Q So the interview, it’s much more of a conversation. So there’s kind of specific areas that I want to cover but really we just want you to share your experiences really. So perhaps we can begin with just you explaining why you were interested in the research and taking part.

A I’m interested because, you know as a Plus 2 sibling carer I feel that I need more people to know what we’re about and how much we take on and have taken on from when our first loved ones were born, and how we are carers for life. You know that is something really big in my mind, to think you know I’m always going to…well I don’t know anything else, I am a carer from a long time. And I am looking for my brothers to move into their own home, but will I ever be just a sister, will I always have that initial role as carer. Maybe this is me, you know, I don’t know any ??? caring. So for me that’s important to let other people know. Maybe if a professional had identified me as a sibling carer when I was younger and supported and guided me, or said not to worry or…maybe my life would have been different. I’m from a family of six so I always used to think, you know out of the six of us, why did I become more passionate and more caring towards my brothers. Maybe that’s why I….I don’t know. But yeah it’s different, it’s powerful, and it’s me. So I want people to know what makes me tick.

Q Yeah. So part of your identity is, you’re saying it’s who you are. Can you tell me then about….just explain your situation and tell me about your experiences kind of over….

A How much do you want?

Q From the beginning, where you feel, where you feel.

A Right, yeah. I’m, like I say, a Plus 2 sibling carer to two brothers younger than me who have learning disabilities, challenging behaviour and epilepsy and elements of autism. They’ve been living with me now over 28 years, in my home, with my family. But my journey really started when my first brother was born and I was 8 years old. To me as a sister I didn’t see anything different, it was just a little baby. I had never experienced in all the time before that of people with disabilities, I’d never seen anybody or come across anyone. Even in Pakistan? when I was younger, I never saw, never came across. So when he was born – I mean you could significantly see that his head was small but as a child I just thought ‘oh isn’t it amazing, we’ve got a baby brother’.

Q Yeah, yeah.

A Because…. Things changed. My parents’ relationship changed, that affected us three siblings. When I say I’m a family of six, there’s 3 girls and then there’s 3 boys. I’ve an older sister and a younger sister, I’m second eldest. And then between my two disabled brothers I have a normal brother who are a lot younger than me. So relationship changed because my parents started to argue. And my mum was always not 100%, so she was on some kind of medication which we didn’t understand. But now looking back they were moaning for a normal child, my dad used to always be angry with my mum, blaming her for giving him three girls and then the first son he has, you know….he was proud that he had a son but at the same time it’s like ‘he’s not normal’. So the way they reacted towards him, you could see it and you could feel it. And the way they used to communicate. Or as he was getting older, I mean his development was very delayed. And I don’t think I really picked up on that until my middle brother from the three brothers was born, and his development was so fast then it sort of hit, why is my other brother not walking, why is he still crawling on the floor, why is he still wearing a nappy, why is he…you know having sloppy foods. You know all those things sort of….

Q Yeah you could see the differences then, yeah.

Time 4:55

A You could see the difference. But even then you don’t think, you know that….they’re still your loved ones. Yeah he is a bit different but I still loved him, still helped out. And that’s the thing, social services weren’t there for my parents. Maybe my parents didn’t know how to contact them. I think a family friend pointed out to my parents that they could get support, because I mean obviously my father was the only earner in the house and wages in the 60s wasn’t that good. So when we were told, well when my father was told, he got someone to help him fill out the forms and that’s when they first got the….I can’t remember even what it was called then, but they got the….I mean it’s called PIP now but I can’t remember the name of it. But they got some money and it sort of helped.

And then from then on it was like taking my brother to nursery, and I’d have to go with my mother because I’d be interpreting for her. And then I’d be also settling him in, so she’d leave him with him and then she’d come home because she had other children to take care of. So it just felt right that she left me there. And then obviously I went to school, so to settling him in. And I can’t remember how long it took but I do feel as if I was there a while, you know, I don’t know two weeks maybe, maybe more or maybe less I don’t know, but it seemed like as a young child I was there a long time helping him settle.

And just helping my mum feed him, because he was awful at eating. And I didn’t know that part of his disability was that he couldn’t chew, that was part of his disability. So he’d have baby… Farley’s Rusk majority of the time, or just milk, and I couldn’t understand why I’d have to give him this sloppy biscuit. And half of the time he’d refuse, you know, and I’d sit and eat it and then come down and say ‘mum he’s eaten it’ you know. So as a child I wanted to be a normal child and go out and play and stuff. So if I were allowed to go out to play it was like ‘take your siblings with you’. So ??? go out to play, my brother with the disabilities and my sister that’s slightly older than him, then my other brother in a buggy, he were a lot younger. So I’d have these three children. So if I wanted to go to the library they came with me. If I wanted to go to the park I’d have to take them with me. So can you imagine and 8, 9 year old, 10 year old you know responsible for two children.

Q Yeah, huge ???

A Yeah. Well three children, one in a pushchair and two either side. And when [my brother] did learn to walk he just darted, run everywhere, it was like a space that he’d all of a sudden found. And he had no sense of danger. And we lived near a main road, our street just came away from a main road so it was only about a few…I don’t know about….I don’t know 50 steps or something, so it was very close to the road. And he’d come out of the gate and go straight down in front of the main road. And as I child, you know you fear for his safety so you’d be chasing after him. So I don’t know how he didn’t get run over or how I didn’t get run over because that road was extremely busy.

And my parents never thought to secure the gate. I mean it wasn’t a very high gate, it was just to your waist, but just so he couldn’t go out. So I’d have to think ‘oh right, I don’t want him to run out, I want him to stay in the garden but he’s my responsibility so I’ll have to sort something out’. So I’d have to find some material or a bit of rope or something and tie it and secure the gate. Or if I wanted to play with my friends in the street from school, you know because the majority of my friends had really nice bikes and toys and stuff, so my parents couldn’t afford any toys so if I wanted to play with my friends then they’d allow me to ride their bikes or play with their dolls or what have you, and I thought ‘ooh that would be nice’. So they’d come and call for me and I’d say ‘oh yeah I’m coming’. So I’d have to take the brother with the disabilities with me where the other two could stay and watch TV or my mum would manage them. I’d have to take him with me.

Time 9:42

And he used to have seizures, he had seizures from when he was a baby. I’d sit him on a high wall, I mean you know the plastic bins, you can see how tall they are. Well this wall was a little bit taller than that and I’d sit him on the top thinking ‘he won’t run if he’s sat’, not thinking ‘if he has a seizure he’d fall and…’ So there was no sense of danger in my mind because you’re naïve, you don’t know do you to have a responsibility like that. My priority was to play.

Q Well you’re young yourself, you’re a small child yourself.

