Q That should be recording now.

A Yeah, ??? being recorded. I think I just need to press OK, which I’ve done.

Q Thank you. Well perhaps to begin with you could perhaps just explain a little bit about what made you interested in taking part in the research.

A Yeah. Well I have subscribed to the [charity] website for a number of years, quite a long time actually, and I’ve attended a couple of their online sort of information days which have been really, really useful. And I mean I think they’re just an amazing organisation because they sort of hit a nerve I think with siblings of people with learning disabilities because there is nobody else who sort of seems to understand. Well yeah it’s very strange, yeah they just really have, you know I think, understood. And I haven’t found that particularly anywhere else as it were you know. I don’t think at one point I knew I was looking for it to be honest, I really, really didn’t until I read about them. And I heard something about them on the radio years and years ago and it just really sort of rung a bell and I thought ‘oh goodness, yeah’, I hadn’t ever thought there would be such a syndrome as being a sibling. And of course then you….you know. So I think that’s what’s very interesting.

And then, yeah I just saw the advert for the Spinning Plates and I thought ‘actually yeah it would be really nice to take part in some research’. I’m a great believer in research and, you know using evidence to obviously try and improve outcomes for people, and care, for carers and those with learning disabilities, and for the whole family you know. So I just think it’s important. And yeah the more that’s understood, that’s great. So for me it’s a nice thing to be able to do. Yeah, try and help out. And yeah.

Q Thank you. What is your situation then? You’re obviously a sister, you’re a sibling, can you explain a little bit about your situation?

A I can. So I’m an only sibling, so it’s myself and my brother. And our [brother] – well we call him ‘[brother]’, but he was born in 1957 so he’s now 66, and I was born in 1960 so I’m now 63, 64 next month. So I’m his younger sibling. And yes so just the two of us. And I mean now it is just the two of us as well. So we’re from actually a very tiny little unit, both of my parents were only children and so we didn’t have any sort of cousins or aunts and uncles; we had friends of the family and so forth. So we’ve actually always been a very small little unit. And obviously from quite a young age – and I think by the time I was born his difficulties were probably becoming more manifested on my parents – and in 1957 there was very little support, help or…you know.

And I mean one of the things that I was struck, my mother did say….she took him up to [hospital] to see, I don’t know who it was but you know at some stage because I think somebody had noticed he’d got some spasticity in one of his hands and he obviously wasn’t meeting his developmental targets so they ended up at [hospital]. And she said to me, you know they said to her then ‘you may as well sort of forget about trying to bring him up, he’ll never be able to go out on his own because he’ll never be able to read a road sign and find his way home’ and that’s what she was sent home with really. And I don’t know whether she was given any options about whether he should, you know be taken into care but I do know that she fiercely fought against that.

And I remember her telling me – we never talked about it very much at all and I know also that my father found it very, very difficult so I don’t think….you know and he actually didn’t go to that appointment with her, another friend of the family went. Again it’s very sketchy but I know it was something I think he found extremely difficult. And I know from later on in life he did as well, he found aspects of my brother’s behaviour difficult. And my mother much less so I think. So yes but she did fought fiercely against that.

Time 5:00

And actually, you know I remember at a very young age going to speech therapy, he went off to speech therapy classes and I can remember sitting in the waiting room. It’s strange because it’s so vague. I can remember some of his behaviour being quite challenging. And I can remember things like him banging his head against the wall. And I can remember being quite frightened I think by some of those things. Again it is terribly, terribly sketchy.

He went to the local primary school I think for a little while but then went off to what would then have been called a Special School. And all I remember about that is that, you know had obviously a range of pupils. I wasn’t particularly ever really involved with it. So he did go to a specialist sort of school.

And then the other thing I remember is he used to go off to a lady who lived in the town where we lived who helped him to learn to read and write - and that was mother’s sort of instigation – and helped him with his arithmetic. So he could read, he can read and he can write. His writing is very….it’s probably like a 5 or 6 year old’s writing but he can write, he can read, he can do a bit of arithmetic. And actually he’s an incredibly intelligent person in very, very many ways.

And of course my mother sort of had a real conviction that she would make sure he was – I remember she used to say this ‘I just want him to be socially acceptable and to grow up in a community’. And in fact, you know she managed to achieve that, and with my father’s help, he was there I know to support, he might have probably found bits of it very hard but….

And so he left school and they started to encourage him to get little jobs and things. And he actually has always worked. And he in the end settled in, he had a very good scheme which was part of the [charity], they sponsored him to work in a local factory in the town that we lived in and he worked there for over 25 years in the end until he retired, just doing general sort of caretaking jobs, you know sweeping up, doing the bins and the recycling.

He loved sport, so he loves football, he loves cricket, and he did his refereeing exam so he could referee football; and he is an active part of the cricket club as well and a much loved character. So actually, you know very socially, incredibly I suppose from what my mother was first told you know, he’s managed to sort of find his little place in a community that largely accepted him. I think sometimes maybe it wasn’t always a healthy acceptance, as in I don’t think somebody with [brother]’s disability they are sometimes aware that actually how they are being accepted as it were. You know I’m not sure it was always entirely healthy. But actually now he’s an older member of that community and everybody knows him and he speaks very highly, of him.

So that’s really his sort of background. And he always lived at home with mum and dad. MY father died quite young, about 64, and I remember again, something I sort of remember when my brother would have probably been in his sort of late 20’s, discussions about really whether he ought to be encouraged to try and live independently. And I think my father felt that’s perhaps what should happen, but I know my mother really wasn’t comfortable and didn’t know or….you know how that might work. And then he died, and that was actually probably the most traumatic sort of….it was very traumatic for all of us, it was traumatic for my mother, traumatic for [brother], and for me. And at that point my mother really, really….I mean she struggled really from then on. And she had a long widowhood until she died at nearly 90 in 2021. But they stuck together at home you know, and I think yeah there was no way she could face the idea I think of him moving out independently. So they carried on living together.

