Q There we go that should be recording. So do you mind beginning by just perhaps telling me what made you interested in taking part in the research?

A Well I think I saw….I’m part of Sibs UK because I’m a sibling carer, yeah. So I care for my sister, she has Down’s Syndrome and autism, she’s got quite a profound learning disability and I’ve been her full-time carer for just over two and a half years now. So it was soon after that that I just basically Googled ‘Adult Sibling Carers’ and [charity] came up. So I’ve been linked in with their national group that’s on a Zoom because I’m in [UK nation]. And recently a Zoom group started for [UK nation] only but at that point it was just a national group I could link into. So [charity]have got a lot of resources, they’ve got Instagram, they’ve got their Facebook page, so just I think maybe it was, I don’t know a couple of weeks ago now I was looking at their Facebook page and I think I saw it pop up there I’m pretty sure.

So yeah and I’m just always into sort of sharing my point of view as a sibling because I’ve not yet….I went to a siblings day – no it was a weekend sorry – down in [city] at the beginning of the year but I’ve not met any sibling carers in person locally. I know there’s one other sibling carer on the [UK Nation] group who lives in my local area but, you know. I’m part of my local carers group, Carers of [region], and I’ve not met any sibling carers through this. So it’s just something that really interested me because it’s quite….although I’ve always actually been involved in my sister’s care, you know I felt a shift in the relationship. So yes I’m just keen to always hear about what other sibling carers are doing or saying or experiencing, or if there’s any research I can contribute to. So yes.

Q Oh brilliant. Well thank you very much for taking part and being here today. Could you perhaps explain more about your experiences as a sibling carer then and kind of what’s brought you up until today kind of caring for your sister?

A Yeah. Well so I think I was 4 years old when [sister] was born. So like I say she has Down’s Syndrome and she has quite a profound learning disability. When she was small, probably still nursery age – and this is from things that my mum told me over the years but our mum died two and a half years ago hence why I became a full-time carer. But this is….you know not all of this I can remember myself because I was quite wee, but she had some sort of home support worker who would come in and do things like alongside my mum and [sister]. And then she had a hearing test and they thought she was deaf – but she wasn’t, she was autistic. But anyway, so she went to deaf nursery. So anyway you know from that young age I remember.

We’ve got a sibling who is younger again, and I remember me and the sibling that’s between me and [sister] we would, that younger sibling, she was unwell when she was a toddler so mum would have to be away in hospital for a night with her. And I remember me and the sibling closest to me we would have to do things for [sister], we would like maybe put her breakfast on, and we were 8 and 6 at the time you know. So when I think about it, that, you know.

But when we were growing up there was no such thing as sib ??? sibling carers. I remember we used to get some input from [children’s charity] locally but I don’t remember it being because we were siblings, you know ??? a child who has disabilities, I don’t remember that. But just, I don’t know if it’s because I’m the oldest or I don’t have any family of my own, I’ve just always gradually over the years I was involved more and more in my sister’s care. So basically to begin with it would be helping out my mum, because she did the main caring role. I mean our dad was around as well but he didn’t really take on…. So just gradually over the years it’s increased, and then so you know going to things like the meetings at my sister’s day centre or social work meetings or, you know any other appointments. But again that would be very much sort of supporting my mum in her role so that’s why I didn’t sort of until two and a half years ago see myself as a sibling carer. But obviously I’ve been a sibling carer since I was, you know 8 years old.

Time 5:13

But yes I think maybe just that transition for me was to do with just the part that I’m doing it solely by myself now. We do have other siblings but I’m….you know it’s my sole responsibility, it’s not something I’m sharing with my mum. Because before we would always do things jointly, like we had joint welfare guardianship, you know we would both go to all the meetings together, or you know do phone calls, whatever it was you know I’d deal with benefits. You know my mum would sort of be deputizing to me or I would just be assisting her sort of thing. So yeah.

And I suppose maybe the sibling carer bit didn’t come into it all that much because we had other things, like we’re a dual heritage family, our dad was from [West Afric], our mum was ??? you know growing up in [UK nation] that sort of thing made it quite different. And you know there’s four? of us young kids, so I think that was a lot going on wasn’t it. So if you just give me a minute, the gardener’s at the door, but I will come back.

Q Yes that’s fine.

Time 8:09

Q There you go. Are you all sorted?

A Yeah, yeah it was just to have someone come and look at this tree in the back garden. So yeah I think maybe because of those factors, that we’re a dual heritage family and plus….you know that there were four of us, you know 8, 6, 4 and 2 you know that sort of age gap, so there was a lot going on. So maybe we didn’t realise the impact of being a sibling carer like I say until two and a half years ago when I became my sister’s main carer really. So yeah that’s the background.

And [sister], her autism, she was only diagnosed about 9 years ago I think, so when she was 34. And that was more to do with sort of services, because obviously you need to have things assessed and accurately sort of labelled as it were, or accurately identified. So for us to say to services ‘actually this is why [sister] sometimes acts like this or like that’, that was why. But I mean I think we always knew it as a family. I remember when [sister] was still at school, it might have been when she was at sort of secondary school age, and they had leaflets in the school about autism. And I remember looking at it and I thought ‘oh she does that and she does that’, you know a whole long list of things, I thought she does all of those things. And really I’ve come to realise that her autism affects her an awful, awful lot more than her Down’s Syndrome.