A Exactly. So I had him sitting on the wall not thinking he’d have a seizure and sustain a terrible injury, had not thought of that but more happy to play on my friends’ bikes and you know up and down the street. So yeah. So that was sort of my growing up. And I was keen to get an education, because when I was 15 my parents decided it would be nice if we went to Pakistan? as a family. And again my parents couldn’t really afford it so my disabled brother and my older sister came via plane and the rest of us went in a transit van via…well via road. It took us 15 days.

Q Gosh.

A I know. My mum were heavily pregnant with my last disabled brother.

Q Oh gosh.

A Exactly. I don’t know where my parents’ heads were, but yeah. And she was heavily pregnant so I think she must have been nearly the beginning of 9 months or end of 8 months or something, so that’s how big my mum was to travel, you know 15 days and sitting all that time. I just don’t know. It’s crazy to think back. But yeah that happened. And then my parents came back and I stayed in Pakistan for 3 years. My oldest sister took care of my eldest disabled brother and the second one was born in Pakistan so… And then we could see that his disability was exactly the same, he had…both born with small heads. And after 3 years staying in Pakistan with my sister younger than me, both of us stayed there for 3 years. And then my father came back, obviously had saved and then called us back and ??? responsibilities were taken up again. And then I had to take care of both my disabled brothers.

But I was keen to. Because I’d missed out on the education, I was very angry with my dad for taking me out, because at 15 you’re just preparing for exams ??? So I thought ‘right I need to do something’. But having said that and looking back, I was angry at the time about my father taking us to Pakistan by road, but looking back I’m thinking ‘my God no-one could pay for an experience like I had’, you know it’s something that I’m going to cherish for ever kind of thing. It was the most….I mean words can’t even describe it, the experience that I had. I mean going through all those different countries. I mean you can’t do that now because of the wars and what have you, but my goodness.

And while I was there, because I’m keen to learn, so I learnt all sort of things. I learnt how to sew Asian clothes on a hand operated sewing machine. My dad got me a tutor who helped me to learn Urdu, so I’m a bit rusty now but I was very fluent at reading and writing. And I also completed my Quran, which again is important for children, which I’m really happy that I was able to do that. So basically I gained my ??? which, you know although in this country there’s a lot more provision now but at that time if you wanted to learn Islamic Studies you’d have to go to some ??? neighbour’s house, or someone that were educated enough to do it. So you were forever going from one house to another house in order to get that. And it wasn’t the most beneficial should I say. So I was quite keen to learn it back in Pakistan because everybody was doing it.

I didn’t go to the Mosque. My dad says, before he got me a tutor ‘let’s see if….’ We’ll get you into school, enrolled into school and see how you go. I hated it. It was so noisy, we had to sit on the floor. We had basic? things. And I thought ‘no, this is not for me’. So he got me a tutor at home and I did really well. I was into, you know Asian outfits, embroidery, learnt to embroider, learnt how to put ??? on. So you know I learnt lots of skills like that. I learnt how to cook on an open stove. I learnt to cook. Yeah exactly, I learnt so many things about my culture and religion, it was so beneficial for me.

Time 15:00

But also at the same time I did experience people with disabilities in Pakistan. They’d come, similar to my brother’s condition, they’d come dressed in orange with loads of beads and stuff round their necks and, you know bangles and stuff. And they’d come begging. So people would give them flour, rice or lentils, or you know whatever they had for these people. And you couldn’t tell if they were boys or girls because all of them had their hair cut really short so you couldn’t identify who was who. Some of them could actually…my brothers can’t articulate but some of those people that came could talk, so I’d say to them ‘oh what have you been doing today’ you know, and ‘oh no, no, we can’t talk, we’re not allowed to talk, quickly give us something, we have to go’. And they’d be left at shrines, you know so they’d be ??? male, I never saw a female take care of them. ??? be taking care of them and I’m thinking, you know this doesn’t sit right with me. So that used to really, really hurt because people from the village used to come to stare at my brother when he came, you know to see how different he was to how they’d experienced people in Pakistan. And that hurt and I used to get really emotional and really ??? say to my dad ‘where the hell have you brought us’, not knowing that I’d left, you know at such a young age, but so mad with him.

But yeah I came back, again thought ‘right I’m here now, I want to know if I can go into sixth form and see if I can get into college’. Went back to school and they said ‘I’m sorry but you’ve taken too….’ you know you’ve been out of education for too long there’s nothing we can do. And I was really upset, I’m thinking ‘oh my God what am I going to do now?’ So for my own self I thought right, this is not what I want out of life, I still want to get an education. So I went to [Name] College and various other colleges. And [Name] College was the only college that said ‘well we can’t offer you GCSEs or anything like that because you’ve been out of education too long, but there is a course that we can offer you which is a 2 year course, what’s your thoughts?’ And I thought to myself I want an education, I don’t care what it is. It was called [programme name], I remember the name. But I wasn’t bothered, I just wanted to be in the education ???

Q Get enrolled, yeah.

A And while I was there and when I completed we did some, what is it, when you….oh gosh…experiences, some experiences that we had. And I wanted to go into a school, so I went…

Q Oh, like work experience?

A That’s it, that’s the word I’m looking for yeah, work experience. So I went into a school and worked with children for about 2 weeks and I loved it. And because the school had given such a good report and the course tutor at college said ‘there is this course you could potentially get on as a mature adult’. And I’m thinking….I’d never heard about students getting in as mature adults and stuff. So I said ‘oh let’s give it go’. So I went and applied for an NNEB at [name of college], got in. Got in, just scraped in because they’d already selected all the students. So I was really late, I think we were going into September when I got in, but I was really pleased that I did. And then again I did that for 2 years and I got my qualification and worked for 12 years as a nursery officer at [name] Family Nursery Centre.

But at the same time as doing all that I was still supporting and helping my mum with my brothers, getting them ready in a morning, changing them, cleaning them; and they’d soil so washing their nappies, their pads, you know pads and stuff, so still helping my mum in that regard. So all the things I could do at home, every now and then I might go to….we had ??? respite near where we lived so just do the odd shopping for my mum, just to make it easier for her, or just look after them while she nipped out. Because when we came to the UK, the area we lived in there wasn’t many Asian families at that time, so the one or two families that there were here my mum and dad used to like to go and visit because it was like connecting with people from home. ??? nice for them. So my eldest sister and myself and my younger sister were at home with my brothers and they’d go out.

Time 19:46

So basically we just carried on doing the….it just became normal, just doing the same routine and not knowing anything different. And school, yeah I’d have friends but I don’t think I really made any friendship with anyone on like a real….I don’t think I really had, talking about relationships and stuff, I don’t think I really had a right good relationship with my mum either. You know like nowadays you see mothers and daughters going out and doing things, I don’t think my mum and I ever did that, or she did that with my other siblings either. So yeah I missed out on that. My father, I mean as a sibling, I looked at the research and in the research it says that sibling carers like myself are lifelong carers and we are the glue to our parents and the family. And that’s what we did – well I did more than the other two. If ever they argued I would try to make it easy and sort of speak up for either and try and calm the situation. If my brothers’ behaviours were out of sorts I’d take them out of the way and say ‘look I’ll watch them, it’s OK’ you know just to alleviate that problem from my parents.