Time 10:00

And that was sort of largely OK, he was still working, mum was fairly active – she was only 63 when my father died so she sort of got on with life a bit. But she did have anxiety and depression herself so it wasn’t easy. And then of course she gradually began to decline, she had mobility issues as years went on. But they sort of coped, rubbed along with a lot of support from me. I mean that for me from then on really from the day my father died I sort of….I suppose, you know did I fall into the role, step into it, I don’t know. I wouldn’t have done anything else. But I lived about 50 miles away but you know used to visit as often as I could to support them. And there were discussions about what could be done to help him live independently but again my mother was very anti that at that point.

And we did have a social work team then, I think we were very lucky that actually we caught the Learning Disability Social Services team at probably their last Hurrah before they have been…what’s the word I’m looking for – their resources have been stretched.

Q Yeah ???

A Yeah. But he had a Learning Disability nurse who used to visit the house very regularly, you know once a month, and the social worker used to visit once a month as well just to see how they were getting on. But you know things declined very, very slowly and I would say around 2011 looking back my mother probably started to exhibit signs of dementia at that point, and so that sort of worsened and her mobility worsened. And then we had these two people – and that was probably at its most difficult – living together in the house. My mother is desperately trying to hang on to support [brother] above everything else, you know in front of her own needs really. And then increasingly….

Q And she’s 80 or so at this stage is she?

A Oh then she would have been, yes, she would have been. She died in 2021 nearly 90 and I would say she would have been nearly 80 then, yeah. And yeah, so she was desperately trying to…you know. And she would not accept help and she wouldn’t accept….you know. She was a fiercely independent woman and very, very intelligent as well and you know she fiercely sort of fought against help, anybody coming in to try and sort things out – including me. So it was hard. Yeah and of course her dementia worsened and then it really got very difficult because….and I don’t know how unique this is and I think it’s a really, really interesting area because as siblings grow older, if they are looked after by a carer who then gets dementia you’ve got this very difficult dynamic. And my brother, she then obviously began to rely on my brother and he was trying to support her and found it very, very distressing.

So that was extremely hard to deal with. And we limped along. And I visited weekly and tried to help in as many ways as I could. And I had to manage finances, both of their finances, both of all their social sort of care. And then I mean this is really a bit of a recap this, but it all fell down in about….I’m trying to think when mum had to go into care, but she really, really wasn’t coping. And I used to go down and find the kitchen in a dreadful mess and all the usual things with dementia – fridge full of expired food and she was ???

And my brother, I remember I stayed one night and she obviously was….until you stay, I mean I stayed on and off but on this occasion, it’s only when you stay with people I think who are struggling that you realise the extent because they can cover up on a short visit. And my brother too, you know wouldn’t have ever said – or been able to verbalise I don’t think how difficult things were. But I remember they wanted to go to bed and I said ‘I can help you mum’, ‘no, no, no’ she said ‘[brother] will help me, [brother] will help me’. And he did. And obviously she went into the bathroom and was in there for ages.

Time 14:54

And I can remember I sat in my little bedroom and I could hear him pacing up and down the landing. And I went out and said ‘what’s the matter [brother]?’ I remember this very distinctly. And he was in such a state, he said ‘I can’t….it’s mum, it’s mum, she’s taking so long, she’s taking so long’. And you know he would hold her hand and get her into bed. And I thought this isn’t right. You know he was almost at snapping point I think trying to help her into bed, and then in the morning. And then he’d try and go to work and she wouldn’t want him to leave. Understandably he didn’t want to leave her. So they really were in a very fragile state.

And I involved Social Services the whole time, you know I used to make sure everybody was very aware of what was happening. And at that point we had the opportunity to get her admitted to care. But I mean she hated that. The first time she went in for a little trial, because I think she had cellulites in her leg or something and things were really difficult, you know she literally stood at the front door with her coat on and refused to stay. And then she went in because she….that’s right, the second time she was really quite unwell and she had to stay. And in fact it was really hard. She’d got a dementia diagnosis by then – oh no it was ongoing and it was finalized and confirmed probably about 2 or 3 months after she’d been there. And the home had to get a Depravation of Liberty order for her as well because she kept wanting to leave.

And of course that whole episode was made doubly distressing because she was separated from my brother. And I mean it was awful, absolutely awful, it makes me cry because it’s so hard. I think it’s probably one of the hardest things I’ve ever had to do. But it was the right thing to do, absolutely the right thing to do. And it’s funny really because I think she went in probably about 2018, 2017/2018, and we were really lucky because the home was literally 5 minutes walk from the house. You know she could have ended up somewhere where my brother would not have even been able to see her, because he couldn’t cope with catching a bus or anything like that. But he used to go round and see her, and that was hard for him because I think you know he obviously suffered greatly from anxiety of her not being in the house, he was lonely and he’d never looked after himself before.

And so I stepped up trying to sort of support him in the house etc, and social services again tried to help him with his courses on how to cook. And he’d do very well until somebody left, the course finished and then he’d have a little disaster and he would not touch the cooker again. So he ended up going round to visit mum every day, and when he could if he wasn’t at work he’d stay for lunch and tea. And you know they’d have to sort of send him home in the evening. And this went on for a couple of years and we really were limping again at that stage.