Time 10:00

Like I used to work in Learning Disability Services and through different groups that we’re part of you know we meet lots of other people who have Down’s Syndrome in particular. And I’ve never met anyone else with Down’s Syndrome who has such a profound learning disability as [sister]. So I really think the autism….and probably, you know I keep harking back to the fact that she was sent to a deaf nursery when she was little, you know what impact did that have. So yeah.

Q OK. I know you said you didn’t kind of recognise yourself as a sibling carer growing up and obviously things changed more recently, but do you think there was an impact on you when you look back?

A This is something that I really, really struggle with being part of this sibling group. Because I have had a lot of mental health difficulties over my life, which I can trace? back to when I was a small child. Like if I think back to when I was maybe like 4 or 5 years old and, you know different things I remember feeling, and then things that I felt when I was a teenager as well, it’s been….you know my mental health issues have been long-standing. But I’ve never related them back to being a sibling carer. We had other issues I could see, being dual heritage, you know a minority in [UK nation] not only being half African but being half English as well you know. And also we had some, I’ll sort of say minor level domestic violence in our family as well. So I feel that those….I don’t feel I sort of….I don’t know, I didn’t feel I was coming second best to my sister, you know these are a lot of the things that I’ve picked up from other sibling carers, I never felt second best to my sister, I never felt that I wasn’t getting to do things because of her. I never felt any pressure of expectations from either of my parents at all, to any sort of supporting role for them. For me it’s just something that evolved quite naturally really.

And so I don’t pick up on anything. For me, what I found difficult growing up was that if I was going somewhere to do something we all had….you know. So it more to do with us as a family unit, I can’t pinpoint that it was my sister’s disability as the reason, it was just very much ‘oh if [my name]’s going to one thing just let all of us go together’, or if one of the other girls…you know. So it was all we had to do everything as a unit. And also my father had a peculiar thing, I think from his culture, was that the youngest child is the most special, the most important, and that wasn’t my sister with disabilities. So that, you know. So I think there were different dynamics at play for me, the eldest, you know having to take responsibility not just for my sister who had disabilities but all three of my younger siblings. And then this peculiar thing that the youngest child is the most special. So yeah.

And in recent years, how I am now as a sort of full-time sibling carer, I feel extremely, extremely isolated. So yeah in recent years it is definitely something. And you know it’s an unusual thing because one of the reasons I’ve looked up Adult Siblings was because my free time now it’s either – well I’m 47 nearly 48 – so my time now, when I go out and about, no disrespect, it’s all pensioners or like parents with young children. And I’m neither of those groups, do you know what I mean? So if I’m going out and about during the day, or if I’m going to groups, or if I’m going to…I don’t know a fitness class, I’m like ‘where is anyone else who looks like me in a similar situation’.

So like I say, growing up you know and continuing to grow, like I say I have reflected on these other issues which for me were more prominent. But certainly since I became my sister’s main carer, you know I definitely find the role of sibling carer very, very isolating. Plus the fact that my sister looks very, very young for her age. And I’ve still kept her in kind of like bright colours and bright haircuts that my mum used to do, so everybody thinks I’m her mother.

Q OK.

Time 15:08

A Yeah so much so that I’ve actually had myself a big badge made that says ‘I am the sister’ X? on? And I’ve put a symbol. Apparently the blue and yellow ribbon is for Down’s Syndrome and then the infinity symbol for autism. And I’ve literally just got those badges off Etsy like last week or something. It’s kind of awkward, I can see people sort of as I start talking they’re like ‘oh alright are you….’ and I’m like ‘yeah we’re sisters’. Because I’d be like ‘oh we did this’ or ‘our mum did that’ or something you know and I can see them sort of twigging ‘oh right, OK’. So yeah that’s a thing, it sort of makes me feel a bit invisible as a sibling carer when people don’t even realise I’m a sibling, you know. So there’s something, so yeah.

Q OK. How did your situation come around then in terms of….your mum obviously passed away and you said you took over caring for your sister. Had you had conversations about that prior to your mum passing?

A No not really, no. I remember someone at church – and this is probably like 15 years ago – he once asked mum, he said ‘well what are the plans for [sister]’. And I remember saying ‘oh I’ll look after [sister]’. But I mean I lived away from the family home for 20 years, I wasn’t living here, so it seems astounding but there wasn’t, I don’t remember having a conversation with my mum. When lockdown happened in March 2020 though the day centres closed so I did have to come to here pretty much full time because mum couldn’t manage with [sister] during the day. So I suppose essentially at that point, you know a year before mum died, I had already sort of become [sister]’s full-time carer because I was having to be here. And I’d maybe get home like one night a week.

So I’d actually stopped full-time employment maybe 2014/2015 because I was becoming….well my mental health was quite poor at that time but also my mum’s health was deteriorating as well. So it used to be maybe, I don’t know, say 20 years I would come through on a Saturday and go home on a Sunday. And then over time it got to the point where it was like I’d come through on a Thursday and go home on a Monday, or come through on a Friday and go home on a Tuesday. So it was pretty much half the week here and half the week at home. So yeah like I say, the onset of the pandemic and that there was a shift in things at that point, and then….yeah I don’t know. I just thought, like I say, because I don’t have my own family, I don’t have my own children, my other sister’s do, they’ve each got 3 children and they both work, you know. So like I say, my employment had stopped, you know how many years ago now, 8 or 9 years ago. So I was just….you know I’m just increasingly available and you know my relationship was different as well, so I just had the availability to do it.