And when they say, you know we are like a glue to them and I’m thinking, I did that, that sounds so much like me. And everything in the research that I read and saw, it resonated with me. I’m thinking how do they know my life, how do they know this is who I am. And it seemed like a….I couldn’t believe it. But we all feel and behave the same. So that’s how the research has come about. Because I mean I went into a caring profession you know, and I’m a carer. And you know even now I still try and support and help other people. I mean I’m still caring now with friends. I mean I’ve not got a really good relationship with anyone as such but I’m very empathetic, I’m very caring to other people, always wanted to help regardless of what the situation is, whatever I can do I’ll do. And so that’s the sort of nature I am, that’s the sort of person I am.

Q And do you think that’s grown because of your relationship with your brothers and kind of from that young age, taking on those roles?

A Well yeah because I had to grow up ??? and I’ve taken on a lot more responsibilities than a normal child would ??? you want the best for your family, you want your best ??? Not only that, I was trying to show my father that, you know you don’t have to look at boys to give them that role, you know you can still respect and be proud of your daughters just as much. So I think I pushed myself even more just to please him and get some recognition from him – and I never got it.

Q Yeah so that cultural kind of undertone there as well kind of, yeah, shaping how you act.

A Yeah. That used to hurt. But then I’m thinking….but then further down the line I thought well, you know that’s who they are, you know I have to love myself, I’ve got to try and do what I want to do. But it’s more, from my culture it’s…I don’t know, maybe from many other girls, we look towards our families for permission, you know, and it’s important to get that permission because that’s how we’re raised. And then I think I was 45 when I realised ‘well why do I need permission’ you know I’m old enough, I can make my own decisions. And things changed for me then.

I mean when I got married, I married my first cousin. But you see I was at that stage where I wanted to leave home and the only way I could leave home was to be married. So I wasn’t bothered who he was or what he was, I says ‘yeah I’ll marry him’ you know. I’d also in my own head decided that if things didn’t work out I’d have a plan A and a plan B, you know I wouldn’t go back to my family, I wouldn’t go back to in-laws, I’d go and live on my own. You know so I was already pre-thinking if, God forbid, anything went wrong. Because I’d seen marriages around that that had failed and girls weren’t happy. And in our culture, as parents, I mean I’ve a daughter myself, you know when you make that decision and do the arranging, you’ve got to be very careful because you know if you’ve overlooked something or you’ve got ??? that’s not right, you’ve got to listen to your ??? So I thought to myself well you know no way am I going to come back to parents because I know that I’ll have to carry on with the responsibility of my brothers, and that’s when….

Q So was that…yeah was that to have some independence then, you wanted to have a break from that?

Time 24:50

A Yes. So not only that, I just didn’t want to go back there because I knew in our culture if girls left a marriage and went back home it wasn’t the same, because your parents keep blaming you ‘oh you should have tried harder’ you know instead of listening. Because our parents – I hope I listen to my children, but yeah it’s one of those things isn’t it. So that’s what I decided. I thought yeah, I’ve got a qualification, if things don’t work out I’ll move to [country] and get myself a job there. Because I’d already heard my friends talking about how you could go to [country]at that time and earn money, you know a lump sum and not have to pay tax or anything and bring it back. So I thought that’s what I’ll do, I’ll go over there with my qualification. So that’s why it was important for me to have a qualification so ??? independence for myself.

So before I got married I started to learn to drive, because again that was like an independence for me. My parents paid for a while and then when I got married my husband paid for me to carry on with my driving. ??? it worked out because my husband is very caring, very thoughtful, very supportive, so all the things…my worst nightmares never happened.

Q But you’re not in [country] right now then, you’re not talking to me from [country]?

A No ??? Yeah so I mean….yes I got married but at the same time my parents, my mother, still needed my support. So she’d often bring my brothers, they’d come to my house here and I’d watch them for an hour or two, sometimes keep them over a night, get them their breakfast or what have you. So I was still…so my role hadn’t been cut off although I was married. And I was working as well, because after being married, six months later I asked my husband ‘oh is it…’ again asking permission ‘is it alright if I can go to work’. He says ‘oh well you need to ask my mum and dad, see what they think’. So I went and asked their permission. They said they were happy for me to, because I’d got a qualification you know they were happy to. So not only was I working in a family nursery, I was doing shifts. Coming home to two children. I had a son and a daughter, my daughter was a year old.

And because I’d got married and I was having my own life, yes I did at this point help my mum, but from the training that I had done as an NNEB we did go into places where people with disabilities lived and they had homes and they were enjoying life and stuff. And I thought oh that would be lovely for my eldest brother. And so I put it to my mum, I said ‘mum it would be nice if [my brother] could move to his own home, it would be easier for you and he could do all the things that he likes’. So she approached the social services, I didn’t have any involvement in any of that sort of stuff other than the interpreting part of it.

So social services came and looked at the situation, and I mean there were no care plans then, they didn’t look at his needs and the family’s needs. Took him out and put him in the first care home that they could find. It was [place name]. He had been there for a couple of months and was unhappy. Every time the family went to visit he didn’t look the same person that we left, you know. So my husband and I when we used to visit, it used to hurt him, he used to say ‘why the hell have your parents done this, why’. I’m not saying that actually it was on my advice that they’d done it! So he says ‘[name] we’ve got our own house, wouldn’t it be nice if he came to live with us, because I can’t bear to see him losing weight, he wasn’t eating, he looked so unhappy’.

And that shocked me. I’m thinking ‘oh my God what are you saying, it’s going to be blooming hard work. I’ve got young children, I’m working, how am I going to do it’. He says ‘don’t worry about it, we’ll both do it together’. And I told him how hard it was when I was growing up, and I mean he knew, he’d come and visit and stuff and help out wherever he could, but he said ‘no, this is not right, it just doesn’t sit right with me’. So I says OK then as long as you don’t think that I’m going to be taking the responsibility totally. Because in my own mind I didn’t want to have the same life my parents had, you know I didn’t want that, I wanted to negotiate and stuff and….

Q Yeah. And you’d worked so hard it sounds like to kind of leave that kind of as much as you could at least and forge your own kind of career and…

A Yeah. So he listened and [my brother] came to live with us in 1995. And I mean I was fortunate enough to have a house with four bedrooms. I had two children at the time, my two children shared a room so my brothers could have a room for themselves. But then things got difficult, because it was like how do I work out….because what is it, my in-laws were very good as well as my husband, they’d help out. So for me to keep my job it was like I’d have to drop my children and my brothers at my in-law’s house on a morning and then pick them up when I came home from work. And you can imagine shift work wasn’t easy either, and then with young children, it’s blooming hard, it’s not easy at all.