But the home was superb, and it’s in this town that they’ve always lived in – you know they lived in for well over 35 years so everybody knew who [brother] was. They were very good. And the manager said to me ‘look, why doesn’t [brother] come in for 2 weeks over Christmas’. This would have been….it was 2019, yeah. And we said ‘that’s great, have a little trial’. He was a bit resistant but he went in and had 2 weeks there, you know quite enjoyed it I think actually but obviously he was pleased to be home afterwards. And then the manager, [name], said ‘look’, they had a lovely little flat which had a bedroom, a sitting room and a bathroom, and she said ‘it’s come up, would he like to come in for a 3 month trial’.

And this is where I felt we were all being so looked after. Because he went in on the 6th of March 2020 for the trial. And I remember my youngest daughter helping me take his bits and bobs round and we made sure he’d got enough. And I said to [name], I said ‘this is probably good because we don’t know what’s going to happen with this COVID virus that’s going around’. And I mean it was just extraordinary, it couldn’t have been better timing. And then literally we went into lockdown 2 or 3 weeks later. But he was there, he was safe. And if he’d not gone in he would not have been able to see my mother, he wouldn’t have been allowed into the home, he could never have coped with lockdown. I don’t quite know what we’d have done.

Time 20:18

Q Gosh, yeah, that’s incredible.

A It is incredible.

Q That’s just fantastic.

A It is. Every time I think of that, if I get stressed I think ‘oh’. Yes the stars were aligned on that occasion. And so there he was. And of course, you know he never came out again, he’s still there now. And it’s an old people’s residential home. But social services again, they were all on board with all of this. And they were very, very good, they were very supportive. And we’d tried all sorts of things. We’d tried to get them into a smaller flat together, supported living, my mother wouldn’t have that – which you know I couldn’t understand at the time but now I think with perspective I think, you know you were just trying to fiercely maintain your independence - it was so important to her - and [brother]’s and the way she looked after [brother]. It was everything to her that she had control over how he was managed and looked after.

But anyway, so there they stayed. But mum, at that Christmas of ’21, she caught COVID and she had to go into hospital. And it was very sad, because that was really hard because she went in just the day after Boxing Day I think and she never came out again. And of course I couldn’t see her at first and my brother couldn’t see her. He sort of just said goodnight to her on Boxing night and then he never saw her again because she went off very early the next morning in an ambulance. But then typical of my mother, she was so strong and fierce and she did not want to die because she did not want to….I know she just could not leave my brother and she was determined to get back. And she was strong, because she had all the dreadful symptoms of COVID, it was before the vaccinations and before really they’d quite worked out…. And they rung me from the hospital and said ‘she’s on day 5’ which was typically when people took a real dive. They said she’s practically unconscious and we don’t expect her to make it through the next sort of 48 hours. But she did. I mean she was extraordinary.

But she then never regained her health and was in hospital for about sort of 8 weeks. And it was ghastly, really ghastly. And I got to see her in the last two weeks but COVID restrictions meant [brother] couldn’t go in because he was in a care home. But that’s hard, he never said goodbye to her, you know in that sense of….

Q In person.

A Yeah. And of course then it’s been another story about managing his grief. And yeah, so that’s been a whole other story you know, and selling the family house. And that’s hard, you know another whole area which I think is another really, really important area. Again I don’t know how much information there is, how many people you’ve come across in your studies that have had to deal with parents dying and siblings trying to understand it, but it’s very hard, very, very hard. And you know he rings me probably every other day, we chat, and we have more or less the same conversation every day. But every day ‘I miss mum, I miss mum’. So it’s hard. Yeah. So really I think that’s the story.

Q Yeah.

A In fact I was looking back, because after my mother died, about a year afterwards, I wrote, I sat and wrote down a little piece which I was going to send to [charity] because they accept….you know, and I never got round to it. And I would like to send it in. And I was going to send it to you and I didn’t know whether you wanted it before you had your first meeting with me, or you might like to see it.

Q Yes please.

Time 24:45

A And I’ve written a bit about managing a sibling’s grief. And I think I’d quite like to share it with [charity] because I think it might be helpful. But yeah. So that’s in a nutshell is all my circumstances. And yeah. And of course because we’re such a tiny little unit it has largely been…well it’s largely been down to me in a sense to manage the journey. And it’s the length of it I think actually, I think that’s one of the things I’ve been reflecting on as well. You know it starts as a sibling at such a young age, and here I am at 66 and I’m still ‘[brother]’s sister’ you know, that’s my identity ‘[brother]’s sister’ really. It’s almost a bigger identity than who I am I think sometimes. Yeah.

Q How has it been for you then over the years? Because obviously you’ve explained what’s happened and that the implications, but there’s a lot of difficult points within that or kind of difficult situations.

A Yeah. No it’s been really hard I think, really hard, there’s been some really, really hard times. And yeah, my mother actually….you know all sorts of things….you know my mother actually used to get very, very angry with me, and I think it was her own frustration, you know that was always hard. And I know she never really meant it, but you know she once said to me ‘well you are lucky, you’ve been given all the gifts’. You know she’d say things like that but I know she didn’t….you know she would never have actually….but it was a frustration I think. And while I was sort of trying to coral them and get them organized, and by this time she was getting dementia. So that was hard, yeah. Lots of bits were hard [name] it’s a bit difficult to know where to start.

But then lots of bits of it are very rewarding. It’s difficult isn’t it, yeah really difficult. But yeah hard and a bit lonely I think because you…and I’ve got amazing family of my own and friends who are so supportive and always have sort of been there for me and listened – as I hope I have been for them, because it’s not unique to have difficult family situations to deal with but it’s a unique scenario I think, a fairly unique scenario having a brother or a sister with a learning disability perhaps, I don’t know, I don’t know. Yeah, and it poses a unique set of challenges.

