing thought patterns but it doesn’t ultimately change the situation you’re in at home does it?

A No.

Q That’s come up in so many interviews, people saying it’s just not the right kind of form of therapy for them because it’s doesn’t….

A ??? yeah. I mean that’s ??? thing actually, yeah I can imagine, I’m sure a lot of people in similar situations, yeah I’m sure the same, it just doesn’t feel like it addresses much really.

Q Yeah. Has there been anything which has helped your mental health, or which has….or support, or [charity] or anything you have accessed over the years which has helped?

A I think things like kind of managing my mental health through exercise has really helped me. Because I think sometimes….it’s difficult to explain but sometimes, for example in the morning say if I’m up and getting my brother sorted or whatever, don’t have time to make myself look nice or feel nice so I sometimes end up feeling really just not nice in myself, and I feel like exercise helps that, which helps everything else, if that kind of makes sense.

Q Yeah and I guess it’s something that kind of sets the tone for the day doesn’t it if you….

A Yeah definitely. And even just going for a walk, I think that’s really nice sometimes, it just clears your head and it gets me out of the house, and you know that kind of thing. But yeah I would look in to some sort of therapy or counselling but just not CBT.

Q Yeah OK. And are you able to get out for walks, do you have time to do that then?

A Yes. So my brother goes to college in the days and so that’s kind of the support that we have. And then other than that me and my mum share his care when he’s at our house, and then at my dad’s house, my dad ??? But my sister had a situation 3 years ago strangely enough that she gave birth without knowing that she was pregnant. So we also have my niece I’ve elected to take care of because my sister’s at uni, so that kind of brings another crazy element to it all. So I ??? her care as well.

Q Oh wow.

A Yeah I know, so it’s a bit of a crazy one but…. So when my brother’s not here essentially I’m looking after her, so it means that the down time is very limited. But I think I’ve learnt to juggle things quite well, so yeah I try to fit in walks, at least in the daytime ???

Q Gosh. How old is your niece now, is she 3 is she did you say?

A She’s 3, yeah she’s 3.

Q And again is that….how did that kind of situation of you taking on that care then, how did that come about, was that conversations amongst you all, was that you putting yourself forward?

A I put myself forward, yeah.

Q That’s a lot to take on.

A Yeah, I was 21 at the time so it’s quite young, but I don’t regret it at all obviously, it’s just….yeah it’s just another element of craziness really.

Q Yeah and more caring on top of….

A Absolutely yeah, exactly.

Q Just another human to care for in there.

A Yeah.

Q Is there anything you can think of that would make things easier for you?

A It would be really nice to have some sort of maybe an online platform or something like that that kind of people in similar situations to me that we could all communicate with each other. Because I haven’t really found that when I’ve done….well I haven’t really done any kind of young carer groups or anything like that, but when I’ve been involved in maybe things with my brother and then I’ve met siblings like that, they haven’t been ??? like me at all. So maybe casting the net a bit wider might help I guess to meet people who are more similar and in similar situations as well, if that makes sense.

Time 15:20

Q Yeah. Can you just expand on that, kind of how are they different or what….

A So it was nothing awful at all, it was more just the fact that the only thing that we had in common was our situation and that was it. And you know we didn’t have similar senses of humour, we didn’t get up to similar things, so ??? so the only thing we’d really be talking about I guess would be our situations at home. Which obviously it’s good and it’s beneficial to some degree but at the same time there’s more than that and it would be nice, even though we are similar in many ways in terms of our situation, it would be nice to connect on other levels as well and just know that we get it ??? you know if that makes sense?

Q Yeah, and it makes it easier doesn’t it to connect with people on….yeah when there’s more in common.

A Yeah definitely. And you just know and you don’t have to ??? into it, you just know how it is, might be, yeah.

Q Have you accessed [charity], any of their stuff?

A Yes I have yeah but I haven’t really kind of got involved in anything – maybe I should, yeah. It’s also a time thing ???

Q Well exactly, yeah. OK. And how has it affected, or how have….are you in a relationship or has it affected relationships you’ve had?

A Yeah. So I am at the moment, yeah. So it has, it really has. I think one thing that I’ve found difficult is, because my brother’s obviously male and I am heterosexual, I’ve found that quite difficult because kind of things like being intimate, it is hard when I’ve been maybe doing personal care earlier on in the day and then kind of transitioning into that. I’ve found that quite difficult and it just makes me feel a bit funny ??? And I think that’s quite a common thing, as far as I’m aware anyway. With my situation it’s quite….it’s an odd one. Because my brother’s my age obviously and it’s like he’s fully grown and he’s been through puberty and everything like that, and that can be quite tricky sometimes I guess.