And I’ve always worked in care services as well, I’ve always worked in social care. I started off you know like when I was a 19 year old in like local care homes and stuff like that. So yeah it just naturally….it was quite a natural progression. You know because of mum’s failing health I was having to become more and more and more and more involved, you know. When it got to a point where maybe sometimes my mum wasn’t able to deal with the phone calls or the benefits or the meetings and things like that so I just gradually took over. But yeah as I said before, I never felt any expectation or any pressure or anything, which yeah which seems to me to be quite unusual, I just don’t know, it just sort of happened that I just….yeah. It just was really a continuation, an expansion of what I was already doing really. So it felt quite a natural progression for me. OK it happened sooner maybe, well actually no I don’t know because I hadn’t thought about how soon it would happen, I just hadn’t thought about it, so it’s not a….to reflect that it happened sooner is not actually accurate because I hadn’t thought when it would happen. So yeah.

Time 20:00

Q Yeah OK. And how, if you don’t mind me asking, how is your mental health now then kind of in this new role where you are full-time caring for your sister?

A Like I say it has been very, very difficult because I do feel extremely isolated. Like it’s just not….I’ve never been a great social person, like I love just staying at home, it’s my sister who likes going out and about and things. But it means I’m not… I can’t just, you know the few things that I do have I can’t just say ‘oh I’ll come and meet you then’, you know I can’t. So I do find that very limiting actually. And I think because of the grief and the isolation I had, I would say probably almost a 9 month spell of extremely poor mental health from the sort of end of last year, but I would say the last couple of months things have picked up a lot.

But initially, and it still continues now, it’s that sense of sort of isolation. Yeah. I mean I do get respite, I basically get the same package of care as my mum used to get in terms of carers coming into the house and respite and social support? at a day centre, so it’s pretty much stayed the same. But then it’s the respite is only 36 nights a year, so it’s not really that much. So I do feel very isolated, I don’t feel that people understand my situation, so I can get quite in my own head about it and quite….almost a wee bit bitter actually that people don’t understand. And nobody has ever directed comments at me but somebody said, oh I think when there had been a holiday weekend or something and I don’t know if it was like the ???, and some group I went to people were feeling tired. And somebody says ‘oh well you’ve just come off a holiday weekend’, I felt like saying ‘well that means it’s been a longer weekend for me because ??? stay with my sister’ do you know what I mean? Just that little thing. And I think well no-one….

Just like we go on family holidays and stuff but obviously that means I’m having to do all of my sister’s care. So yeah that’s a holiday we’re going on but it actually means more work for me as it were. So just little things like that. And, oh I don’t know, I feel like sometimes I feel angry towards my other two siblings that they don’t understand – but that’s up to me to speak to them and say how it is and whatever. But one of my sisters said ‘oh is the carer not coming tonight’ and I feel like saying ‘the carer’s not been coming on a Friday’ or a Sunday night whenever ‘for…you know 2 years now’. Or like on a Saturday night, and I’m like the carer’s have never ever come on a Saturday night, you know, how do you not know that. So little things like that are a bugbear.

Oh I had a thing, I’ve got an unusual situation as in I would say since about maybe 2014/2015 I was getting some funding from [sister], it’s called Independent Living Fund in [UK nation], it used to be a UK-wide government but now it’s devolved. Anyway, so you’re not meant to get it if you live with the person that you care for, but the assessor for the award when she came out to see us 18 months ago is it now, she said I’m going to ask for you to continue getting the award [my name] on a discretionary basis. So you know prior to that point me and my mum had always met jointly with the SS you know because they come out to do the award of money etc etc and so I’d always been involved in communicating with the SS.

And then setting up, we had to set up a payroll thing through an independent organisation, you know they support a payroll for PA’s and that don’t they, so all of that. So I recently emailed the new, I think it’s a specialist case worker Independent Living Fund [UK nation}, and I got back what I thought was this really impersonal email. And I was just asking about funding, which is something that the previous assessor had discussed with me – like I say it was always me and my mum. Although I was employed as a PA me and mum was the award manager, we were treated like equals. So I got this email back and it said something like ‘I am not at liberty to discuss funding with you, this is something that should be discussed with the award manager’. Now the award manager is our younger sister, even though? our younger sister her family are up there older.

Time 25:00

So anyway I’d sent that email and I said ‘oh I don’t like this impersonal approach’. And she told me that earlier that day the specialist case worker had phoned her and said something to the effect of ‘this is highly unusual for a PA to contact us’. So I spoke to my younger sister, I said well she’s not aware of our….I said [name] who was our previous assessor, she would never have written an email like that to me. So that make me feel devalued, totally underappreciated. You know I was like I’m not asking a really….but it seemed like my younger sister had expected what the specialist case worker had said. But I’m the one who is supporting my sister day to day, I’m the one who is always….you know it made me really angry. And I’m going to speak to my younger sister about just to…because she just accepted what the case worker….you know ‘it’s highly unusual for a PA to contact us directly’, you know I thought it was that sort of tone. And I thought that’s totally disrespecting me. Yes I’m employed as my sister’s PA but I’m not just her PA, I am here 24/7 caring.