And I think the fact that I still feel hugely responsible for my brother, and it’s right here in my heart and my stomach, I think it’s never going to go away ever. I’m the only person still. And he rings. And if there’s a problem it’s only me who can ever deal with it, I’m the only relative, the only sibling and….you know, yeah. It’s not that I want it to go away because I think actually one day maybe my brother won’t be here and that will be a whole other scenario. Yeah. So difficult to know where to start with the difficult bits.

Q Yeah. And I guess at every juncture which can be tricky anyway dealing with your own grief or ??? moving into a care home, every juncture it’s that bit more tricky because you’ve got your brother as well isn’t it?

A Yeah. And I think I’ve always had to put them first, which sounds a bit self….I don’t mean that to sound like I’m trying to be a saint because it isn’t, I’m not a saint, I haven’t been a saint at all. And there comes in huge guilt because you know I used to get so frustrated with both of them. But I feel like you really do have to side step, and that I guess feeds into slightly your whole being really. And I think I probably would have learnt that from a very early age actually as well. I can remember, I think, quite a bit of challenging behaviour when he was younger and I suppose you learn to just try not to upset the apple cart too much. But then I’m a fairly strong sort of person and a bit mischievous, I don’t suppose I….you know I’m not entirely subservient and timid and retiring. But I think you do, you think ‘right no…’ they always came first.

Time 30:11

And of course that had an impact on my own family. And they will tell you, my children will tell you that they remember you know when they were younger making sure I was there for my mother and [brother]. And my husband, who has been incredible and has never, ever complained, he’s always been supportive and understanding, but you know they probably would all say….yeah, yeah. And I think it was hard for them as well, the children you know. When they were younger they didn’t quite understand some of my brother’s more bizarre behaviours. Yeah, which he still exhibits now – in fact increasingly so the older he gets in some ways, yeah. So he’s complex. He’s funny, he’s intelligent, but complex difficult. And I think again probably like a lot of people born in 1957, never really had a firm diagnosis of what was the matter. But latterly social workers who have seen him would say he’s definitely autistic and has OCD. Yeah. And he’s very anxious and gets quite depressed. So yeah, so that’s sort of it really. Yes. I can’t pinpoint one particular difficulty, but yeah.

Q I guess rather than focusing on the difficulties, what’s helped or what’s kind of helped? You’ve obviously mentioned about family and friends, is there anything else you can think of which has really helped kind of support you through it at different times – or what you could have benefited from and didn’t have?

A Yes I mean I think there are massive benefits. You know it teaches I think from a very, very young age tolerance and defending those less able. I mean it teaches you all of those things I think in spade loads. I mean I think a lot of people have that anyway, but I think perhaps it’s….you know. And yeah I ended up nursing. I mean I think my mother was a nurse. You know I loved my job, yeah that kind of caring side I think. Yeah. So that’s good I would say, an empathy and an understanding for those less fortunate, those whose behaviours perhaps are less usual, you know you have a tolerance for that. I think it teaches you a huge amount I think. But then that would be like saying other people don’t have that – and I think they do but I think you do have more of an understanding of….yeah.

Q So they are qualities that you took into your nursing then and took into your work.

A Yes, yes and I think I did my job largely well and I’m sure it helped with that. As I say, [charity] I think is a wonderful organisation because it was one of the only….I mean it is the only organisation I know that particularly focuses on that relationship and what that means and how that….so it’s incredibly important I think, incredibly important. And I haven’t found that anywhere else actually. Yeah because I think it’s a funny thing.

And I think I’ve often reflected on the fact that if you have a brother or sister with a learning disability your sibling experience as a youngster is different, you don’t have anybody who….I mean I watch my children and my grandchildren as they sort of spar against each other and they are equals in a sense. And as my children have grown up they are intellectually equal, they’ve all got good jobs that are equivalent, they’re bright, they’re intelligent. And they always get on but they can spar against each other on an intellectual level and one of them isn’t significantly more vulnerable than the other – do you know what I mean? I don’t know, I don’t know if that has an influence on how you grow up. And if you don’t have another sibling as well. If you’re perhaps a group of siblings. Yeah so I don’t know whether that’s something that’s…..

Q When you talk about the responsibility I guess it’s all on you, you haven’t got anyone to share that or kind of share the decisions with.

A No absolutely not no. And you know when it came to getting rid of my mother’s house and, you know which [brother] obviously had lived in with her all those years. And he was by then in the care home and I was trying to do it sort of as lockdown eased a little bit – you know that was a very difficult experience. But in a way I mean I had to get on and do it.

But the house, that was hard because not only had my mother hoarded all sorts of stuff but my brother was a terrible hoarder. I mean we had medication, money, all sorts in extreme. Yeah he had well over £10,000 in his bedroom that he hoarded. And my mother knew about all of these things and because she wouldn’t ever, you know sort of didn’t know how to deal with it. And medication, the pair of them just used to send these repeat prescriptions in and not use the stuff. And yeah, chewing gum, toiletries. I made inventories of….I mean he had 75 of everything, sort of aerosols, shampoos, Lynx sprays, everything. I mean so much stuff you wouldn’t have believed it.

And again you know social services knew. And when my mother was alive I could never get….and I wouldn’t have gone into his room to sort of sort it out, it was his space, but I remember opening the door and it was getting a bit like this, you know there was less and less room. But I had to empty all that out, deal with it, and he wasn’t there then, he was in the care home. But I dealt with it as carefully as I could saying ‘now look [brother] what are we going to do?’ But we managed somehow to deal with it. We gave the toiletries….there was a refugee organisation in Town, which is where they live near Town and [town], and I said we’ll take it all there so we can give it to the refugees and they’ll be able to have a nice clean shower. And he loved the idea of that. Yeah so that sort of thing was hard.

