Q OK, does that say it’s recording for you?

A Yeah, yeah absolutely.

Q OK. If you’re OK to start perhaps we could begin then with you just explaining why you were interested in taking part in the research?

A Yeah, no absolutely. I’m a sibling carer so I kind of became my brother’s main advocate well over 20 years ago when both our parents had died. Personally I’d had a career in sort of the disability field anyway and I kind of had always had a really quite major involvement in my brother’s life. He’s younger than me and so just always had done. And so I kind of naively assumed I’d manage OK. And yet I think what I’ve experienced and continue to experience in terms of the emotional drains and demands and what have you, they’re just relentless really. And I think I don’t…I’m not…I don’t provide my brother’s direct care, I actually live a distance from him but I’m very involved sort of still on a daily basis all his appointments and all of that.

And I think there’s a kind of…it’s hard for people outside of that lived experience to relate to it because they just think ‘oh you probably visit now and again and that’s it’, like you might do an elderly relative. But it’s just so different. And I think the whole life experience of someone with a learning disability is so different to most people’s, you know nothing seems to be straightforward, it relies on…well my brother has a profound learning disability so it relies on me being proactive and responsive and just always have my finger on the pulse. And that’s…. at different times in his and my life together it’s taken a real toll on my health, sort of mental health but shown in physical health signs, if you know what I mean, mostly.

And I just know, you know obviously I’ve got friends who are family carers in different sort of roles and what have you and it’s just such a common thing that we share. Not just the emotional drain but the trauma we experience and how easily that’s kind of triggered or re-brought to the fore, you know just however…even when a concern is not extreme it kind of…you suddenly go right back up to that high anxiety, whether it’s appropriate or not, you know there’s no logic in it.

Q Do you mind just explaining a bit more then when you say the ‘trauma experience’, kind of just unpicking what you mean by the trauma and what the trauma is?

A Yeah. I suppose going right back to when our mother first died and in effect my brother became homeless kind of literally overnight. He was in an emergency respite situation because our mother had become ill sort of quite unexpectedly, and just that whole thing of, you know finding him somewhere to live. And assuming, because I’d worked in the disability field myself I was very much about supporting and enabling and being there for families, helping them get their needs met, and I’d naively assumed everybody would be like that. And it was just a real shock to the system that it wasn’t. You know so it’s hard to know, you know my background obviously has influenced the way I think about the role and value of families, although it wasn’t in my awareness. I just assumed I was a professional, everybody does their best you know.

Time 4:43

And I think early on it was that realization that you’d go along to meetings that were about funding or getting the right support and the professionals had all had a pre-meeting, they’d already made their decisions. And there’d be, I don’t know, 6, 8, 9 people on the other side of the table who had a consensus, and then I had a different view you know. And you just realise that whole power imbalance of status or, you know just…. And that kind of started that realization and that need. You know I’m quite a timid person who doesn’t like confrontation or demanding things, so it was kind of not my natural way to be assertive or what have you, and I found that quite hard and challenging.

But the bits that really kind of set the trauma were….well just, my brother’s experienced every form of abuse you can imagine and even those you don’t want to imagine, and some of those have been really just awful, involving Police that never got anywhere. Because my brother doesn’t communicate with words. He had physical injuries. There was lots of kind of circumstantial evidence but nothing that would take to a prosecution. So that was a real biggy for me just how vulnerable he was. But also how lightly people kind of took it. And I think because there was no proper outcome, it was just ‘oh tough’ kind of thing. And exactly the same thing happened a year later and the same person in the picture, all of it. And that was just….yeah. So that was something that made me realise. I always thought he was so protected. I trusted people and all of that.

So a lot of stuff like that really, and that kind of just sits with you. Lots of safe-guarding over the last 20 years, more than 20 kind of situations that have had investigations and what have you. And even I suppose in terms of the trauma and my ability to manage it, or not manage it, you know that whole thing, sometimes I just have to bury my head in the sand because I just can’t keep going and just pretend it’s not happening, just to kind of bounce back and then I can have another go.

But there was a time he was living with people, sort of fellow residents if you like that were hurting him. And he doesn’t have the understanding to kind of protect himself or move away. And he’s such a sensitive chap he kind of gravitates if he knows people aren’t happy or something’s not right. So he would put himself in positions that led to him being harmed. And he got really, really anxious, so anxious and kind of overwhelmed and I thought he would have a stroke or a heart attack. I thought he would die. And I actually wanted him to die because it felt like that was the only kind of way of stopping it, which I realise you know just wasn’t the case. But then that’s probably 15 years ago. But just the thought that I could think that still is awful.

Q It stays with you.

A Yeah absolutely, yeah. So I’ve kind of gone off track now but I don’t know whether that explains some of that sort of trauma that’s….

Q Yeah definitely.

A ….it’s just so close to the….you know it’s sort of under your skin but it takes nothing for it just to come back again.

Q And I guess then that shapes all your kind of future interactions that you have with professionals and services and your ability to trust people around your brother.

A Yeah, no absolutely. Sorry I didn’t think I was going to do this but….

Q No, I’m so sorry, it sounds absolutely horrendous.