So I am going to speak to my younger sister about it because she…you know I kept saying to her again and again, ‘the previous assessor would never have spoken to me as….’ you know. I don’t think she realised the effect. Because I’ve lost my professional role, I worked as a social care worker, I was a supervisor, I was a manager at some point you know. You know, I can deal with….not to boast but I do have skills, you know.

Q Yeah of course.

A And I felt so devalued, you know as if I was ??? are amazing, you know carers and support workers are amazing, we all know how underpaid people in this particular? work are. And for that moment, you know I just….yeah it just….and it just made me feel like, as I say, so undervalued and as if I was some person speaking out of turn or challenging authority, all this. And I thought it wasn’t. You know like I said, the previous assessor would not have taken that tone. So I’m sorry that’s brought up a lot of ??? things for me. But yeah I was like, you know I was like ‘I don’t think so’. I know better than my younger sister how to deal with social work, how to deal with funding, how to deal with benefits, the whole shebang. I know what I’m doing. And in actual fact my sister got a letter that she didn’t act on in March of this year – I really need to talk to my sister about it. And because of that I’ve had to backtrack. And the payroll providers, they’ve contacted me about something that she should have answered. So do you know what I mean, I was lucky, I’m the one who actually knows what I’m talking about. So yeah it’s lots of things like that. I think it’s just the lack of value isn’t it.

Q Yeah.

A Like I’m doing a sort of ‘Let’s Get Listening’ course thing online at the moment anyway. My sister can’t speak. She’s very affectionate, you know she will hug me and she’ll want to interact with me but it’s quite repetitive because of the autism. So sometimes I feel that’s her satisfying a need for her repetition. She can’t verbally say ‘thank you’ to me. My mum would say ‘oh thanks for doing that’ or ‘oh thanks for taking [sister] out’ or you know she was writing my birthday card and she was like ‘thanks for all you do for her’. But there’s nobody to say thank you to me any more.

Q Interesting, yeah.

A Which affects me really, really deeply you know. Nobody sort of….and I’m not doing it for anyone to say ‘well….’ nobody does, you know.

Q But appreciation of the role that you are doing and acknowledging that, yeah.

A Yeah. But nobody sort of says, you know there isn’t anybody to say that any more, so I really, really miss that. People say things like ‘oh I know you’ve got a lot on your plate’. Or someone said to me ‘oh you must have a big heart to do what you are doing’, and you know that’s fair and I do appreciate those comments. But there’s no-one….yeah just little things like ‘oh thanks for making me a cup of tea’ or you know ‘thanks for that dinner that you’ve made’ or whatever. So yeah.

Q Yeah interesting. And I guess when you are doing those….yeah the gratitude and thanks, it’s not why we do things but it is so important isn’t it. And when you’re doing those tasks day in, day out and no-one’s saying thank you, I can see….yeah. And then not only that, when you get that kind of email from professionals not even acknowledging your role and….

A I know, yeah, yeah. I’m sure you can tell there’s a lot of stuff that I’m still processing and stuff like that and I’m probably going off at tangents and all over the place. But yeah.

Time 30:00

Q No not at all, it’s really helpful what you are saying, so thank you. What support, I know you said you get respite but is there anything which does benefit your mental health currently, or what do you think would be beneficial for you at the moment?

A I think in my local….I am linked, I’m well linked up with Carers of [region] so I think I put it on a recent feedback thing maybe if they had something for sibling carers. Because they have things for parent carers, they have groups for carers of someone who has mental health problems ??? autism, bereaved carers, you know I could go on. So that’s something I might explore more with them. But they have a lot of different schemes. I’ve really benefitted, they have a thing which I’ve been part of for a year where you get a reduced rate for going to fitness classes at the local leisure centre. And it’s not the thing about oh if you’re supporting someone you get ???

Q Yeah, it’s for you.

A So I think the standard price is like £6 but I get it for £2. So that’s really, really helped me. Because I’ve identified a few classes that I enjoy and that I can get to in the time I’ve got available, so that’s really helped me as a resource, so having that sort of cheaper access to like leisure facilities and stuff. Carers of [region] also do, there’s walking activities that I’ve linked in with them which I found really helpful. And we have a coffee morning for carers. We also have had – well it’s still ongoing – they’ve got some input from a local group called Generation Arts. So they’re doing some arts and crafts and creative writing sessions. So you’re having things like that on offer. I think having different resources and opportunities I can take advantage of for free and at a time that suits me as well. So yeah.

But I’ve found that so beneficial and it really….you know if I can keep motivating myself to get out and about to these activities it really benefits me. And it’s not necessarily about talking to other carers you know, because like I say I’ve not found anyone yet through Carers of West Lothian who shares my experience. And they might not, because as I’ve said, only on one of the I think national Zoom calls with [charity] have I heard someone reflecting something similar to it, which is along the lines of there was other issues for them growing up in addition to having a sibling with disabilities. You know they had some, I think neurodivergence themselves and things, and that person was also from an ethnic minority as well. So that was really interesting to me. So yeah those kind of activities really, yeah health and well-being and just motivation and the time to take advantage of it.