And there were times when I thought it would have been lovely to have had another pair of hands just to come and see it all, it’s not the doing it it’s the seeing it. And I used to document it all and take photographs because I think people won’t believe all of this. You know there’s almost like nobody to share….and that’s actually quite….I’ve never thought of that but that’s an example of what you witness and see as you go through the years, only you are witness to it. I mean my children and husband saw a lot of it but in latter years it was me going up and down and having to deal with them. And you are a lone witness. And I guess you begin to question yourself a bit. But I say ‘no this is here’.

And the money, my husband was with me on that occasion because he has financial Power of Attorney for my brother. And because he used to get paid at this little job he had, I can’t remember what he got but he used to get paid. Every single week he used to go down to the Building Society, the money went into the Building Society. He’d go down, get £100 out housekeeping for my mother and he’d get about £130 out for himself and then leave the rest in the Building Society. But of course that money, he never needed to spend it other than buying his toiletries and his chewing gum. And he’s put it in a tin upstairs, and of course that went on for over 20 years and that’s how that amount of money arrived in a tin. Yeah.

Q Yeah, wow.

A Yeah there’s some funny stories. I mean we laugh about that now. Because when we found that he’d by then gone into [name], he’d been there about 2 weeks, it was before we were all locked down. It was the last day we were able to see them before lockdown I think. And we went to the house, because I said to my husband ‘we know there’s money in the bedroom, we’ve got to sort this, we can’t…. when you know a lockdown might come’. And I said we’ve got to make sure that’s not in an empty house. And so we managed to get him to open his tin up.

Time 39:50

And it got to something like half 11 on the Saturday and the Building Society shut at 12 – it was just down the hill in the town – and my husband counted the money out and he said to [brother] ‘we’ve got to go down now, we’ve got to go down before they shut’. And my brother’s a bit slow and my husband ran down with it. And he said ‘it’s [brother], it’s [brother], it’s his money’. And they knew him and they said ‘alright’. And my husband said ‘he’s following down’ and they counted it all up and put it away. So I mean that was a funny story. And I remember my husband saying ‘[brother] do you understand how much money you had in the tin’, ‘oh no [name]’ he said ‘no I don’t really’. And my husband said ‘well it’s enough to buy a small car’. And yeah.

So they’re very funny stories along the years, which we all share. My mother used to…she had a great sense of humour, so there were those times that were good you know. We all laughed at and about each other. We had a very humorous family, I think we were quite robust in that sense. Which is another interesting thing to think about actually, that perhaps we had quite robust relationships, you know we could disagree and get cross with each other but ultimately usually used to be able to sort of laugh about it, yeah. And we were loyal, I was loyal, yeah we all were. So that’s an interesting one as well actually, yeah. For all the difficulties there is no way I would have walked away from it at all, yeah.

Q And where do you think that came from then, was that kind of your parents, your mum kind of instilling that somewhere in you do you think?

A Yes I think so, I think so. Yes very interesting, that’s a really interesting question actually. Well there was a strong loyal bond. And I don’t know again with siblings whether that’s very common, that actually siblings do stick, you know it’s like sticking like glue. And it’s so sticky sometimes when you meet and healthily pull away it’s really, really hard. But it is like there’s a unibond thing going on there. I don’t know again if that’s unique or…. but again I think something really interesting to… Because I did have some counselling which was really, really helpful at one point and I remember the counsellor, a couple of people have said to me on occasion, when I actually have tried to separate myself slightly you know they’ve said ‘actually that’s a healthy thing, you need to do it’. Because I don’t think I could. And I there are times now where I know I can’t separate my needs from my brother’s. And it is, it’s like this glue that brings you back. So there’s a real positive side to that but I think that’s also tricky. So I think that’s a good analogy really, the unibond of siblings.

Q Yeah. And if you don’t mind me asking, the counselling then, was that a lot about your relationships, your family, or was that….

A Yes. So first of all – oh I remember the first session was with a psychologist who was connected to the community learning disability team because, and this is quite funny in a way because it was around the time about 2011 when my mother I think was beginning to get dementia. And they had wanted to see my mother, they really wanted to talk to my mother this psychologist, and my mother refused. So to get an insight on what was going on, what was beginning to go wrong – and it was by then and the social workers were concerned so they’d got the psychologist. My mother absolutely refused to go, which is just like her. And I remember the social worker said to me ‘[name], you’re very welcome to come along and chat to the psychologist and explain the situation, explain the story’ which is really the story I’ve told you.

And by then actually we’d moved away and was a bit further away from my mother and brother, and I remember her saying ‘that’s probably the healthiest thing you’ve ever done’. And I think it was in a way because I did find my own life. I went back to work you know and started my career again in nursing and found other talents that I knew I’d got but never really sort of explored. That wasn’t entirely because I’d moved away, it was age and….

Time 44:51

And then I had some counselling after mum went into the home actually, yeah, and I’m trying to think….no [brother] had gone in as well by then, and that was from Carer Support. Because somebody referred me to Carer Support, the social workers, because I just wasn’t coping. And that was the time I was getting [brother] into the home as well and I’d been trying to sort the home and I really was in pieces at that point. So Carer Support referred me and that was very, very helpful as well. And she talked about me trying to see myself with a separate identity to them both. And I think that’s hard actually and I’m not sure I’ve ever really managed to achieve that. I think I’m still a bit glued to the pair of them. It’s funny isn’t it?

Q Yeah.

A Yeah they came as a pair almost. One was my mother, one was my brother. And my mother was needy as well, you know she had great anxiety and depression and used to ring me constantly for reassurance and to tell me her problems. So I did just keep getting drawn back. So it is interesting where you’re asking where did that come from.