A No, no, no. I mean the whole kind of thing about being involved is just, I really wanted to support it because it’s about people feeling valued and listened to. I know there are far worse stories than ours, you know I’m very aware of that. And I think it’s such an isolating role to have in life.

Time 10:10

Q Yeah. You said a bit earlier about the toll that it’s taken on your physical and your mental health. Do you mind just explaining kind of what kind of toll it has taken or how that’s manifested?

A Yeah. So I’ve had quite a few episodes of really poor health that I know are completely related to the stress and, you know the emotional toll. In the past I’ve been diagnosed with depression and had medication for that, and all…you know I can trace it right back to when it started and why. And fortunately I’m kind of not in that place any more. I’m very aware of it and there are times where it feels just such a tightrope of fear of dropping off again. But I think in some ways I can recognise those sort of, I don’t know, symptoms in myself and try to kind of protect or remedy those things the best I can. But my physical health seems to be then the weak area. So I’ve had times where, again I was so stressed because of worry and concerns about different things, you know I’d got all the heart palpitations and all of those sorts of things. Had lots of, what do you call them, EEGs and things, and they just kind of dismissed the whole notion of stress or emotional strain. And even though you say ‘I’m a carer’, it has…it just doesn’t register you know.

I’ve had times where my brother has had a whole series of health crises. And he’s had loads of changes in his life that just kind of were one after another and he wasn’t in a great place. And he started to show signs of improving and getting back to where he was. And the minute he started to recover then my health just collapsed if you like. And just loads of things, you know my immune system basically was battered so I got deficiencies in all sorts of things, you know sleepless night, hair falling out. And I’ve still got bald patches because that’s just seems to be something that happens routinely now. And those kind of episodes are quite common, you know I kind of know they’re coming but there’s not a lot I can do to kind of prevent them.

Q Is there anything kind of….or what kind of supports do you think you would benefit from, or could benefit from kind of over the past 20 years since you’ve been kind of your brother’s main carer?

A I think one of the big differences I’ve experienced in the last few years – well a few things really. I suppose one of the….the big things I’ve felt very aware of, you know I was saying about feeling so isolated and you’re going through all of this alone. I mean you know I’ve got an amazing husband and son who are really supportive but it’s still not the same as going through it yourself. But I recently became part of a team of family members for the social care provider that my brother is supported by actually. And it was the first time I’d had peers if you like that I could relate to. And it was also I think the first time I’d really acknowledged that kind of hat, or that role over my head of ‘family carer’. I’d never used that term to describe myself before, I was just ‘my brother’s sister’ or you know his advocate, his next of kin, that kind of thing. And it just felt that sense of belonging was incredible.

Time 15:00

But even though there’s probably about 6 or 8 of us on the team at any one time all our relatives are so different and unique, as people are. But there’s just something you didn’t have to explain, people understood without having to talk about the details, people just got it, you were on the same page. And people would also kind of relate to that emotional side of things. And I just…because most support groups are for parents in the main, everything is…and all through school there are all sorts of….. but there’s very little for siblings and other people who are relatives. And it was just something I hadn’t experienced and was overwhelmed by the difference that’s made, you know. And I feel I know my colleagues, friends, really well at one level, you know the bit about the lived experience is so much a sense of belonging – and yet I probably know very little about the rest of their lives. So I don’t know whether that…. So that’s a big thing in terms of just that feeling like a sense of belonging, feeling people understand what you’re going through.

I am and I’ve always been involved in lots of things, mostly as a volunteer, sort of advisory groups and things like that. I’ve been part of LEDR? sort of as a family carer member since that started, and now the Independent. And I suppose some of that is just knowing that people are listening, are…well not always, not always, but because I’ve been part of some of those groups for some time my view and the perspective I bring about people with profound and multiple learning disabilities is listened to now. And that’s part of who I am, you know as a….I can’t say I’m a representative of that community or that population but I can represent some of those views. And it has, you know knowing it can make a difference has been useful. It’s hard to kind of know what would help if you haven’t got it sometimes.

Q Yeah. Is there anything kind of specific I guess to mental health, like through your GP or that kind of side of things I guess where there could be more support or anything which would help, or recognition of your role as a carer?

A Yeah. I’ve never felt any recognition or acknowledgement from my own GP sort of surgery or any of the health professionals there. I kind of got the impression that if you told a health professional, you know quite specifically, that you were a carer, a family carer or whatever type of carer then it would be on your record. But I don’t think that’s the case. Even though so often I’ve gone and talked about my experiences or symptoms that were related very specifically to my role as a carer but nobody’s ever kind of picked up on that at all. So that would be something that could help. But I think some of that is the whole links between stress, anxieties, you know that mental health or mental well-being just isn’t really given the same credence as physical health symptoms. I mean that’s sort of not just GPs, it’s the world over isn’t it? And they’d far rather kind of treat physical symptoms it feels like.