I also do a few things volunteering locally as well, and that’s through church connections that I have. So one is a toddler group, and then there’s two different cafes that run on the other side of the town and we are linking into them as well. So yeah.

Q OK. Is there anything you’ve found which doesn’t work for you, or kind of doesn’t benefit you, and particularly in terms of your well-being and mental health?

A I think unfortunately not finding a common experience. It’s difficult to find a common experience with other siblings through [charity]. I’ve not given that through any sort of feedback because from what I’ve experienced on the Zoom calls and also when I went away for the weekend early this year, so many of them do find a commonality ??? So you know that’s not for me to discount other people’s experience. But I think a lot of time for me, you know being from a dual heritage family, that factor of ethnicity isn’t always taken into account. You know being from a minority ethnicity and other layers you know that that brings into someone’s experience. And I think there has been, I think on the Sibs National group, the What’s App group, there’s been at least one or two people looking at people who are non-white British, although it was focused on like carers in a younger age group, I think maybe 18-30. So it is coming through, you know that other dimension of experience is coming through.

Time 35:25

But yeah I’d say that’s….yeah hearing people reflect, you know particularly about feeling neglected as a sibling of someone who has a disability, that’s not…. And you know it’s just hard isn’t it when I’m on a group and you know I’m hearing things and I’m like I don’t connect with that. And the thing about feeling pressure from parents as well, I don’t connect with that either. These are really big factors for a lot of sibling carers. But like I say that’s something I struggle with anyway, finding a connection with other people, so that’s not a new thing for me. But yeah. But I still really, you know I’ve maybe not been joining the national group so much recently but I’ve enjoyed joining the [UK nation] group that is also on Zoom, so yeah.

Q OK. What do you think needs to change for carers to be well supported?

A I think more….a true acknowledgement of people’s roles. Because like in [UK Nation] I think there is….there’s going to be….I think is it the [UK nation], oh I can’t remember, is it the [UK nation]social security, they’re going to be taking on the carer’s allowance, you know carer’s allowance, carer’s credit and stuff. So I don’t know. I mean there’s a Carer’s Parliament I think in the next couple of weeks or something. And there just seems to be so many, whether it’s focus groups or, I don’t know you know people wanting feedback and things, but does it actually lead to real….Like we need money, that’s what it ??? we need the will to change things and the money. And the money isn’t there. So no matter how much research, how much discussion there is, gathering feedback, focus groups, whether it might be….like I came across something recently that again was session on Zoom and sessions in person, and I thought well what’s…. to my mind we know what needs to happen, you know you need better wages for staff who are involved and providing care and support. You know you need more flexibility in services. And it does come down to money.

And I think the first obstacle is that people who need support, people who need to be cared for, they’re not valued. Therefore the people helping them and caring for them are not valued. So I think actually it starts from the step before carers. It’s about, yeah people with support needs, disabilities, any kind of frailty, those people being valued and a range or abilities and contributions being valued. Because a lot of the time it’s ‘oh this person has X disability, look at what they can do’ you know. And it’s about reading, writing, speaking, being active, being talented in maybe music or singing you know. And there’s lots and lots and lots of people who cannot do any of those things, so are we not valuing those people. Like [sister] doesn’t speak, you know she’s limited at walking as well. So it’s like what’s….

And that happens to a lot of people as they get older, there’s kind of groups for kids and there’s groups for teenagers. Then it’s all groups for young people and they’ve got this ‘teen space’ and ‘oh we’re on Zoom’ and always doing activities, and ‘oh we’ve put this magazine together’. What happens when your loved one can’t do any of that? But I think it’s the step before carers, of people who need care truly being valued for what they can do. And that still isn’t happening. You know because the good news stories are always about people who can do loads of stuff.

Time 40:00

Like there’s a gentleman I know through an autism working group I’m part of and he feels the same because his son is never going to be able to get a job. His son, you know can chat – he sort of chats too much, but you know and so I know he’s reflected a bit ‘well my son’s not going to get a job so what’s his value’. I used to work in mental health services and a colleague of mine went to visit someone on a Monday, and he said to the guy ‘oh how was your weekend’ and the guy said ‘oh I had a great weekend, I finished a crossword’. And that has stuck with me. And that was probably 15 years ago now. So how many people would see that as a good weekend – not many people would they?

Q No, no. But for that person that was very ???

A Yeah it was like that was a great thing. And I’m like ‘wow’ that’s been one of the most profound things I’ve ever heard. So you know that’s what would really help I think carers, to value the people that are being cared for because I think that’s the step that’s missing. So yeah.

Q Yeah, and then the valuing of carers become naturally following that.

A Yeah.

Q Yeah I agree.

A ??? also I do have a friend and she cares for her son, and what we laugh about sometimes, you know I don’t know how….I think between me and her there’s maybe only 7 or 8 years difference but her son is like over 20 years younger than my sister anyway. And it’s practical, just you know very private things. Like we once had a conversation about nappy bags, and we were laughing because we knew ‘oh the ones in Sainsburys are that colour, the ones in Morrisons are….’ you know. So it’s sometimes sharing little practical…you know. And obviously you’re not going to share that private information with everybody but it just made me chuckle because I thought that’s so funny, we knew the colour. ‘Oh no but those ones in Morrisons are good’, ‘oh yeah they’re the yellow ones aren’t they, yeah I like them because they’re a bit bigger’. So all things like that you know, practical things, just silly things there as well. So yeah.