Time 30:26

Q I struggle working with two little kids let alone caring for a sibling, yeah.

A So yeah that’s what I did, I worked. My in-law’s helped out. So my in-laws took my children to school, my brothers were picked up and dropped off at my in-laws, they’d get them tea and I’d bring them home when the shift was finished, and then I’d get them to bed. So I did that, oh gosh how many years did I do that? And then it got to a stage where my mother-in-law was saying ‘look [name], I’m getting tired, this is too much for me’. I mean I did put a lot on them. And I mean not only that, bless her, she also made our meals. So she’d cook for us so I could bring it home.

Q Oh gosh, yeah.

A So all I’d have to do was make chapatti for my husband and myself and you know the tea’s already ready. So that was very good of them, I’m really pleased that, you know they were spot? on? with that. But you see when you take a role on like that, I hadn’t really had time to plan how it was going to work. I knew my brothers needed routine. I knew that, you know I could plan that and sort that and I could talk to professionals because that’s what I was doing on a day to day. Because the children we were taking care of had some difficult backgrounds and we were having interactions with social workers all the time, so I thought this can’t be that hard.

But my God, when after a few months things did get difficult, six months maybe things did get difficult because all my focus was put on them two. I had to take one brother at a time to work right through all of their things that needed doing, like their health, medication, day services, respite, because they’re individuals so I had to look at them individually. And because the majority of that stuff was done by my mother I wasn’t really sure, you know which doctors she saw, what pediatricians? or whatever, so I had to get a real good handle on that so if anyone asked questions or wanted to know then I was able to answer them. And also to make their life a lot better, because my brothers don’t know how to personal care, they’ve no ideas how to clean their bottoms, so that was something big for me to sort of help out and educate them.

But you see they’d already developed their routines and stuff, so some of it was hard to change, it took a while to get well-established. So at the beginning one of my brothers used to run out from the door and run all the way home and we’d be looking everywhere for him. So it’s those things that were part and parcel of settling them in, I hadn’t really looked into how that would work. But yeah I knew it was going to be hard, and it was hard, but I seem to have managed somehow.

And I knew about respite but again in my mind I thought respite was for them, not for me, so they’d both go on different dates. And you know I’m thinking ‘oh I’m doing really good because they’re having a wonderful time and they’re coming back’ not recognising the impact it was having on me. So I think it must have been about 4 years and I was burning out and ??? But at the same time, the family were putting a lot of demands on me. I thought…you know…I had, no I had a third child, my youngest, and that’s where my mother-in-law said ‘it’s too much now’. So I thought right, OK then I’ll give my work up. So when I was at home with him, I’d stayed a year and then I had to go back and finish my work, the last bit, I don’t know what they call it now where you had to, you know your maternity leave, you had to pay back….

Q Yeah, you’ve got to work a bit don’t you otherwise you have to pay it back.

A So I had to go back, I thought I can do six months but then call it quits. But while I was home – or even while I was caring and working they’d still say, you know if I took any annual leave or anything ‘oh [name]’s at home, let’s go ask her if she can take us to hospital’, ‘can she fill this form out, can she do this for us’. And it was like constant, constant pressure of ‘oh do this, do this’. And as a carer you don’t know how to say no. Because I just thought it was a culture thing, but it’s not, it’s all carers do that don’t they?

Q OK.

Time 35:00

A So then I thought ‘no, this is not right’. And by going to Carers Leaders I’m so blessed to have – well lucky enough to live in a council where they have got provisions for carers. And I went on lots of different trainings with them and I learnt….on one course I learnt how to say no. My God, once I learnt to say no I used to feel guilty. But then they taught us how not to feel guilty and how to have get-out clauses on the phone and, you know to say things. Because I used to think I don’t want to lie, but it wasn’t a lie at all because it was just…. I mean I knew what my situation was and I’d just say ‘well actually I can’t come today because I’ve got to be here’ or ‘I need to do this appointment’ or ‘I need to phone the social worker’ you know, so I’d make something up like that just to give me a breathing space. And it worked.

So because I was saying no to the majority of things, my own parents, my mother and father and my brother went against me thinking ‘this is not right, she’s not listening to us any more’ you know, so I had some conflicts from them. Both my parents have passed away now but I don’t speak with my brother in between my two disabled brothers because when my dad died and the inheritance, my dad told my brother to be the…what’s it called…

Q The Executor or something of the Will, yeah.

A So he didn’t honour it so I took him to court via my brothers, so he didn’t like that, that took 10 years. Gosh that was the longest 10 years ever. But yeah I pursued it. So anything in life that I’ve done I’ve done it to the best of my ability and continued until I got the outcome. Even ??? into my brothers’ health. I felt as if I needed to make sure I did what I did was right by them, so even if it took six months, a year, two years, I pursued it until I got the result. Which is good really, because you do find that people with disabilities can be on medication that’s not necessary. So I had to be sure what they were taking was really good for them and not for the reasons that I was pushed into doing, you know like….let’s for example, their challenging behaviour. To make sure that I was looking at them and finding the support that they needed to make sure it was right, to make sure that they were happy. At the end of the day if they’re happy then I’m happy; if they’re not happy then obviously it’s going to affect me. So it’s all those sorts of things that had to be worked out, which I’ve done.

And then also, because I felt my other siblings were affected by having my two disabled brothers in the family – because children are, you know when you’re a carer the whole family is affected. And because my brother that I don’t speak with any more went on to drugs and my younger sister, you know she wasn’t focused at all so she did her own thing kind of thing. So I’m thinking now that they’re here with me I want my children not to be affected. So I tried to do as much as I could for them. So for instance my younger son wanted to…he wanted to swim. So I was…well both my younger two went swimming and they got all the badges that they needed so I was literally chauffeuring them about. My daughter wanted to learn to horse ride, so took her horse riding. My youngest son wanted to do gymnastics so I took him gymnastics. So I had to incorporate all that within my busy schedule anyway. So that….

A I don’t know how you do it?

Q No I don’t know how I did it. But you see for me at the time it was important that they weren’t affected. So I didn’t want them to come back to me and say….well I mean they still do, I don’t think you can take that away. But children, my children still feel that I’ve always put my brothers first. Which is true, I have, because they can’t communicate. And that has affected them. But I’ve tried to be as balanced as I can but it’s not easy. So yeah I try and do the best. But my children have become very empathetic to other people, they’re very supportive. My daughter’s ended up doing a course on, what’s it called, counselling. So she’s a very good listener, and that is because I’ve got my brothers and she’s grown up…. And my youngest, I felt like I didn’t give him enough time for…. You know because the eldest and the youngest, my daughter, I had paid more attention to their education, so helping them with their homeworks, getting additional tuition in and stuff like that.