Time 20:00

I mean I suppose because I’m informed enough, you know I have a good diet, you know I understand nutrition you know, and compared to a lot of people my diet’s OK. My sort of levels of physical activities aren’t brilliant and I’m aware of that, but that’s kind of my lifestyle’s changed with working at home and all of those sort of things sort of into retirement and what have you, and ageing. And I suppose the other thing on the mental well-being, emotional well-being, is that whole thing of ageing and you know like any family worry about what happens when I’m not here. And being older than my brother, you know quite a bit older, that’s more….you know. I had some recent ill health over the last few months after having COVID, and again I’m convinced it was my resilience…you know my immunity with constant stress just isn’t helpful and it just really brings your mortality to the fore really.

Q Yeah. Obviously you said there is worry about the future, are you doing anything with that worry, any kind of planning, or how….

A I know the theory, I just haven’t got round to it. Yeah. And my brother was really ill with COVID and has long COVID now and that’s been pretty life-changing for him. And we’ve had to I suppose in that….I mean we thought he was heading towards end of life at one time, after he’s kind of recovered, but just we weren’t sure whether it was dementia or just the long COVID. But we made lots of adaptations around his life. So on good days we made it as active as he wanted it to be but we also had a plan B for the days where he was just out of it, or…

Q Wiped out.

A Yeah, didn’t have the energy or the understanding. You know there were days where he just wasn’t able to understand what was going on and things. So even down to….he has a modified diet anyway but we had two steps of diet, you know days when he was really well and could enjoy it, and then a much easier safer diet for days where he couldn’t do anything, if you know what I mean?

Q Yeah.

A So there’s a degree of that. And certainly adjusting as I see him rapidly ageing. You know he’s just 60 But I know, I’m constantly researching, I know the whole thing of ageing and frailty is at such a younger earlier age in people with learning disabilities. I mean the kind of current research is saying, you know a 20 year difference if not more, and certainly that’s what I see in my brother. So again we’ve got lots of things in place, you know wheelchair for the days he can’t walk or just hasn’t got the energy, or runs out of steam and suddenly you’ve got to….you know. So I suppose it’s much more about managing the here and now but with an eye to the future.

His annual health check just a few weeks ago we were asked about….well they asked about ‘do not resuscitate’ which obviously we….well not obviously we didn’t want that to be something to think about now, and we certainly didn’t want it to be something on his record for no reason. But they did talk about us completing, I think it’s called a Respect Form, which I think is just advanced planning of the type of treatment you would or wouldn’t want in the event of, you know eventual, I don’t know end of life I guess or situations.

Time 25:00

But that’s just so hard to have a generic decision, you know it depends on so many other factors and, you know quality of life at that moment in time, and pain levels and all sorts of things you know. Yeah so like a lot of people I guess I’m just putting off doing that sort of thing. I mean I haven’t done it for myself and I’m a lot older than him you know. Again, it’s on the list of ‘to do’ but it’s just….it’s not intentionally not doing it but it doesn’t always come to the top of the list.

Q Yeah. I guess like you say it’s often a case of managing the here and now kind of emergencies and things which crop up kind of daily.

A Yeah, and they are often daily.

Q Yeah. Did you….I know just going back you said when your mum passed away kind of he was made homeless, so there hadn’t been any I guess kind of future planning then. Did you have conversations or….

A Well certainly in her situation things were in motion, but it was just the classic the social worker went on sick leave for 6 months and then started again, and you know just…. And very much over 20 years ago it was very much about looking for vacancies, you know there was none of this ‘what are your needs’ you know, it was just ‘where can we squeeze you in’ you know. And they talked about voids and empty beds and….

Q Yeah they didn’t have the beds, ??? beds, yeah.

A Yeah. And sadly it’s not very different now, you know he’s never had a say in where he’s lived or who he’s lived with. So he’s moved 4 times since he left the family home, none of them by choice. But yeah. So in terms of the planning, I mean I’ve done lots of thinking about it and we sort of had some warning about….well our father died 50 years ago nearly so we were all quite young when he died, my brother was just a teenager and I was sort of in my early 20s. And he didn’t come to that funeral, and that was just children didn’t go and it just was deemed inappropriate. But when we knew our mum was dying I was determined he would be part of it, although she was so worried you know ‘you shouldn’t do that’ you know and all this. And we put a lot of time into it. It still wasn’t meaningful to him, that was the first kind of thing he’d ever come across. And it was very hard. He’d seen her in hospital when she was kind of unconscious by that stage and obviously he just didn’t know what on earth was going on. You know the hospital was alien to him, seeing mum sleeping or whatever, and she got distressed at times, you know he just wasn’t able to understand it.

But he’s got an amazing kind of brain, there are things he’s got real strengths, people’s faces and some places that have some sort of significance to him, and whenever we used to drive past the hospital or he had to go to hospital for an appointment he would get so excited. And we knew it was because he thought he was going to see our mum. So it was so sad, you know that whole thing.

And I took him to see her in the morgue because I thought, just to try and help him understand it was different. And I’d never seen anyone dead before either. But he was just getting more and more…well I say excited, but anxious and overwhelmed and he was almost skipping along the corridor. And this poor woman that was sort of escorting us was just….you know didn’t know what to think. And I was saying ‘he thinks he’s going to see our mum alive again’ you know. Anyway, we went in and she was there, kind of laid out, and I didn’t really know what to do next you know because it kind of didn’t look like her. So I got him to touch her. And she was cold so he wouldn’t touch her. So we ended up sitting and having a drink and a biscuit just talking about nothing, just to be with her. And in a way that’s what he would have done with mum you know.