Q Sharing those moments. If you think kind of over your experience is there any kind of one particular story or experience which stands out in your memory as kind of sums up your experience as a sibling carer?

A Oh gosh that’s really, really difficult. I can’t…no I can’t really think. I mean I can think of….not as a sibling carer, I’m just thinking about when me and my sister had to leave, it was a small concert at a church hall and we had to leave because my sister was grinding her teeth and she was clapping. And it was a classical music concert and it was disturbing, you know distracting people. But that’s not really about me being a sibling carer. It’s probably an experience that’s shared by a lot of carers, but yeah.

Q What was that experience like for you?

A It was horrible. I could have ??? like time. It was just, you know. Because we actually knew one of the people playing in the ensemble and who does specific classes at that church for children with autism, and also at that point was leading the music group that my sister goes to here in Livingston. But we’d arrived late and things like that and it was just….yeah and I can’t stop her. Like we were at another classical music concert, again in a small church hall, on Friday and she was grinding her teeth. So I’m sitting there getting more and more tense, and I’m like….you know I can sort of try and distract her a little bit but then it just becomes too much. So yeah.

I mean it’s not….I don’t know. I know some people who hate the sound of grinding teeth, I know that. But yeah. Maybe just that sadness I think about being a carer and your loved one not because accepted or being excluded, you know being looked at as ‘other’. It’s actually heartbreaking for me, you know. Yeah so maybe that’s something that sums up, just a sadness for my sister that you know she is still excluded from things or she is still seen as very, very different. I think also because of her autism how she’s sometimes not able to participate. Because if someone approaches her she won’t always give them that interaction so I think that causes her to be excluded.

Time 45:20

Like even at her day centre when I’ve been to a couple of things recently and the staff are busy interacting with other people there who, you know will make eye contact with them, will put their hand out, will laugh or whatever it be, interacting in some way. And my sister, you know she hides her face a lot and things like that, she looks away. You put your hand out to her, she’ll withdraw. Yeah so I think it’s a sadness sometimes that I feel that she…

But you know she will interact with you but you know you just need to persevere with her and take….you know she pushes me away a lot, you know sometimes she’ll physically push me away and not want to interact. So yeah that sort of lack of connection makes me sad. So I think that’s maybe….oh…sometimes that is the over-riding feeling of sadness just, you know.

Q Yes, OK thank you. Do you, and again you don’t have to talk about this if you don’t want to and I appreciate you’ve only recently come into this kind of full-time role. But do you think about the future, you know your future as well now?

A Yeah I do absolutely yeah. Sorry I just need to move because I need to just plug this tablet in. Yeah I do actually yeah. Because my youngest sister, she had said ‘oh do we have to put [sister]’s name down for something’ you know. And I was like ‘no that’s not how it works’. I was like ‘no that’s not how it works’.

Q It’s not quite that simple.

A I know, I know, I just laughed because I was like that’s showing her ignorance of her sister again to me. Yeah well basically someone else has said that to me ‘oh you must think as well about what you are going to do in the future’ and I felt like….because they were talking about someone else who had been having….it’s a mother who is in her late 70s and her son I think is a year….I think he’s maybe 42 now. So she was saying ‘oh yeah I wonder what is she going to do about the future’. And then she said ‘oh and you must think about that as well for you and [sister]’. And I said well no because there’s only 4 years between us. But at the end of the day, you know if I wasn’t here to care for [sister] she would need to go into supporting living.

And there’s always that thing of, I know parents have it as well but it’s probably more pressing for them than I think a sibling close in age is, you know what if I’m not able to care for [sister] any more, and is it more sensible to forward plan and say ‘well…’ you know. Well I suppose first of all in my mind I think ‘well I will be able to care for [sister] always’ but then the reality is that that isn’t the reality is it? So it would be better for [sister] to be settled, you know where I could just support that would be better for her in the long run possibly. I just don’t think it is. I mean I just know….yeah, I would rather not her go into supported living, yeah. So I do think about the future but I don’t do anything about it, that’s the ??? so yeah.

Q Yeah, and do you find any….you’ve mentioned kind of I guess your siblings’ lack of understanding of the current situation. Do you have people that you can have those kind of conversations with or like sounding boards or….?

A ??? Of course I can. No both of our other sisters are really….it’s just like I say because I held on to a couple of things recently, they’re getting on my nerves and I’ve still not spoken to my sister about them. But they do, like our younger sister, she’s taken on like the welfare guardianship because I can’t hold that, but under the self-directed support legislation here in [UK nation] you can’t be employed as a PA and be someone’s guardian. But they hadn’t enforced it because me and my mum were joint guardians. So my sister has taken on that. You know she’s taken on….you know she will do it, she says ‘do you want me to do that phone call, do you want me to do this, do you want me to do that’. She’ll come and look…you know she will come and look after [sister] if I’ve got….I had a day out with the volunteers at the café where I help out and she came, well she had something on in [city] herself so she came and she took [sister] to that thing in [city] with her. I’m going to something I think in a couple of weeks and she’ll take….you know so she will. Yeah so she can do, you know she can support [sister] practically, she is able to do that.