Q Yeah that makes sense.

A Yeah. But not only that, I guess it’s also the time thing and also kind of in a relationship being able to relate to your partner, I’ve found that quite challenging because I haven’t really had that…with my current partner I haven’t….he doesn’t understand the situation, he doesn’t get it. And it doesn’t really matter how much I explain it he won’t understand it because he’s never really experienced it I guess. But I think that’s something that to some degree you’ve got to accept, because not everyone’s going to kind of understand.

Q Yeah they haven’t been in your shoes have they growing up, so….

A Exactly, yeah.

Q And does he visit your family and stuff though?

A Yeah, yeah. So he’s met my brother and that sort of thing. But he has a lot of questions and I can tell that he doesn’t…. So I know my brother obviously really well and he doesn’t kind of get it, and he doesn’t really quite know how to interact with him and you know ??? I’m sure it will come with time because we haven’t been together for very long, but at the same time….yeah I’m not sure. It’s a tricky one.

Q Yeah, yeah completely, completely. When you were growing up was there any support? So obviously you said your mum didn’t have any outside help so you were doing it, so you were doing caring then and for your younger sister. What was that like when you were at school and, you know kind of your younger years – well not younger years but before you left them to go to uni, can you tell me a little bit more about that?

A What about kind of….

Q What it was like being at home and having a sibling who was disabled I guess when you were younger.

Time 19:40

A Yeah. It can be....I found that…. I just remember really vividly when I was revising for GCSEs it was quite frustrating at times. Because I remember speaking to peers and their parents would be bringing them up dinner or, you know ??? with revision with them and that sort of thing. But I didn’t have any of that and I had to kind of work in my revision time when my brother either wasn’t there or around the times that he was there but also being very aware that I might be called down at any minute to, you know do ??? or that sort of thing. So it was quite tricky with things like that because I wanted to do well and I….I really, really wanted to do really well. So I found that a little bit challenging at points because I thought, I guess I was only 15, but I thought that this was the most important thing in the world and it was annoying because I wasn’t getting the time that I really wanted and that all my peers were getting to put into it, you know to do as well as I could. So I found that frustrating and that was, yeah I guess that relation to school.

Also things like I remember I would kind of go out some evenings maybe – this is probably more like college time – and every single time if I was leaving my mum on her own with my brother I felt awful, really, really guilty to the point where I’d maybe….sometimes I’d bring back some flowers or just bits like that. And it wasn’t anything that she ??? it was just….I just felt awful. So there’s a lot of guilt I think.

Q Yeah, and that again is something which is common kind of within interviews, is just guilt, yeah.

A Yeah.

Q What do you think could have been done differently at that stage, or what do you think could have helped manage that guilt or….

A I think maybe some sort of…maybe having better conversations as a family, maybe even in more of a structured setting. So maybe some sort of family therapy, or you know something like that just to kind of…. so we were all on the same page of what was going on and how we were all feeling. I think that essentially could have helped. Maybe….to be honest probably just more….having a cleaner or something like that would have made such a difference. And that would have been quite easy to find because I know carers can be really tough to find, but cleaners maybe not so much. So something like that would have been amazing because then at least I would have been able to go out knowing that the house was clean at least. So ??? the care. Because there was a lot of cleaning and washing and you know all of that sort of stuff.

Q So really taking off some of those physical tasks from you then, away where you can.

A Definitely yeah, absolutely definitely.

Q Yeah that makes sense. This might be a bit of a difficult question but I guess is there….I mean you said the kind of story around your GCSEs, but kind of thinking across your life and your caring kind of role and the family situation, is there any kind of one story or theme particularly about kind of your mental health that stands out for you?

A I think it’s guilt to be honest. I can’t think of a story so much or….yeah nothing really stands out too much. But I just remember feeling so guilty all of the time. And even to this day as well. And I found that difficult to manage and that brought me quite a lot of anxiety growing up, and you know even through to now. I know I’ve got a lot of worries about the future and moving out and kind of going on with my life, and a lot of guilt around that as well because I feel like I’m abandoning them. And I know that….my rational brain knows that’s not the case and I need to kind of pursue my own goals and my own life, but at the same time I feel a lot of guilt, yeah.

Q OK. And have you had that conversation about moving out with your mum?