Time 30:30

Whereas one of our brothers died about 4 or 5 years ago and we knew he was coming to the end of his life so we had lots of experiences together and took photos and things so we knew there could be things to remember. And you know it was very weird and hard on my brother that was dying knowing that’s what we were doing for him. But that brother chose not to have a funeral, so we had his ashes and we did a little family thing where my brother helped. We all took it in turns to scatter the ashes around a place we’d visited. And he knew it was something serious and kind of solemn. And we go some special photos and things for him to keep. But normally he just wouldn’t be interested in getting involved in stuff. And he won’t use his hands, he had a go at holding the canister and shaking the…so he….yeah. So there’s things like that I’ve thought about, but it’s a bit different when it’s going to be him – or me.

Q Yeah. So it sounds like you’ve really made an effort to involve him in family events and family life I guess.

A Yeah, wherever we can, yeah. But I guess that was my day job so….

Q OK. What was it that you did?

A Well I did 20 years as a special school teacher and working with families, sort of supporting families at home and things. And then I had 20 years as an academic you know working around learning disabilities and profound learning disabilities in particular. So yeah.

Q OK. And was your career choice then influenced by your experiences as a sibling?

A Well it wasn’t to start with because I really didn’t know what I wanted to do and it was a just a case of what I was offered, it was the first place I got offered. But once I started I just knew. Again, never really thought about the connection. I mean everybody makes the assumptions that’s why I do what I did, but obviously at some subconscious level it’s been a driver of making a difference.

Q Just the fact I guess that you’re aware of disabilities, so many people aren’t aware of disabilities are they, or learning disabilities, so just the fact that you’re open to that, you know the experiences, it enters into your radar those kind of jobs I guess.

A Yeah absolutely, yeah.

Q And you mentioned your brother, another brother passing away. Are there other family members?

A Yeah we’ve got an older brother, the oldest of….there were four of us. So he’s in his…I don’t know, what is he, 75 now. He’s never particularly been involved. I think he was about 15 when my brother was born so he was already kind of, you know not around very much. He sees my brother occasionally, every few months he’ll call in for a cup of tea, but he doesn’t have a huge idea of everything really. And yeah had no kind of….even the awful times when my brother – well I’m convinced – was sexually abused, he didn’t…I thought at least he’d be around for that. But he came to one kind of review meeting and then just….yeah just doesn’t want any involvement really.

Time 35:00

Q How is that for you I guess, the kind of different relationships that your brother has with them, and also the taking on some of the caring responsibilities?

A Well I’ve learnt I guess that he’s not going to change, and much as it upsets me it’s kind of wasted really. And so I try whenever I can to just see, if he is involved, if he does visit my brother – because my brother loves to see him – it’s a bonus you know and that’s the best way to kind of manage that really. He…yeah, just sort of like sibling stuff. He, interestingly, always felt he was the one that missed out on everything because of my brother, which couldn’t have been further from the truth you know. My parents always said he should have been an only child because he expected everything around him. But yeah our parents were incredible though, my brother was….he was very difficult to manage, you know he was like a whirling dervish kind of thing. Very different now, years of being on drugs have altered his brain and what have you. But yeah it’s just one of those sad things really, you know just when you think what it could be like.

So he has no real understanding at all of what’s involved and doesn’t want to have any understanding. I remember my sister-in-law before our mother died saying ‘when she died what would happen, who was going to be the responsible one and not…’ you know I couldn’t expect any help from them and all this. So it was quite clear from the start. But yeah in some ways it’s easier just to get on with it really.

Q Does that affect your relationship with him then, does it kind of come into how close you are with that brother, does it at all?

A The brother with learning disabilities?

Q No sorry, so the older brother ???

A No. I think we’re estranged I guess you’d say.

Q OK. And is that to do with that situation?

A Yeah that and the other brother who died, who again he didn’t want anything to do with. And so it’s his choice. I mean I regularly email and you know just give an open invitation, but he’s just….yeah. His life’s easier without it I think.

Q OK, OK. And your brother who passed away then, was he more…well you said at the end of his life you were doing a lot together, so was he more involved ???

A Yeah he was always much more involved just being that bit closer in age. But he lived a lot of time in America so he wasn’t always around. But he came to live with me and my family for the sort of last, well year, until he died, so we had lots more. But he and my brother, learning disabled brother, got on really well, they loved hanging out together and things. So yeah.

Q OK, thank you. It’s a bit of a funny question but I’m just wondering if there’s one story or one theme kind of about related to kind of carers’ mental health which really stands out for you, or kind of sums up your experiences over the years.

A I think sometimes there’s a sadness that so much of the time that I get to spend with my brother, he lives sort of two and a half, 3 hours away so we visit, sort of spend a whole day with him twice a month really. But sometimes it can take us sort of 3 or 4 hours each way and as we’re getting older that’s just so hard. And it’s really intense for my brother to have that kind of time, you know.