Time 50:25

And then my sister that’s between me and [sister], she’s just got a lot going on in her own life. Her kids are 10…oh I can’t remember their ages, 11, 9 and nearly 6 I think, or 7, I don’t know. And her youngest has autism, and he’s….well it’s not that he’s non-verbal, he doesn’t sort of communicate in an intentional way. So he wouldn’t say ‘oh mummy, biscuit’ you know he’ll take your hand and take you to the kitchen and look up at the cupboard where the biscuits are. So he’s got a lot. And she’s got a social work background so she does understand the sort of notion of services and things like that. And in her current job she supports carers, like foster carers for child and adult placements, so people with disabilities. So they’ve both got between them like a professional, personal, practical understanding of everything that goes on.

So yeah I mean when I was speaking to my sister the other day I did say ‘oh [sister]….’ you know I was talking about, because she said how is she and I rounded up all the things of ‘well she has this now, nose was running and her eyes were streaming, and oh the pharmacist wanted to give her eye drops but you know how that went’ blah, blah, blah. So they do understand. And my partner as well, I can talk to him about things. But I suppose just day to day sometimes I kind of get ‘grrr’ all turned around and ??? isolated and I just get obsessed with this kind of ‘nobody knows how it feels’, you know it’s that sort of negative train of thought isn’t it where you’re not opening yourself up to others and you’re not sharing things with others and you do get quite bogged down or….you know.

So I do have, I can speak to my sisters you know and I’ll keep my younger sister up to date because she’s the welfare guardian you know. Like [sister]’s got a GP appointment in a couple of weeks, she’s got the dentist….and yeah. So we do have. But I just find it difficult when we’re not always able to see each other in person a lot of the time. So I think that’s maybe why, because we’ve not I think since the summertime maybe not have a lot of time with each other in person. And obviously, you know with their kids and that, things….you know there’s an awful lot going on with them and the kids and work and stuff like that. So yeah.

Q So just to clarify, you are paid as a PA as well as being your sister’s….you are paid a number of hours are you for being a PA for her?

A Yes 20 hours a week.

Q 20 hours a week.

A It covers a lot. So you’re basically under this ILF award. I used to get…my mum would get money you know to purchase additional things for [sister] and she used to get help around the house. But then things changed and the assessor would come out to see my mum – I’m trying to think how long ago it would be now, probably about 12 years or something like that. And my mum was saying ‘oh [my name] comes through to help me’ and the assessor said ‘oh well you could be giving some of the funding to [my name]’. But that’s how it all started. And then it changed again with the assessor saying well it should be going through payroll, so she set that up. So yeah I was paid, it was 10 hours a week, and then when I became [sister]’s full-time carer that’s when the assessor said ‘well I can ask for the award to continue on a discretionary basis for 20 hours a week’ and so I said yeah that’s fine. But yeah it doesn’t really cover all that much the 20 hours. But yeah. So it was weird, I mean I am….yeah I’m a paid PA but most of the time as an unpaid carer. So yeah.

Q Yeah, different roles.

A Yeah. I mean I just…you know because on the timesheet that I’ve put in it says circle the days of the week which you usually work. And you know I just….I just don’t, I’m like well….I’ve never. I mean obviously when I lived in [city], I used to live in [city], I could do that, you know there were a few days each that I’m here. But now I’m here 24/7.

Q Which hours of the day should you put down kind of, kind of which ones will you pick today.

Time 55:00

A Yeah ??? I just put, you know it’s 20. But essentially I am, yeah. It’s just weird, but I still class myself as an unpaid carer, just 20 hours you know.

Q Of course. It barely touches….

A ??? on our own you know. And although I sat down and worked it out because I thought am I really being truthful. But you know she’s out at her day centre like 4 days a week let’s say from 9 til 3, or 9 til 4, and then she’s out three and a half hours on a Monday. And even if I count the time that she has her home care, because she’s like 5 mornings and 4 nights, so even when I’ve calculated all that, the rest of the time that I’m here you know 20 hours doesn’t even touch it.

Q No I can imagine, yeah. OK thank you. Sorry I’m just looking, I’m working across two laptops so that’s why I’m just looking to see if there’s anything else to cover. Just to bring it back to kind of a discussion about mental health – a bit of a difficult question maybe but what is your understanding of mental health?

A Just that we….well we all have mental health needs more. There seems to be this short hand of saying ‘oh being mental health’ when people are living in poor mental health. But I think just because I worked in mental health services for 10 years – because I worked, it was like a thing in [city] where you had Health, so the psychiatrist and the psychologist and the nurses and social work, and you had social care, so I worked for a social care organisation. So it was a holistic approach for who are needing support. So yeah mental health is, basically it’s just how you’re doing mentally and emotionally, and it might include spiritually as well. But you need to work on your and look after your mental health the same as with your physical health.

And we all have I suppose different….I was going to say strengths and weaknesses, well it’s maybe not a bad thing calling it strengths and weaknesses, whereas you know some of us are more prone to things physically it’s the same mentally. And it’s the same with to do with our genetics and our upbringing affects our mental health ??? does our physical health. So yeah. So we all have a responsibility ourselves you know to do what we can to look after our physical health and our mental health. But we all know sometimes that’s easier said than done. So there’s still lots of people who smoke, there are still lots of people who drink too much. Or you know I eat too much of the wrong food and you know I don’t look after my physical and my mental health as much as I should.