Time 40:00

But the youngest, he was so different, I’m thinking ‘I’m failing him, I’m failing him, he’s not interested in what I’m offering him’, you know. Because gymnastics, he was really excelling and then he had a health issue and then he just pulled back and didn’t got back to swimming. Because I was hoping he’d pursue his swimming as well, because again he was another tier, after he’d got all his badges he was on another tier. And he was fast, and he’s still a fast swimmer, and I was hoping you know he’d excel in that. But things changed after his health so he pulled out. And then with his education, he started to pull back on that. And I’m thinking ‘what am I going to do, he’s not going to achieve, he’s not going to get his GCSEs or anything’. But when he left school, I don’t think he had that many qualifications but he got into college – not college – he…I can’t even remember. I know that he’d had enough to get into, what is it, Foundation at uni, and then with the support and friends that he had at that time… I had to drop him off at [city] because that’s where he wanted to do this…. He wants to learn about aviation so that’s a course he could do that was in [city]

I’m thinking how am I going to support him in London, how am I going to get him a flat, you know how is it going to work out. But luckily I had family there and they were happy to keep him on for a year, which was very good of them. So he learnt to be away from the family. The help he had from his friends sort of excelled him. So after the Foundation he did two years, can’t remember the course but it’s to do with mechanics of the plane and stuff, and he’s qualified now and he’s got an amazing job.

And you know sometimes as a parent you think you want to do your best and you hope you’ve imparted enough good information for your children to do well. My daughter’s still struggling because she just went from one job to another. And I was hoping she’d go back and do her Masters in Counselling but she says no. So she’s been having different jobs, at the minute she’s applying for another one but… So you know emotions have affected her in a way.

But the eldest, sorry I mean the youngest, he’s got hands of it and you know he respects and he’s pleased for what he’s been able to achieve. But then he keeps saying ‘mum, it’s up to you and dad that’s helped me to get where I am’. And my daughter says that I haven’t been there, you know with her being the one girl I haven’t done enough for her. But I think it’s just her as an individual. But my eldest son and my daughter have got some hearing issues so I don’t know if some of that plays a part for them too. The eldest is married, he’s got two children, I’ve got two grandsons, so I have them on a Wednesday and a Thursday.

Q More caring.

A Yeah. So yeah my household is very busy. COVID was awful. But yeah it’s…that’s me, all these things that I do. And on top of that I do pull out time for myself in regards I like to go to [city] University. Because you know like I said, I want to make a change. An opportunity came up many years ago – I’m part of [charity] and when we had [city] branch one of the members from there said ‘oh universities are wanting people like us to come and talk to the students what’s just started’. And I said ‘ooh’. At that time I thought ‘I want to be different from my parents, I want to be able to offer different things to my own family, to my brothers, I want to make sure I’ve got enough information, go out there and find it’ because no-one’s going to come and give it to me. Because that’s the thing as I was growing up, it was like ‘oh you can’t go out there, you can’t do this, you can’t do that’ and I’m thinking how am I going to learn anything if I don’t go out there. So I go out there to find that information.

So when [city] Partnership Forum was being formed I was there at the meetings. I’m on the Carers Reference Group, because again anything I want changed – and not only for myself but I feel it’s important to make those changes for other people. And at [city] University I’d go and talk to the social work students as a care educator. And I’m involved at the [city] Uni from the time when students come on the Open Day right towards when they qualify and they get their degrees. So I’m literally embedded in the course. But not only that, because I’m on the Advisory Involvement Group at [city] Uni, other bodies come and ask for support and help, you know like the nurses and midwives and mental health, and wherever they want support you know. And if I’ve got the skills or if I’m interested I will go.

Time 45:00

And also for the, this is School of Healthcare, the School of Medicine I’m part of the PCC Patient Carer Community. It’s an honour to be on that because we’re well-known, and again changing perceptions and teaching ??? education skills with the student doctors, which is really good as well. So I only last night had four students, first year students, it was like a home visit but we did it online, so that was good, so yeah. But I do keep extremely busy. And I’ve also helped ??? an organisation called [charity] which is doing really, really well, and now I’m on the Trustee Board. But yeah I’m extremely busy. I don’t know how I do it but ??? because I want to do it.

Q I’m in awe of you. Like I said, I struggle with two kids and work.

A Is that enough explaining for you?

Q Well yeah, plenty of ??? Oh my gosh. What is the impact, or what has the impact been? I know you’ve kind of described how actions you’ve taken I guess and kind of getting your education and finding your own path amongst the caring, but has there been an impact on your kind of physical or mental health at all?

A It has yeah because….I always put myself last and when I get stressed I eat, so I’m overweight. And I mean I’ve done courses, I’m a community health educator so I know everything that there is to know about health, but when it comes to applying it to yourself it’s a different matter isn’t it? So when I get stressed, like I say, I eat, which is not good. But then it’s also learning why I do that. So I’ve done other things as well to help me understand. And being part of Sibs has been amazing because that’s really helped me to untangle some of my thoughts and try to find myself again. Because that’s the thing isn’t it, I don’t know who Corsa is and I’ve forgotten who Corsa is – has there ever been a Corsa, do you know what I mean, I just don’t know ???

There’s a lot of things I would like. I’ve got a bad back. My children, all three we born by a C Section so I don’t know whether my back aches because of that. I’ve had a hernia repair with all the lifting and pulling and because of my weight. I’ve got sleep apnea at the minute. And my back ache is sciatica which keeps coming and going, so again it’s…. I mean going to Carers [city] and the courses that I’ve done, they’ve helped you to have like a toolkit with information. So when I look at myself, and if my shoulders are tense and I think ‘oh’, and then I think I need to stretch them out. So you’ve got tools to help yourself. So the same with my back, you know if it’s in a lot of pain then I think ‘well I must have picked something up wrong’ so I try to go for more walks. So my knees are hurting at the minute, so stretching my knees out and things. And looking at what I’m eating and trying to figure out what’s working and what’s not working. Yeah so there’s lots of things I do like that for myself.

But I’m reaching a stage where I just want someone to care for me. I’m 61 now and it’s like in my culture what I’ve known, and sometimes you want to go back to your culture. Because I was there for my mother-in-law, I mean although I had a busy life I still supported and helped her as much as I could. So now my daughter-in-law, she lived with us for 9 years and you know there was a lot of support and help. But then I said ‘stay with us until you can save’ and then they bought their own home and now they’ve got their own lives so they haven’t got time to come back and check up on me. You know so I think wouldn’t it have been nice you know if I had a daughter-in-law that could, you know help me out now. But that ??? culture, I’m thinking I would like a bit of that back, but it isn’t…

Q Have some of it, yeah.

A Yeah, well I can’t because I’ve ??? so therefore I’ve got different things to deal with. And my daughter, she helps out but I mean again I want her to work, you know, do what she needs to do and get herself in a place where she’s the most content and happy.