Time 40:00

And I think the thing that I’m sad about is, so much of my time with him is for appointments and meetings and being his advocate. You know whenever we just go to visit we go just to visit him and, you know hang out together and be together and just do nothing together, you know just share the space and things. But it’s always monopolized by ‘oh while you’re here’ and….

Q Can you just do….yeah, yeah.

A And that’s disappointing I think, you know that whole, well right to a family life. And you know when our mum was alive they used to come over and stay with us twice a year. I mean he’d struggle now, he wouldn’t be able to use our bathroom and things, but he hasn’t even visited for about 8 years. And it’s one of the things that’s really hard is just….he lives on his own now in a flat. He had a fabulous sort of housemate before who died and so he’s lived on his own for about 2 years now. But it is his home but it’s not because there’s always someone else there you know. And as much as it must feel, for me, not that people are observing us, but they are you know, because you’re sort of demonstrating or living your relationships in front of someone all the time, you know unless you are out in the car or something. But it must feel the same for them. You know I know it’s their workplace and whatever but….you know that’s hard, that whole thing about….you know much worse for my brother who, like so many people, is so reliant on absolute consistency and predictability and familiar people.

And yet you know our two lives, I moved house at the same time as he had to leave the family home and in that whole sort of 20 odd years I’ve changed….well I retired from my job and that’s the only change in my life, I’m still in the same home. He’s moved 4 times. He’s had about 20 managers. He’s had thousands – and I mean thousands – of support workers and each time there are new people. You know I struggle to start again and build the relationship, the trust, but he’s got that right in his face all the time. And that’s some of the stuff I can’t bear thinking about, what it must be like.

Q So it sounds like you’re really striving for that ordinary kind of family kind of relationship.

A Yeah absolutely.

Q But just constant things there which act as barriers to that and prevent that from happening.

A Yeah, no completely. And yeah. I don’t know whether I would have done things differently now if the situation arose, but I didn’t know anything about Direct Payments or any of that kind of thing. So you know he lives such a long way away, and at the time we always wanted him to stay as near to where he’d spent sort of 40 years growing up at home, people he knew, places, you know. If he moved over to Peterborough where I live all he would know was our family, you know that would be the only….and that didn’t seem the right thing to do. And yet maybe we should have just bit the bullet and done that. I don’t know.

Q Yeah. Hindsight ???

A Yeah. And you need people to explain what opportunities or options there are, and people really don’t. You know it’s left to families.

Q And share that responsibility as well of taking that decision.

Time 44:50

A Yeah, no absolutely. And I mean if there is any sort of choice making, decision making, it’s usually an either/or, a black or a white, rather than ‘well what do we really want’ or ‘what would be the best option’ and you know looking at opportunities rather than choices almost. But it’s just we’re in times of financial drivers and things, it’s not the ideal landscape is it?

Q Is your brother…sorry just to clarify then, is your brother on Direct Payments now?

A No he isn’t, no.

Q ??? it’s a care home set up.

A Well he lived in a care home I think for about the first 12 years and then it de-registered, and then he’s moved twice since then. And so he’s in supported living now, and in the main the council or local authority where he lives, that’s their…

Q But it’s managed by the local authority that. is it, it’s that kind of ???

A Yeah, yeah absolutely, and a care provider sort of manages his care team. I mean one thing, the sort of two recent moves have been with the same care provider and they are an organisation who I have more trust in. And he’s got a great manager who is really open, we have a very open and honest relationship, which makes a huge difference and she really welcomes my involvement, which hasn’t been the case in the past. Very different from other people. And that is really beneficial to my mental health.

Q OK yeah.

A You know, so I can share concerns, however trivial or huge they are. And more often than not we are exactly on the same page anyway with the same concerns, so that mutual sharing is really valid, or valued by me. Yeah sorry I’m going all over, rambling.

Q No not at all, not at all, it’s really helpful for us, so thank you. I’m just looking through kind of the list of prompts.

A I’ve probably deviated so much from your list, sorry.

Q No not at all. ??? because we want the interviews to be more a conversation than, you know strict patterns because you never know what comes out when people are talking, and what areas are important for different people. You know if we married it down to a set of specific questions then we probably wouldn’t get half of what is important for you and your experiences. So yeah, thank you. We spoke a bit, I guess just going back, because we spoke a bit about support, so kind of what has worked for you, so in terms of reducing isolation….or what would work kind of reducing isolation and having those opportunities to share experiences. And just now in terms of sharing with the provider in terms of being able to ???

A Yeah, and I hadn’t really acknowledged that, although I do at other times, you know I really value that.

Q Is there anything kind of, again thinking about your mental health, is there anything which you’ve tried or have been put in place, or anything which doesn’t work or you haven’t found supportive or helpful?

A Personally I’m not one for kind of groups. And I don’t know whether that’s just because I don’t necessarily fit the group or what have you. It’s a bit hard to know how to describe it really, but there are often events for families and what have you to get your views and things but it’s quite daunting to go along to those. You know again because you’re either walking into a room or joining and online chat with people you have no idea who is going to be there or what this is about, are there hidden agendas – which you get very suspicious about.