A I have, we’ve touched on it yeah. I’m saving for a deposit for a house so she knows kind of what I’m….and she’s aware of that, so she knows what I’m doing. We don’t really have time to ??? at the moment, but yeah that is kind of….it would be probably quite beneficial for me to speak to her more about how I’m feeling about it. But I don’t think she quite gets the guilt thing, I don’t think she understands it. Because when I have tried to speak to her before, I think it’s kind of like she doesn’t want to, because it must be quite difficult for her to accept that….you know how it’s not only my brother who is in this situation, it’s us as well. And I know ??? that in a physical sense but I don’t think she quite acknowledges emotionally how it can affect us as well.

Time 25:00

Q So if you were kind of able to talk completely openly and honestly with her, would it be about raising those feelings of the guilt and….

A I would think so yeah, I would say so, yeah.

Q Do you think there is anything she could have done differently to support with that then, or to lessen some of that guilt do you think?

A Yeah I think part of it is actually about funding and about the fact that there’s not much provision for people like my brother. But also I think maybe just being brought into more conversations about what might be the best thing for everyone would probably have been quite good. Even if it was just the conversations and even if I wasn’t actually making any decisions it would have been nice to be involved. Because I think one thing that was really difficult as a carer growing up was the fact that I was given so much responsibility but also not the benefits of that responsibility, if that makes sense? Because obviously when you’re an adult you can be free and you’ve got responsibilities but you’ve got that freedom that comes with that as well.

Q You’re in control of it, yeah.

A Yeah. But I guess I was being treated like both a child and an adult but only had the bad parts of both, not the good parts of both, which was difficult. So I think maybe being involved in those conversations a bit more, and maybe making….or helping to make some decisions could have been quite nice as well.

Q Yeah, so recognising your role as a young carer and valuing that I guess, and therefore giving you that kind of….yeah.

A Yeah. I remember kind of in hospitals and things like that, I remember being spoken down to and being spoken to like I was a child, even though these doctors have no idea about my brother’s condition and I could have explained it to them so much better than they might have been able to explain things to me. And I remember finding that really frustrating.

Q Yeah, yeah of course. And part of what we want to do with the findings is sharing them with that kind of wider community so that people understand the role of carers and sibling carers so in terms of those health professionals, and valuing and understanding the position you’re in and why that would be frustrating to be spoken to in that way.

A Yeah, no that sounds amazing.

Q So that’s really interesting, thank you.

A No that’s OK, no worries at all.

Q Is there anything else? I know we’ve kind of whizzed through stuff but is there anything else which we haven’t touched upon which you think is important?

A Nothing that’s jumping out, no not really. I guess it’s quite hard to condense down so many years.

Q Yeah of course.

A But you know I think the main thing that I’ve always felt is a lot of guilt, and I think that’s kind of quite prominent in my mind. But also, yeah feelings of being patronized and things like that I found difficult to deal with too. So I think that would be really….you know that’s quite important.

Q Yeah that’s really helpful, thank you. Just going back to the CBT you mentioned, did you say you’ve accessed any other kind of mental health support?

A No I’ve only had….I’ve had a few different kind of courses of CBT, and yeah I didn’t find them very helpful.

Q OK. And is that then through your GP or…

A Yeah, yeah. And when my brother was at [place name] do you know [place name]?

Q Yeah I’ve heard of that, yeah.

A Yeah, he had a little bit of respite there at one point. I think we accessed one ??? through them as well.

Q OK, OK so different ??? So you kind of keep giving it a go but it obviously doesn’t help.

A Yeah. If I’m feeling anxious then maybe it’s ??? because my degree was in Psychology so I’m well aware of the ??? of CBT, but at the same time for me it just didn’t really work, it didn’t help really. I just felt as though it was….I don’t know if this makes sense, but maybe kind of oriented towards males in the sense of ‘problem and then solution’, as opposed to ‘let’s talk about what’s happening and maybe why you are feeling like that’. But yeah that’s just how it made me feel anyway.

Q Yeah OK. And just skipping again forward, sorry I’m jumping all over the place as things come to mind. But in terms of the future, so obviously you said you are saving up for a house deposit.

A Yeah.

Q Presumably because of your caring and caring for your niece you are not working at the moment, or are you….sorry.

A No. So I am studying at the moment for a Solicitors exam so I’m on a break from work at the moment, yeah. But just before I started, which was…last month I started studying and my exams are January, just before I left my job as a 999 operator at the Police, so I was working shifts.

Time 30:00

Q Oh crikey, OK.

A Yeah, which was quite a difficult one to manage with everything going on, but we did it.