Q Yeah, yeah.

Time 49:40

A Yeah, socializing has affected, because again in my culture you do in your own community get together you know at funerals, at births, visiting families. And for me that is hard because I always have to put my brothers first, thinking ‘where can I pull that time out to go visit the family’. And sometimes I can’t even get to funerals, and I’m thinking ‘people are going to think I’m dead ignorant because, you know they’re not seeing me because it’s important’. That’s the time that the whole area is out, you know to be able ??? is that you can get to see. You know rather than going to someone’s home and say ‘I’ve come to check…’ because you can’t do that any more. Where my mum used to be able to do that, she’d leave us kids with the children and say ‘oh I’m just nipping to so-and-so’s’. But I can’t do that. I have to pull that time out and I’d have…. I’ll say to a friend or a relative ‘oh I’ll meet you and we’ll go for a coffee and we’ll have a good catch-up’ and that’s the way I’m having to do it now for instance, not….

There’s loads of people on my tick list that I need to go and see. You know one young lass, her mum died and she were right emotional. She says ‘oh I’ve no assistant’, you know and she were getting really emotional. And I’m thinking ‘oh I need to be there for her and I’ve not…I need to fit her into my diary to go and visit her’, and various other people that I’m really close to that I don’t get chance to see. So I try and fit them in where I can. But yeah that’s…yeah that’s the part of my life that’s missing. I want to do more holidays. Again I’m still struggling to be able to organize and book. That is because respite I have to book a year in advance, so I can’t plan a holiday because I haven’t got the headspace to think….you know I’m not going to stress out. It just doesn’t…. So, and then going on the internet to look for a holiday, you need to be relaxed enough to be able to take something in.

Q Yeah, and it’s more work, it’s more work isn’t it?

A Yeah it’s more stressful. So yeah that’s what I would like. And maybe do, like I say, more things for myself like pampering, massages and stuff like that and going to spas. Again it’s about organizing it isn’t it?

Q Yeah, yeah. What help, I mean I know you’ve mentioned accessing… you’re part of Sibs now and that’s helped as well as being part of the [charity] and things, so accessing those kind of groups where there are other people in similar situations and they provide those kind of, I guess, tools and materials to help you find your own way to manage. Has that been beneficial to you?

A It has, it has. [Charity], they have adult day every year when they’ve got enough funding, and one of them I went to before COVID in [city] it was the first time I ever met other siblings. And I was so impressed with the way they organized things and how I was able to sit and just talk. And people could empathise and not give me funny looks or, you know. I felt that easy. It was like a community that was just my community, you know my family. Does that make sense? I felt as if I’d come home. And then when they’d recently done – at the beginning of the year they did like a retreat and you could apply for it. And I put my name down. I didn’t think I’d get it, but I was lucky enough to get a place. I went there and that was like a long weekend and that was amazing, so much information. I mean meeting other people and sitting just talking. And before long you were talking about situations and you were getting deeper and deeper and deeper you know, just off-loading on each other. And I made some really good bonds. But that’s the thing in [city], I am trying to set one up, a [charity] group here, you know a face to face one. But not many sibling carers are coming forward.

Q OK.

A So we’ve approached Carers [city] as support. I mean I’ve made so many links and people know me really well in [city] you know for some of the things that I do. Because of all the positions that I have been in, you know the counsellors, your commissioners, there’s a lot of people that know me and I know them. So [city]? supported me to put something together but nothing’s happening so far. So I’m thinking ‘why?’ But then again, if you’re not sure of what is available you’re not going to come forward or… And if you’re in a situation like myself, it’s like when am I going to get the time to pull that time out. So I do understand it in a way, but then I’m thinking ‘please give it a go because ??? benefit you’. So it’s one of those things. So I’m trying very hard to have that in place. Yeah so…

Time 55:00

And I did the adult day again which I went to, and I was a speaker so I really enjoyed that. But it’s all about being able to be with people that really understand you, do get you, make you feel at home. And you can just relax and not have to worry about anything that you say that…you know it’s in an environment that it’s all confidential anyway so you can have that peace of mind to be able to talk about. And you need a space like that don’t you, you need a space where you have like-minded people that you can talk to and share each other’s thoughts and ideas. And you may have experienced something that you might share and might be beneficial to someone else, and vice versa. So it’s a learning thing as well isn’t it, and sharing and all the rest of it.

Q Is there any kind of support I guess that services could do differently, or professionals provide differently to support carers, and you know particularly in mental health?

A Well this is what everywhere I’m going and everyone I’m speaking to, you know I’m sharing what it’s like for me as a sibling, sibling carer you know. I’m saying to them ‘please, in your professional capacity please look out and make sure you’re very supportive. Listen and support and encourage you know, and not let people like myself feel alone’. Because the amount of things that we take on, you might not even realise how much responsibility we are taking on, not only just for our loved ones but the whole family, and how much it’s detrimental to our own lives. Because there’s lots of carers that I met, sibling carers that I met that were having relationships and were scared about getting married and you know how it would impact their relationship. And it’s those sorts of things. And some sibling carers were talking about their own children and how their relationship with their siblings, Sibs were having an effect on it. So it has….how can I explain it? It’s something that happens all over in our….I mean even most of the sibling carers that I’ve met, the jobs that they went into was reflecting their caring role, like myself. That’s how intense it is.

Q Yeah definitely. It’s so engrained, yeah.

A All our life is round caring, and we go out and support and help others you know. So yeah it’s just to make people aware. And that’s what I’m trying to do within [city], because again with all the links I’ve got I’ve been saying to people ‘please go on to [charity] please pass the information on, please read the research’. Because mental health is there. Because I mean I get stressed out and there’s days when…well I did for a while go on Prozac and I thought ‘well this is not what I envisaged, I don’t want this’ went back to the doctors and said ‘look can I have something else other than the medication’. So he gave me a book to read, I can’t remember the name of it – oh gosh – something like Don’t Stress Over the Small Stuff or something, something on those lines.

But we’re all different, we all need different things, so it’s about getting the professional to hear you and listen to you to help you. Because I mean if the doctor hadn’t done that, maybe I might still have been on Prozac, I don’t know where my situation would have been. And I’ve had panic attacks as well, so I mean again how the professionals supported me took them out of that. I could have still been having panic attacks because not knowing how to support and look after myself. So there’s that element of it. And then it’s also about communication, being able to be around people that really understand me. So I mean like I say, I’m really pleased that [charity] is there for adults.

But them other groups and stuff, it’s not the same. I mean I have gone to groups from the time I started caring for my brothers, but some groups were, for me, you know I mean we all need different things. So some groups I went they offered us cups of tea and you could sit and have a natter. And at that time I didn’t want that, I wanted something more, I wanted to talk to professionals, I wanted to learn more about the situation I was in, more about what ??? positions we’re in. And through that I ended up doing a course called Partners in Policymaking, I don’t know if you’ve heard of it? And I had to go back to our Commissioner, [name] at the time, and asked her if she could pay for it. And she did, she paid for six people in [city] and had it delivered in [city] because us carers couldn’t go to [region] or somewhere up there that they wanted us to go to do training.