Time 50:00

I mean again, going back to my sort of keeping good mental health, sleep deprivation has been a huge issue for me since our mum died and I kind of took on that role, it literally was almost overnight that I had chronic sleep problems. And I think I’ve probably tried most things there. And I know if I am sleep deprived, which is usually all about not being able to switch off the constant monkey brain thinking of over-thinking stuff. But you kind of lose any resilience you might have had to bounce back. It has a real impact on health and well-being. And I’ve tried all the, you know like stretches, mindfulness and guided visualizations and had teas and all sorts of herbal remedies and things. But they’re not specifically aimed at sort of promoting good mental health, but for me there’s a strong link between not sleeping well or quality of sleep, not just the hours.

I’ve had a series of counselling years ago. But I don’t know whether it was the particular person I had of the style of, it was very….I don’t know, it wasn’t anything like cognitive behaviour therapy or anything, it was the real old school stuff. And the guy was sort of trying pin all of my problems on not coming to terms with my brother’s disability; and I had problems with men obviously because of, you know….just kind of like something out of the films. And I just ??? So that wasn’t a positive experience. And I went weekly for almost a year because you had to kind of sign up to it. And in the end it was just making me more anxious about having to go.

Q And do you think that was then, from his part obviously that style, but was there a lack of understanding again about disabilities? and sibling carer?

A Completely, yeah, yeah. Yeah he had no clue about disability, or even any insights into the lived experience and how different that might have been. I mean I’d done some, like lots of people, some sort of self, whatever, reflections and things you know and growing up. And everyone talks about feeling left out as a child. And I never particularly….I mean our parents just kind of never stopped, they worked their socks off just making sure everything was as good as it could be in quite challenging situations. Because my brother was born in the 60s and that was the era where they were offered for him to go and….you know to put him away in an institution and just get on with their lives you know and never have to think about him ever again, which obviously was not what they wanted you know. And our lives have been so much richer for that decision.

But one of the things at some point I did realise was that it wasn’t that I felt ignored or anything like that but somehow, myself, I’d kind of decided I couldn’t make any demands on them. You know that I’d decided I wouldn’t or couldn’t ask for time or help. But that was just how I perceived things, if that makes sense.

Time 55:00

Q Yeah, yeah. So kind of more just a sense of responsibility.

A Yeah maybe, just….yeah, yeah.

Q ??? you know to not add to their load.

A And I suppose as a child, you know we would now describe me as a young carer because I spent a lot of my time looking after my brother so my mum could do the mundane washing, cooking and that kind of stuff, because it wasn’t safe when my brother was around to do things like that. But yeah it’s just you don’t know you’re different until someone kind of spells it out really, it’s just what you know isn’t it?

Q Yeah completely.

A But yeah. And my brother [name] and I, we’ve always got on and you know just….I’m kind of convinced we sort of came here together as a team to do stuff and change people’s attitudes and things.

Q Yeah, lovely.

A So yeah, he’s a great joy.

Q Mmm, a lot of love there. It really comes across. You love for him is really, really coming across.

A Yeah. And I think one of the things for me – well I can’t say for sure – but because he’s got profound multiple learning disabilities he doesn’t communicate with words, and there’s a lot of things you’re having…well most things you’re having to second guess the whole time. You know when something’s not right very often and it’s kind of the detective work that I think adds to the anxiety, you know particularly so often. I mean the most recent time when he was being abused about 18 months ago by a support worker, and his health hadn’t been great and we’d been sort of taking him to the GP, blood tests, checking his ears, dentist all of that. We thought something was really wrong with his health. And then because he lives on his own, people alone working. And it was just by chance another support worker witnessed some of the abuse, and then another one did, and we realised that’s what had been wrong. And you know it’s that kind of vulnerability that….well feels like it makes it harder but I’m sure it’s all relative, you know whoever your loved one is. But the fact that he can’t tell you what’s wrong or what’s happened. And I kind of think, you know he must carry trauma around, he must do.

Q Yeah of course, of course.

A You can’t imagine really.

Q Yeah. So just to expand on that, kind of the double guessing I guess that you’re doing, is that a worry about them not getting it, you’re not getting it, like if you don’t get it right.

A Oh absolutely, absolutely. And the hard bit about the people supporting him, it takes a really long time to get to know him, and much longer than people think. And so often….you know I mean we are so fortunate, we have some wonderful people in our lives you know, incredible, who are just amazing and fabulous people, you’d choose them yourself you know. But they only know what they know. And one of the things, as families, people come along and in five minutes they’re suddenly experts and think they know someone. And you think ‘you haven’t even scratched the surface’ you know.

Time 59:30

And my brother also has a sense of knowing – well like all of us, he communicates differently with different people. So people he knows really well and trusts and who understand his forms of communication he’s much more expressive, whereas he’ll just accept lots of other staff even if he doesn’t like it, even if it’s really uncomfortable, whatever, if it’s someone he doesn’t know as well. And it’s hard because people will say ‘oh he doesn’t do that for me’ you know, kind of like you must be doing it wrong. And I’m thinking ‘no, you just aren’t seeing it’. But yeah.