Q Yeah.

A And I think I remember the counsellor saying ‘at a very early age that sort of loyalty to your brother who is less able than you’. But I don’t know, yeah.

Q Do you think you would have benefitted from any kind of support, or different support then either to manage that bond or ???

A At an earlier age?

Q Yeah.

A When I was younger?

Q Yeah.

A I think I would have done, yeah, I think I would have done. Absolutely. I think if somebody had said ‘oh yeah this sibling needs help to understand what’s going on’. And it’s very, very, very interesting because I don’t have aunts, uncles, cousins, there nobody again particularly to have witnessed that stage. Although interestingly there was a…she was a sort of aunt in a sense of the family and I met up with her and her daughter about 2 and a half years ago after a long time we’d not met, and they came to lunch and it was just lovely, it was really, really nice. And we were talking about my mother and [brother] and she said to me ‘your mother never ever took time to explain [brother]’s behaviour, she just used to pretend it was normal and accept it was normal’.

And it was a really interesting comment because, yeah she didn’t ever put it in a context and say ‘this is not normal and this is how we might deal with it’, she said she just used to….yeah and so it was quite an interesting comment. And so perhaps I just sort of thought well it’s normal, and nobody’s explaining why it’s happening. Yeah. But again I think then, that was the early 60s when he would have been young, but I don’t think anybody really was terribly in tune then to….yeah I’m not sure there was a great deal of support for my mother really.

Q Yeah it’s interesting you say that actually, a discussion about that came up in another interview with a sibling about just their being no discussion around the behaviour. It kind of happened and then you move on, there wasn’t any kind of reflection as a family or ‘gosh that was difficult what just happened’, it was….

A Yes, and I didn’t notice that until this person who came for lunch a couple of years ago said ‘your mother always just used to pretend it was completely normal, we’ll move on, nothing’s happened here’ sort of thing. And it was never explained. Or ‘[brother] is behaving like this because….’ you know. Which perhaps nowadays that might be encouraged a lot more with trying to understand why a child’s behaviour is such.

Q Yeah. And acknowledging for you that it was different or it was difficult or….

Time 49:40

A Yeah. And of course it is difficult as a child and I do remember at times being so embarrassed, you know you are so embarrassed you feel like everybody’s looking at you because you’ve got this…. And that…..yeah, so you sort of hide behind being that person’s sister – not a sister but being THAT person’s sister. Because it’s hard, it’s really hard. And yeah, yeah. Yes so I think that’s another whole thing. And I do think the value of being able to perhaps support younger siblings is immense, yeah, yeah. But it certainly wasn’t there. And again that’s how you lose your identity a bit. I think I might have mentioned that a bit earlier, you know I was always ‘[brother]’s sister’ you know ‘[brother]’s sister’, you’re not….yeah you are…. And in the end that becomes easier really I think than trying to explain anything, you just sort of ….yeah, until you get old enough to be able to understand.

Q You said you discovered [charity] kind of almost by accident.

A Yes. Well I heard an article on the radio and that would have been, it was on Radio 4 on a Saturday morning programme and I would have said that’s probably about 10 or 12 years ago. And I just heard this woman talking about the organisation and that she was a sibling, and everything she said I thought ‘my goodness me, she’s talking about me’.

Q Oh wow.

A A real light bulb moment. And I thought ‘wow, that’s incredible’ yeah.

Q Do you think you would then again have benfitted from their support earlier on, or someone kind of introducing you, signposting you to that kind of organisation before?

A Yes immensely helpful, yeah. And I remember I think one of the social workers at a later date produced a leaflet about [charity], but by then I’d sort of discovered them myself. But yeah I think it’s immensely important.

Q And what is it that you get from them, kind of what is beneficial about it?

A I think just that shared experience really because it’s unique and it’s the share experience. And they’ve done good workshops on managing money, finances, power of attorneys and you know how….the practical things as well as the emotional things as well. But I think there’s a huge amount to be gained from sharing experiences like we’ve all had actually because then you can say ‘well this is what happened to me’. And my journey’s been very much about supporting them both, supporting them both going into care and now supporting one of them having died. And now my brother’s health is not particularly good and…yeah it goes on and it goes on and on. So I think to share any of that is really helpful, yeah, so you’re not alone.

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

A For parents to be well supported?

Q For carers. For you as a sibling carer, yeah. What do you think, if anything, needs to change?

A I’m not sure really. I’m really not sure. I think you’re a carer and if you look at it in that sense. I think the sense it’s the same things that need to be changed for any carer in any circumstances – and I’m thinking particularly you know around dealing with social services. And when my brother finally went into care he used up his money first in the first sort of year that he had to pay for his fees, and then he got down to his £23,000 and we had to….you know social services promised me all the way along ‘oh he’ll be funded, he’ll be funded, we’ll do everything we can to help’. And when push came to shove that was incredibly difficult to get the care? But by then the social services team had begun to rather disintegrate a bit I think and the people we’d had as supporting us in previous years who had been amazing present, were suddenly not there. And I couldn’t get a finance assessment done and time was slipping on, and I’d already gone through a lot of trauma at that stage. But I don’t think that’s unique to me as a sibling carer, that’s unique to being a carer. And I had to really fight to even get a care assessment done so that then they could assess him to say he’s only got £23,000 ??? And there was nobody there all of a sudden. But that’s….yeah.