So I see mental health the same as physical health. But yeah. It’s very important and it needs to be looked after and cared for just as much as your physical health, or in terms of what you put into your body, how you sleep, how much you drink, all of those factors you know have an influence. But it’s really, really important to your well-being as a person to have good mental health. And my understanding is that mental health is different from a diagnosed mental illness, that’s you know a different thing. So someone with a diagnosed mental illness might have good mental health because the condition is well managed, whether that is your medication or other kind of things like that. And you might get someone who does not have a diagnosed mental illness that has very poor mental health. And you know that might be because of things going on in their life, or it might be….yeah it could be lifestyle factors, environment, it could be genetics as well. So yeah. So the two things are different for me, mental health is different from mental illness.

Q Yeah, thank you. Have you, because obviously you said….I guess you’ve had difficulties with your mental health over the years.

A Yes I have, I have.

Time 1:00:00

Q Have you had difficulties accessing support for it when you’ve wanted to?

A Yeah I have. I was initially through my GP referred to primary mental health services. So the model in [city]when I lived there was that was a short term of 6 to 8 weeks and it was focused on cognitive behavioural therapy. I think one time I did get referred to a person centred therapist I think. Yeah so waiting lists and also the cognitive behaviour therapy not being appropriate, you know that short term 6 to 8 week input not being enough for me. So I think maybe after I’d been through that cycle two or three times the GP recognised but then it was about how was I going to access the community mental health team the secondary care phase, you know would I jump through hoops to get access to that service.

So yeah I think in those terms for me having what turned out to be a kind of long standing depression and anxiety, getting access to longer term input was difficult. And then I recently spoke to Carers of [region] about accessing counselling through them. And probably it was just a worker that I spoke to, I got the impression from her I would get a phone call the following week just to sort of check in and see. So it’s only been two weeks but I think, you know I was kind of holding on to that expectation that I’m going to get a phone call. And just because I am prone to thinking quite negatively, you know I’ve taken that as a knock-back and I’m like ‘oh that’s another way that I’m not valued’. But yeah. So in those terms, yeah it is.

And a lot of the time, like you know it’s hard to access because you have to really build up your courage to go and ask for help, and when you then don’t get anything back as soon as you were expecting it it does knock you down a bit, you know. But I think it’s just a general problem overall isn’t it in accessing services and support really. So yeah.

Q OK thank you. Did you find….sorry just to go back to that question since it’s come up in quite a few interviews actually about, you know that sort term CBT isn’t appropriate for people. Did you have CBT? Did it….

A Oh yeah I had it.

Q Did you find it helpful?

A Well I suppose in the short term yes. But no it wasn’t appropriate for me because if I look back I’ve had long standing mental health problems. Because I remember feeling a deep sadness when I was a small child you know nd that’s not…reflecting back on it I think well that’s….you know, yeah, aha. Or having really negative thoughts, or thoughts of suicide when I was a teenager. But it’s one of these things isn’t it, things have come along and it’s a new buzz word or it’s a new ‘oh this is going to solve everything, so yeah’. 6 to 8 weeks of CBT and that’s you on your way. And it’s not appropriate for everyone. CBT isn’t appropriate for everybody. But no maybe it would, I think it maybe worked for the 6 to 8 weeks that I was seeing the therapist, but very quickly you know I was back to my old ways you know.

Q Yeah, OK.

A But it can help. I know it can help some people. But nothing’s ever going to help everybody.

Q No. But for you in your situation it wasn’t helpful.

A No, no it wasn’t helpful.

Q OK thank you. Is there anything else that we haven’t covered or spoken about that you think would be useful to raise?

A No I don’t think so, I think it’s been really good, it’s been a good process for me. Because I think as carers we don’t often get to speak about ourselves, or we’re not used to speaking about ourselves. Because I still do it now, someone will say to me ‘oh how are you’ and I’ll say ‘well I’m OK, oh and [sister]’s…..’ you know. And there’s so much of what you do is to do with your loved one isn’t it. So it’s just been nice for me to truly speak about myself. Yeah I’ve been speaking about myself as a kid, but I’ve been able to reflect on things for me. You know a lot of this I just think about in my head and I just talk to myself about it. So you know, yeah. And I hope it’s beneficial for you guys in terms of the research and that, and it’s just bringing different voices isn’t it.

Q Yeah it’s been really, really helpful. And I’m just so grateful that people are so honest and open of coming and sharing their experiences and things, yeah.

A I think it’s because we don’t get to speak about it a lot really you know, and we’re just not used to like I said. You know because people do ask how you are and then you’re like ‘oh yeah’ and then move on. So yeah.

Q Yeah. And we all do that kind of like ‘oh I’m fine’ don’t we, when actually things aren’t necessarily fine.

A Yes.

Q Well thank you so much, it’s been really, really helpful. And I think really interesting kind of, lots of other things that you’ve been saying you know about your dual heritage as well and how that needs to be considered. There’s a gap there as well isn’t there ???

A Yes. Well thank you for listening and thank you for acknowledging that as well, because not every gets that really, so yeah thank you.

Q Brilliant, thank you. In terms of….sorry I’ll just stop the recording there actually.