Time 1:00:00

But yeah. So it’s those kind of links that have been helpful. People, when they sit back and listen and support you. I mean all the six of us are doing amazing work, we’re giving back. So she paid for it but she’s got 100% back from it, so she’s got her money’s worth. But yeah so if people listen. That’s where your mental health is being looked after then isn’t it?

Q Yeah, so your role being valued and recognised and kind of drawn on to improve things, yeah.

A Yeah.

Q Is there anything which hasn’t worked? Kind of I guess you’ve mentioned Prozac, is there anything else along those lines or anything that you’ve experienced and tried which you haven’t found helpful?

A I’d rarely go to the doctors, because again it’s like I haven’t got the time. So I self-manage myself, unless it’s really dire, you know like my hernia repair or my varicose veins or something like that that I’ve had treatments for. What hasn’t worked is actually coming back from hospital and still having a caring role when I had my last child. The only support I got was two weeks respite. I mean ???

Q Oh my God, and you had a C section?

A Yeah. And you’ve not to pick and lift anything up for 12 weeks. And I was expected to…well I had to, I had no choice, get up and…. So you know it’s that sort of stuff that’s not very good. Or when I’ve been for my hernia repair, trying to find my brothers to go in….while I go for my operation, stressing out about where they’d be placed. And I mean respite is where they’re happiest going and I’ve been pushing for them to….I mean they have got an emergency bed but those five beds are literally taken up by people that need to move on, you know if their parents ??? But it’s not the right situation because I mean they should have a bed or two beds for when parent carers want to go for an op. Because what we have to do is, we have to take a respite for that, and that’s not….why….you know I mean if I was working I’d get sick leave wouldn’t I?

Q Yeah.

A You don’t get sick leave when you’re….

Q You don’t get sick leave, no.

A No. So all you get is a respite. And how can you….yes social service help you and they’re fine, but you know so I feel lucky? to go. But how can you rest when you know it’s at a place that they’re not familiar with, especially when they need routine. And you know you’re worrying all the time are they going to be settled, are they going to be happy, will they have an outburst. You can’t settle. So when you go in for an operation, how are you going to heal? How are you going to get better if you’ve got stress on your head? So for me, I pushed for my brothers to go in respite when I went for hernia repair, but my God that was hard, it wasn’t easy. They did eventually get to respite but, like I say, as carers you’ve got to fight for everything. Although we save the government a heck of a lot of money it’s a big ask really to have something as simple as that just to put you ??? at rest. But yeah those are the things that’s not worked.

Q OK. Do you….I know it’s a tricky area….

A Now because remember we’re also, because I’ve got two brothers, both of them go to different places for respite.

Q Oh gosh.

A One goes to health respite and the other one goes to social services respite. So I have to communicate with two different places to match the respite dates.

Q Getting the dates the same. Nightmare, absolutely nightmare.

A The thing is with that is, health respite have one week for women, which I’m happy about, but they don’t tell you when that’s going to be until you’ve submitted your dates. So it could fall on the date that you’ve asked for, which you’ve already tried to match with the other place.

Q Oh my gosh.

A That is stressful as well. So you know, yeah I’ve got my stuff together but at the same time there’s a lot of hell. I don’t know what’s going to happen on that ??? that we have to deal with.

Q And out of your control.

A I mean we’re having to deal with the passports, didn’t realise that one of my brother’s name was spelt wrong on there, so I’m trying to get that changed. And I’ve got to find X, Y and Z paperwork. And I’m thinking ‘oh my God why is this so complicated’ you know. So yeah everything is not easy. And having to ??? for my brothers for over 10 years, at that time Mental Capacity Act hadn’t come in so I had to wait for that to come in to get the best of interest. Because they are adults I couldn’t really get the Power of Attorney or Lasting Power or any of those because they can’t give consent. So that was horrendous. Yeah, so life’s not easy. You know in my situation I’ve had to….

Time 1:0500

And also when my brothers wanted their own space in my own home, it took me about 6 years to fight for the Adaptions to listen to what I wanted. They wanted to break down all my rooms into box rooms for them. And the way that my two brothers are, they need personal care, they need support and help. So if they’ve soiled, trying to get them out of bed in a boxroom, it’s not ideal, and if they’re struggling they won’t move. So yeah, lots of things I’ve had to do.

Q I know it can be a difficult area but do you think about the future then for your brothers and for you, kind of what might happen?

A I am thinking of the future. I am planning towards it, but it’s not easy. I’m trying to look for them to both be in a home together, in their own home with lots of space. Their names are on Nomination and some of the places that have come up have not been appropriate. And with me having the experience of what happened with one of my brothers when he went into a home, and then when you hear on the News about Winterbourne, it’s scary stuff.

So I want it to be right, so that communication I’m having with the care managers that I’ve got are very experienced in adults moving, but ??? with me, the care managers now have been working with me nearly two and a half years, I haven’t got very far, so it’s… Because the things I’m asking for, the care manager’s saying ‘well no-one’s asked us that before’ and I said ‘well why not?’ You know in my culture it’s important, I want my brothers to be in the community because that’s what it says in the Mental Capacity Act ??? that your loved ones should be, why are they not, why can you not place them somewhere near? You know two places came up and I got so excited and I asked the care manager to look into it, and they came back and said ‘oh no it’s not happening’. So I don’t know why, but yeah.

And not only that, people from my own culture are working with them, you know so they’d have people that understand my religion and my culture to support. I mean they’ve grown up in this community, why can they not be placed here? They’re got community support, they’ve got the meat shop here, they’ve got the barbers, you know the Mosque, everything’s here, why can I not have somewhere near? And that’s the thing that you were saying, that no-one’s ever asked that question before. I’m thinking ‘well now I’ve asked it it’s your job to put it in place or talk to the people above you and sort this out’. So I’m still having that communication but it’s…

Q Yeah there’s a real lack isn’t there of cultural kind of awareness and appropriate provision based on culture, yeah.

A Not many carers out there. Because I know people who got personalized budgets that can’t employ because there’s no-one coming forward. So all the money that they get for the support that they desperately need are not getting it, so the money’s being taken off. So that’s stressing people out. And both the social workers have been pushing me to get personalized budgets and I’ve refused, I said ‘no I’m sorry, I’m already stressed as it is, I’m not taking any more stress’, you know.

Q Yeah. So you’re doing what you can to prepare for the future but obviously it takes time and there’s a lot of hurdles in place by social services, yeah. We’ve covered so much and I’m conscious of time. Is there anything else that we kind of haven’t covered that you think is important?