Time 55:00

So is there anything special that could be done? I think just the support generally that carers need. But I think maybe all organisations that support carers could have perhaps a bit of understanding or awareness training that people who care for people with learning disabilities and that may have its unique challenges, you know as opposed for caring for somebody with long term illness like ??? or MS or a cancer diagnosis or dementia, do you know what I mean? Perhaps there could be some more information around....yeah for healthcare professionals, yeah. That’s another area of course, dealing with his medical needs in hospital which we’ve had to do on occasions. And again how the medical profession respond to somebody with a learning disability and your position as their carer. It’s interesting. I guess it’s awareness isn’t it? A training so people understand some of the unique problems that you face around supporting somebody who can make some of their own decisions but can’t make some others, you know. Because it is…..yeah.

Q And again, I don’t know how unique it is but how you’ve ended up caring for both your mother and your brother, which is perhaps different to parent carers who are caring….they might have a spouse they might care for but they’re kind of predominantly caring for I guess their learning disabled child, not having to also necessarily care for a parent like you ended up in that scenario.

A Yeah. Yes. I think trying to support both of them and care for both of them at the same time was very, very hard, yeah. So it was like a dual caring role, yeah. Yeah I think that was quite unique, but it won’t be unique as siblings age and….you know other people….yeah, I don’t know what the sort of age profile of the people that you are tending to interview is, is it older or younger?

Q It’s been quite mixed actually, it’s been really lovely. Certainly the people I’ve spoken to it’s been a whole mix of ages. And yeah it’s definitely in some of the interviews there has been discussions about the dual caring, and navigating grief and those kind of situations which are difficult at any time let alone then when you are caring for a sibling as well and trying to support them to navigate their grief as well.

A Exactly, yeah, yeah. Again you have to sort of….yeah put your own situation slightly to one side for a bit while you try and work out a bit of space to do that for yourself. I think it’s….yeah, yeah. And actually allowing yourself the space. The space is probably there but it’s whether you can allow yourself to use that space. And I think that’s something….you know it’s a bit of guilt around the fact that you….yeah can you allow yourself that space.

Q You mentioned guilt earlier as well. Do you mind just expanding on that a little bit, kind of how that…

A Yeah. I think guilt around enjoying your life and being free to go off and….you know. I mean holiday I guess is a great example, you know should you go off and have a 6 week cruise you know when your brother can’t ever do that and is stuck in a care home. Christmas is ghastly, really, really difficult you know. What do you do, do you spend Christmas with your children and grandchildren? In fact funnily enough this year one of the things we did do – and it’s quite funny that I’ve spoken to you after Christmas – so we had decided this year amongst everything else moving, that we would for all sorts of reasons it was a good year to say ‘well we’re actually going to go and spend Christmas with my brother’. Because we hadn’t done that for a number of years because of all the things I’ve talking about, COVID and mum dying. And we’d moved a little bit further away to be near our own children and grandchildren. There’s another area of guilt, should we have done that or should I have stayed 50 miles from my brother because he’s got significant needs. There’s nobody else you know. So that’s a big area of guilt. But we decided for our family’s sake it was OK to try and move to be nearer the grandchildren.

Time 1:00:20

But anyway, so we head back after having moved into this little flat we’re in – we got a little Air B&B in the town where his care home is and where it was home for us for many years so we’re very familiar with it, and you know got all the Christmas lunch organized so that we could bring him out to cook Christmas lunch. Which was great except Christmas morning I woke up with COVID. So then I had to.…I knew it was COVID and I did a test because he’s in a care home – I didn’t have any tests, I didn’t even have any Paracetamol – but the care home gave me some tests and I was really positive. And I felt awful for him because we’d pl[name]ed all of this and got all the lunch so we could bring him and cook him a Christmas dinner. And he couldn’t come. So that was just….you know. But I had seen him before on Christmas Eve. And my husband was brilliant, he went up to the care home because he was negative, opened presents with him, we did a family zoom and he had his lunch. And then my husband took him out for a walk on Boxing Day, which was great. But I mean that was just…you couldn’t have made it up. So there’s all those sorts of things.

I guess it’s trying to make, that’s a very good example of me trying so hard to make it OK for him. Because he misses mum at Christmas and there’s nobody else to have Christmas with him. And that is an example of trying hard. And perhaps that’s what you do the whole of your life, you’re sort of trying hard to make it better, to make it OK, that there is this person that’s significantly disadvantaged in many ways in the world. And you can’t make it OK. But you feel you should because it’s OK for you, you’ve managed to get a job and a relationship and a family and they haven’t. So there’s this sense of guilt.

So I don’t know again if other siblings do this, you do ??? where you’ve got to bend over backwards to try and make it OK. But it won’t be OK I suppose, it is what it is isn’t it? And then there should be some acceptance around ‘well yeah that is what it is, that is his life’ yeah.

Q And do you end up as well….it kind of sounds like it’s a bit of a no-win situation because you want to do all you can for him but also you’re thinking about your own family, your children and your grandchildren, so you’re kind of just really caught in the middle of kind of….yeah.

A Yeah absolutely, absolutely. Yes you are, you are. And that’s not going to go anywhere you know. And I had that with my mother as well because I tried to make it right for her. I tried to make it right for her because I knew she had such a difficult time with [brother], especially after my father died, I felt so responsible for trying to make that better for her and for them. And I don’t know whether I did but it was a huge weight to try and somehow make it OK.

Now why did I feel like that? And that would be a really interesting area that perhaps younger siblings could benefit from support in that area, that they can’t take responsibility for the situation. They don’t need to. They don’t need to ??? responsibility. Or helping them understand why they feel that but they don’t necessarily need to act on it at all times. Yeah that’s some support I think that would be very, very valuable perhaps from a younger age, you know this has happened, somebody – your sibling – you know, yeah. They need help but it’s not just your responsibility to provide that. Yeah.