And I think people are always quite shocked. I mean he doesn’t do it a lot but when we visit and we always go out in the car and that’s one of the things we do together and whatever, go out. And when we come back to the flat he knows it’s getting close to the time where we have to say goodbye, and he often gets quite….well either angry or stroppy. And in the main people…because he’ll tell me to, in effect, buzz off kind of, makes it quite clear he’s not happy with me. And people are just amazed because he’s normally this sociable, smiley, very compliant kind of bloke, happy chap. Which he is, he’s a fabulous guy. But I suppose the other side of that is thank goodness he can say when he’s not happy sometimes or with some people, and that’s got to be a positive.

Q Yeah definitely. Sorry I’m just getting my interview guide back up.

A Sorry, gone completely off topic for you, sorry.

Q No, no, not at all, honestly I can’t stress enough it’s just about the things, your experience really and, you know we can ??? them but it’s really about what comes to mind for you. Is there anything you think, just thinking about the overall topic about sibling carers and mental health specifically, is there anything you can think of that we haven’t covered perhaps? I think we’ve covered a lot but if there’s anything which springs to mind for you?

A Something that another sibling carer that I’ve met in the last few years kind of raised that I’ve never questioned it before, but she’s…I think she’s 40 now and she is sort of part of, with her parents and some other support workers, they’re the team that support her two brothers. And she was always assumed she would have a single life, because who would take her on and her brother? And I mean I’m so lucky, you know my husband loves my brother and my brother absolutely adores my husband. But you come as a kind of package. And I suppose that’s something a bit weird – well not weird, it’s part of the difference isn’t it?

Q Yeah and interestingly that has come up in a few interviews is that ??? consideration which leads into kind of either finding or choosing a partner, you know yeah. And the impact on that partner as well ???

A Yeah. You see in the past, sort of over 20 years, obviously I was a lot younger and a lot more able to manage the driving and things. I mean my brother lives further away with the most recent moves. But I would go over to see him weekly, sometimes twice in a week if things…you know he’d got appointments or things to do. And it obviously had a knock-on, my husband, or my son was young at the time that it was just accepted. And now that I find the driving exhausting my husband, you know from his own….I mean he loves spending time with my brother, it’s a whole day, twice a month sometimes more often, and you know that sort of 8 hours driving sometimes on top of the day, you know we usually go on a Saturday and spend the Sunday recovering. But he does that, I know he does that to enable me to keep that going, you know so that’s really amazing and sort of supportive. If I was on my own I don’t know how I’d do it.

Time 1:05:12

I mean we have looked to move over there now my son’s almost 30 so he’s not at home now, but we just couldn’t afford to live….my brother lives in Worcestershire and it’s…so we’re in Peterborough which is sort of like a really cheap part of the world, you know we just couldn’t afford to do it. And that whole kind of scary bit of just up-rooting where you don’t know anyone. And the place he lives, he’s lived in Worcester for 5 or 6 years now, we’ve got no roots there, we don’t know anyone else there apart from him. We don’t even know, you know we’ve got set routes and places we go, but it’s weird really. And it’s not the sort of life you’d have if he was a brother without a learning disability. But that’s how it is.

Q Yeah. I guess just as you said earlier about making that decision to leave him….not to leave him, sorry that’s the wrong word, but for him to stay living close to where he grew up and your mum lived and things like that, if you up-root him it’s similar difficulties for you to be up-rooted.

A Yeah, yeah, no absolutely yeah. But no in my head it’s certainly….I imagine it would be so much easier if I lived nearby and could just pop in regularly and what have you. But that’s not how it is.

Q Yeah and I guess that was, going back to what you were saying about that kind of ordinary family life and popping in for a cup of tea, rather than it having to be a whole day and then having to have all this other stuff that he can catch you with whilst you’re there.

A A big ordeal, yeah. No absolutely, yeah. I mean one of the things that has really helped me and my brother I think, through like lots of people during lockdown he learnt to understand Skype. So he’s got a severe vision impairment and his hearing sort of fluctuates, and he’s got cerebral palsy and he’s got this, they call it blocked head syndrome, so he can’t hold his head up for long. And it’s really hard because he can only use his vision when his head’s up, so to see the screen and things. But I mean sort of historically I’ve always spoken to him on the phone, I mean when he lived at home I’d speak to him and my mum every day you know and it was just that bit about I always want him to know I’m still around, even if I’m not there all the time.

Q Yeah exactly.

A And that’s hard now because there aren’t people that talk to him about me and, you know like it would have done. But one of the things with him learning to use Skype is that he gets it now. I mean to start with you had to keep moving because he would just think it was a photograph, he doesn’t have that concept. But now…and that’s been a great way of other people, the people that support him, seeing how we interact and our style of communication together. And some of them have kind of built on what they’ve seen, which is lovely.

Q Oh fantastic, yeah. Kind of an unintentional consequence of ???

A Yeah absolutely, a sort of 3-way conversation. So that’s been nice. But there aren’t many of his staff who are happy doing that, so you know it’s just make the most of it when it happens.

Q Do you think then there’s something there about staff valuing the sibling relationship more, or valuing those connections more and doing more to be able to reinforce that for your brother?