Q And a stressful role as well presumably.

A Yes it was quite stressful, yeah. It was 6 days on, 4 days off, and it included nights. But weirdly that was OK with….so my mum works as well 9 to 5 and we kind of managed to balance it with those, so it was quite good having that difference in shift patterns so we could kind of support each other. But I am hoping to get a kind of paralegal role eventually as well, yeah, so that would be 9 to 5.

Q Yeah, so you’ve got a kind of clear direction and focus that you’re wanting to go in.

A Yeah. So I’m just kind of having a little break so I can study at the moment ??? so yeah.

Q And has your mum kind of been supportive of that, has she….

A Oh yeah definitely yeah. In terms of everything to do with education. So she qualified as a teacher firstly and now she works as an educational advisor, so she’s very education driven. So yeah, ??? very pro and she’s been really supportive.

Q Oh that’s good.

A Yeah.

Q Brilliant, thank you. Is there anything else? I think I’ve kind of covered the bits that I wanted to and needed to.

A Yeah. I think the only thing I’d really say is, I think I feel quite a lot of worries about the future and like where [my brother] will end up, that worries me.

Q OK yeah, the longer term future.

A Yeah, and having to kind of manage that from afar while maybe I put my own family and my own….you know other things going on. But that also makes me feel guilty, I don’t want him to be left and abandoned and you know, so that brings quite a lot of anxiety I guess.

Q Yeah. And are they conversations your mum has again?

A Yes. We’ve started to kind of speak about it now as he’s 19 and we know that…. and mum’s kind of getting to the point where she’s now pretty much struggling to do it really, especially without any help. We’ve started having those conversations so that’s good, yeah.

Q Yeah good. So you are being involved in those ones now.

A Yes, yeah.

Q And is your younger sister involved in those conversations then, or not because of her different relationships?

A Not really, yeah not really. But that’s more on her, that’s what she ??? she’s choosing not to be really.

Q What would you like the future to be like for your brother? Or what would your, I guess if there is, I don’t know if there is, but if you kind of imagine the ideal situation? I know that might be quite tricky.

A Yeah. I’d like him to be close to me, a place maybe with people similar to him. So one idea that we’ve been speaking about a little bit recently is setting up a house and kind of choosing some of his friends to be involved in it, and then for us to manage that.

Q Yeah like supported living, yeah.

A Yeah, so we can kind of…near here, near to where we live so we can kind of oversee it and it wouldn’t be like…because we’ve been offered a few places but they’re just so far away, like a few hour drive, and we just don’t want to do that. So I think somewhere near, somewhere where he’s surrounded by similar people to him. And somewhere that we’d be able to manage and kind of take him out as and when we want to and do whatever we want to do with him, that to be the priority. I think that would be nice, yeah.

Q And in that situation your kind of relationship with him would change as well wouldn’t it, kind of be more a sibling relationship than a….

A Absolutely. Yeah so, yeah I think it would be a really positive thing. But it will just take a while for all of us to get our heads around.

Q Yeah, and a lot of work involved in setting it up and getting it right to get the right support and things.

A Yes exactly. Mum’s kind of looking into that and I think it does seem like there’s a lot of hurdles, but I think she’s very determined to make it happen, so hopefully.

Q Oh brilliant. Oh I hope it does work out.

A Yeah thank you very much.

Q Yeah for all of you, yeah. Brilliant, thank you. Have you, on the information sheet did you see about the digital story telling workshops as well which are taking place?

A Yeah.

Q Is that something you’d be interested in taking part in?

A Yeah absolutely. Just the only thing would be kind of when that would be. But if it’s flexible then yeah absolutely.

Q Oh brilliant. I’ll let Martina know. Anyway she’ll be in touch though with….because there’s like a voucher for taking part today and like a demographic form and a few bits and pieces. So Martina will be in touch with that kind of admin side of things and give more information about the digital story telling workshops as well. So I can let her know that you are interested in them as well. That would be fantastic, thank you.

A No worries at all.

Q Brilliant. Thank you so much for your time, it’s been really, really lovely finally getting to speak to you after all that kind of backwards and forwards.

A Sorry it took so long.

Q No not at all, not at all. It must just have been such a pain not having decent wifi.

A It is. With studying it is a bit tricky.

Q Yeah, God.

A It will be alright.

Q Just another thing to add to your pile of things to manage and….you know.

A Absolutely, just one more.

Q Yeah. Brilliant, thank you so, so much [name].

A No worries at all, thanks.

Q Thank you, take care. Bye.