Q Yeah. And I guess that kind of thing is perhaps where counselling then or something like that isn’t it kind of, to really find acceptance in those ???

A Yeah, yeah.

Time 1:05:00

Q Kind of like that’s beneficial. Kind of almost pre-emptive counselling isn’t it, kind of….

A Yes, yes. Which again that’s where younger support groups for younger siblings can really hopefully help to just….yeah, lay some groundwork for feelings that might come up and how you might deal with them. And why they are there, those feelings and what you might do with them. Yeah.

Q With the [charity] do you attend groups, are they kind of mixed ages?

A No I don’t actually. There are adult support groups, and I think in many ways I’ve sort of felt I haven’t really had the headspace or time for it actually, which sounds awful doesn’t it? I don’t. I don’t know whether I would benefit – I think I’m sure I probably would. But they are there and if I felt I needed to, yeah I know I could access one. There’s some online workshops and things that I have been on. Sorry Francesca I interrupted you.

Q No I was just thinking of the mixed age groups, kind of people at the start, you know earlier adults kind of at the start of the journey and you kind of reflecting back over the years.

A I think that would be actually really, really interesting actually, really interesting yeah. And in fact they had a support group training for running a group for younger siblings, so that sort of thing. I did talk to one of the organizers of [charity] some years ago about doing a facilitation training. I mean that was something I did a lot of in my nursing career, support group work, and I love things like that. And I’d said, you know, but at the time…I said things are just too difficult at the moment, there’s no way I could do that. But I feel maybe that is something I wouldn’t mind doing actually, yeah, because I think it would be hugely valuable. And I love the idea of the mixed ages actually in a way, yeah.

Q It certainly sounds there’s a lot to share, or a lot that can be shared with others and ???

A Mmm.

Q I don’t know in what formats but certainly there’s….

A Exactly yeah.

Q Thank you. I’m conscious of time, we’ve been just over an hour and I don’t know how long you have, but is there anything that we haven’t covered do you feel, or kind of….I know there’s a lot of ground to cover in such a short space, kind of the whole history.

A No I don’t think so. I think one of the things that….yeah, would be some of my brother’s behaviours are quite challenging and I guess some help, you know that’s an area that I think is quite important, you know how to manage it. So they have covered that in [charity] actually, managing you know behaviour that challenges and how you deal with that. But again that’s a difficulty area I think, you know. Yeah some of the things that are very bizarre in a way in our, for want of a better word a sort of able-minded and bodied world, but in my brother’s world are utterly real. And that’s hard. And that’s hard with the family you know, and yeah and how far you go with that and how far you tolerate it. And this goes back to my mother maybe when he was little, like ‘there’s nothing to see here, let’s move on’, or ??? yeah this needs to be not challenged but managed, and how on earth do you manage it, yeah.

He’s quite obsessive, he has an obsessive….he thinks he’s Australian, that’s one thing. That’s quite difficult to manage. So he talks in an Australian accent, and that’s caused problems over the years, especially when we go to hospital and people say to him ‘where were you born’ and he says ‘Melbourne’. And then they look at me and ‘you’re his sister but you haven’t got an Australian accent’, and ??? ‘no we moved away a long time ago’. And I’m sitting there, you know. That’s just an ???

Q Yeah ???

A Utterly obsessive behaviour around one of the nurses at the practice who is just totally in love with and he thinks she’s in love with him. But you know that’s very difficult, he calls her ‘ma darling’. And this has gone on for years and years and years. And everybody knows about it. And I’ve asked social services, you know ‘please help me try and ???’ So it’s those sorts of things.

Q ???

Time 1:10:00

A ??? anybody about ‘ma darling’ and to him it’s utterly real. And you want to sometimes just say ‘oooh….’ you know. So there are some difficult things, yeah.

Q Yeah. And I guess they are things that maybe kind of paid formal care workers and support workers might perhaps get training in kind of, whereas unpaid carers you don’t.

A Yeah, yeah exactly. And I think actually, I was just thinking then, he’s now in a care home and it’s an older person’s residential home, it’s not a learning disability facility. And although he is funded as an adult with a learning disability but because he’s 66, and he interestingly does not at all identify as somebody with a learning disability, so if you took him to a group with a mixture of people with learning disabilities he’d come away and say ‘poor things, I feel really sorry for them [name]’. But he sees himself as an older person – which I suppose is quite healthy in a way. Again that would be very much my mother sort of, and this determination that he would be normal. But of course he isn’t. And you know that’s interesting. So he’s in an older person’s care home and I do sometimes feel that the staff in the care home could perhaps just benefit from a little bit of help with managing a learning disabled person. He’s not just an old person with dementia. Quite similar some of the symptoms but…with very mild dementia I suppose, yeah. But again, yeah. If it’s something you missed out on as a child, how to deal with the challenging behaviour, it’s never too late to learn is it?

Q No, no. But that’s just kind of taken for granted that as a sister, as a family member, you know or you’ll get to a point yourself kind of, no-one scores that ‘actually there is a need here’.

A Yeah, it’s still baffling, after all these years, very baffling yeah.

Q And again I guess is that an area where obviously you’ve got your family and friends but no other sibling to talk over, to share those kinds of discussions about what’s going on here or what’s….yeah.

A Yeah.

Q Thank you. It’s so rich, there’s so much you’ve shared which has been really fascinating, so thank you so much for it.

A Would you like me to send you the little piece I’ve written, because I thought perhaps it would be better to wait until you’ve actually met me before you read that.

Q Yes thank you, I’d love to. You’ve got my email address.

A Yes I will.

Q And are you happy if I share it with the rest of the team as well?

A Absolutely, yes please do.

Q In the information that you were given…..so I can stop the recording now actually.