Time 1:09:38

A Yeah very much so. I mean the people who really know him and know him best of his team are the people that Skype with me. And there’s two of them. And they – well because they see it they know how much he enjoys being with us, or we enjoy being together. You know he’s a different person – and he is genuinely a different person – as we all are you know when you’re relaxed and… And just recently he’d been to some art group that wasn’t accessible to him at all, and they’d been talking about creating something on paper that was all about the things that were important in their lives. And someone had sat with him and just written these words, which wouldn’t have had any meaning. And what really sort of hit me hard was it had music therapy, hydro therapy, sensory, stories, all of this kind of thing, but nothing about family.

Q Oh gosh.

A And I just thought….and it tore my heart.

Q Yeah. Fundamental family.

A Yeah. And for me, if anyone was to say ‘what are his interests, what are the important things in his life’ and I would always say ‘it’s people’, you know he is such a people person. He can do without everything else, apart from maybe rides in the car, but you know it’s about people who are interested in him and want to interact with him. And despite his disabilities he has this incredible talent, gift, quality whatever it is, of making you feel special, just simply the way he greets you, you know. And you just think ‘oh all of that was what…’ you know that 3 hour drive on the motorway and whatever, it’s all worth it. Yeah he’s….yeah.

Q Thank you. Thank you so much for sharing everything with us.

A Yeah well most of it’s completely off topic, I’m sorry.

Q It’s not at all, it’s not at all and it’s been a real joy and privilege to listen to you speak. I appreciate lots of it is a very difficult subject matter as well, and of course what you and your brother have been through is awful. So I do really appreciate you sharing it with us.

A Well thinking of some of those things, I mean from my understanding the recording is just so that you can do transcripts and things rather than ??? else ???

Q Yeah that’s completely right. What happens is, it gets sent off to a professional company who do the transcribing. We get the transcript back and then Martina my colleague will share it with you in case there’s anything you change your mind about or want to take out or edit, you’ve got that kind of final say ??? what we do have and what we do use. So she will share that transcript with you. You don’t have to go through it if you don’t want to, but if you do want to go through it you’re more than welcome to so you’ve kind of got that say. And then yeah the recording, once we have the transcript, the recordings are deleted, we don’t keep or use ??? And everything in the transcript is anonymised as well, so we take out names, places, anything which might be identifiable would be changed as well.

A Yeah. I suppose, and I don’t know why I’m saying it really, I mean there’s a couple of people I think are either on your Advisory Board or something that are…one’s a friend and the other’s a colleague, so I mean….yeah one of them will know some of the stories that I’ve shared anyway.

Q Yeah, yeah they wouldn’t….

A They probably wouldn’t have that level of detail, no.

Q No exactly, exactly. And yeah they wouldn’t have access to the transcript or anything, even the anonymised version, they wouldn’t have access to it. But I can flag that with Katherine, you know Katherine Runswick-Cole the PI, to just be mindful of that. Yeah. I mean she will be but….

A Yeah, I mean I suppose it’s that whole thing of….I’m really cautious with giving consent that’s talking about my brother [name]. And it’s a bit like photographs, I tend to say no if they’re going to not to sort of….because I really don’t know how he’d choose. You know he’s a sort of sensitive guy. But it’s that thing about once….and I don’t want…. some of the things I’ve sort of shared about him, you know aren’t nice things and I don’t want people to think….

Time 1:15:20

Q No, no.

A …you know that he was the guy that was abused or what have you. Because he’s so much more than that, he’s part of his history.

Q Yeah of course, of course. So yeah you don’t want people to focus on just ???

A No, no, and those things kind of tend to jump out a bit don’t they?

Q Yeah. Not at all. And like I said, kind of I guess the main focus is about you ultimately and your experience of mental health. But ??? if anything which is ??? they’re the kind of themes I guess we’re looking at. But yes I will ??? to be mindful.

A But I think it’s interesting just the whole kind of focus really, that it’s quite hard to actually consider it as a theme because you just kind of accept it’s part and parcel of the lived experience. And I suppose my default is always to talk about my brother because that’s tangible and concrete and I can be much more positive about that, or feel I’ve got more….I don’t know, influence over that. But yeah.

Q Yeah, it’s interesting and it’s similar you know, again it’s come out of some of the interviews you know, people saying it’s their first…just having those conversations being their first chance to share their sibling story or to, you know ??? that side of things like you say. Because the default is your brother isn’t it?

A Yeah, yeah absolutely, that’s the focus, yeah.

Q And if you do have any concerns, or you know you go away and think about something and you are worrying about it or how information might be used, feel free to just get in touch.

A No, and I don’t really at all. I mean I spent 20 years as an academic and kind of know the theory of ethics and things, you know. But I just wasn’t sure. It’s [name] who I know really quite well, so worked with her before. And then [name] who I’ve sort of just had sort of various….we’ve connected at different times. I just wasn’t sure what their role was. Are they more of an advisory group than research team?

Q Exactly yeah, they don’t come along to the regular team meetings or anything like that.

A OK, yeah.

Q And we are….you know it is a small world, particularly with Twitter and social media and stuff, so it is something that everyone’s very mindful of, that people do know each other, so it’s kind of ??? awareness of that. Because I think there are connections left, right and centre ???

A Oh I’m sure, yes absolutely.

Q Yeah. The other thing I guess just to mention – oh actually I can stop the recording now.