A Yeah my own relationship.

Q Of course, yeah.

A It’s not easy. I’m so bogged down with the caring role. I mean I had to give up work so you know my husband’s the only earner in the family, so trying to keep everything afloat. And especially with the cost of living is affecting us all isn’t it so… ??? So it’s all that stress as well isn’t it.

Q Yeah, yeah, it’s like you said, the caring, it affects the whole family doesn’t it, it’s not just you as the carer, it’s your whole family.

A So yeah. My relation….my husband’s, we’re just like two adults you know….what’s the word…co-habitees, not husband and wife or anything. So it’s…we had ??? We used to be able to go out to the pictures and go out for meals and stuff, and we haven’t been able to do that for I don’t know how long. And going away on holidays and stuff, you know to take that time out for ourselves. I mean having said that, we did manage to go this year, we went to Turkey for ??? and we did nothing, we just laid in the sun, because that’s all we needed. You know because that’s how tired we were. So yeah.

Time 1:10:18

Q Yeah, so not having time for each other then and, yeah as well as the impact of the stress and financial strain and stuff.

A So in your mind’s eye you think ‘oh I’ll do this and I’ll do that’ but when we got there it was like ‘ugh’.

Q Just sleep, just curl up and sleep, gosh.

A We just needed to soak up the sun, so all we did was soak up the sun. And so yeah, that’s my life.

Q And what do your brothers do during the day, do they go to a day centre or something similar?

A They’re at respite at the minute so I was trying to chill out, but I haven’t, not really. Because you’re still having to clean up the rooms, go through all their rubbish – well the things that ??? I need to throw out. So you know making sure that all the clothes that are all tatty and, you know where you get rid of and just give it a good spring-clean so it’s ??? for them before they come back. So ??? and do all that. So that can take time. So if there’s any clothes that need replacing I’m out shopping and sorting that out and stuff like that. So yeah they’re at respite, they’re back tomorrow. Sorry what was the question again, I’ve gone off.

Q Yeah I was just asking what they were doing kind of….

A Oh yeah. Yeah one has…well they both have PAs, one PA collects one brother and takes him out for the day. So he goes from 9 til 4. And the other brother has transport pick him up and takes him to a base, and from the base his PA takes him out for the day, again depending on what mood he’s in. And with them both having challenging behaviours the day could look like anything. I mean they both have routine and they have an activity chart and stuff that they follow, but sometimes it’s never followed because ??? and they want to do someat different. So it really goes on how they’re feeling.

But the eldest one went through a bit of a, not a good time, because social services….he used to have [organization] come and collect him and he got into a routine, and now they’ve changed that back to minibuses again. And if the drivers change or the escorts change and the buses, the look of it’s change, it throws him so he can have a meltdown and not get on. So sometimes we’re having to go to the centre to pick him up. Or sometimes if the PA has taken him out on the bus and he refuses to get off the bus, so the bus could go around [city] God knows how many times by the time we go to collect him, so he could be on the bus for ages. So he’s still having some issues which I’m trying to work up on. And yeah, so every day is different, you just don’t know what’s going to happen. And at one stage when they were at respite I would always be on tenterhooks thinking I’m going to get called ??? not happy. So thank goodness that’s not happened for a while, but it’s always there ???

Q Yeah, you’re on edge kind of waiting for, yeah. Right at the start you obviously….you’d spoken about kind of the brother that you’re not in touch with any more as a result of the inheritance. What about…because there’s six of you you said, so what about the other two siblings, are you….?

A The other two, my sisters, they live in [city], they’re too far away. My youngest, recently….I mean I stopped talking to them. When my father died there was a bit of unpleasantness because I raised an advocated for my two brothers and none of them liked that, they thought I was doing it for my own gain – and I wasn’t. So that’s why I ended up having to seek a solicitor’s support.

Q OK.

A Yeah, and then my mum was still alive, so I stopped talking to my mum. And then my mum a few years later passed away and I wasn’t allowed to go to the funeral. So I wasn’t talking to my sisters for many, many years, and I’ve only just started to talk with them. Because my eldest sister had breast cancer so I felt what I was doing and not communicating wasn’t good, I really needed to get back in touch. So I started to speak to her. And my youngest has been chasing to talk to me for a long time and I kept ignoring, I’m thinking ‘you know I still remember what you did to me, you wouldn’t let me in’ you know for a Pakistani Asian girl to bathe her mother is like an honour, so I had that taken away from me. So that’s the reason I stopped speaking to them. But now I am talking to them.

Time 1:15:00

And the youngest was saying ‘oh it would be nice if both my brothers can come and stay with me for a weekend or something’. And I’m thinking ‘I know what you’re like’ no disrespect. I mean I didn’t say it out loud but in my own mind I’m thinking I know what you’re like, no disrespect but you wouldn’t be able to cope because you know it’s so important that they have a routine. So it’s that sort of stuff that people don’t understand. And they’ve not had that involvement for many, many years, they forget. Because you paint such a wonderful picture and you’re always saying….I mean I never tell them negativity, you know ??? you don’t tell that to anybody, you keep all that to yourself. So in my own head I’m thinking ‘well no you won’t be able to cope’. Out of routine, if they’re at your house they’re going to think ‘well where are we, why are we, where’s my PA, why am I not going out, I should have been swimming, I should be going on bikes, why am I not?’ You know she won’t understand that. So I’m saying ‘yeah that sounds like a good idea, one day yeah we’ll talk about it’. So yeah she thought…and I’m thinking yeah it’s a bit too late, you should have done that right at the beginning and we could have….I don’t know.

I mean I know I don’t talk to my brother but ideally it would be lovely if I could make connections with him as well. But at one stage before we had any disagreements he’d be saying things like ‘we’ll care for them together and when I’m able’ because I think he’s still on drugs, I’m not quite sure because I don’t speak to him so I don’t really get to know. But he did say that one day he would take the role back on. He has 12/13 children of his own so there’s no way he’s ever going to do that, so it’s down to me to make sure that I’ve got my brothers in a place that they’re the happiest because I know them more than these other three. So if they want to go and visit that’s their choice but I want to make sure that ??? and place them in a place where….

Q All the responsibility is on you then, you’re not able to share it with anybody?

A Well that’s it, that’s something I’d be raising with my mum. Because again, for me, living, everyone can live but it’s the dying that you’ve got to be always thoughtful of and mindful of. Like I said ‘what sort of arrangements have you got, what sort of things have you thought God forbid anything happened to them’. So I didn’t really get much back from either my brother or my mum. So I thought right, OK, that’s my responsibility so you know I’ll have to look into that. So doing a bereavement plan, you know with them, with me, is something that I’m working towards, that they know.

Q OK.

A Because again with my dad dying and a couple of months before when he was really ill, I felt it was important for me to make sure that my brothers understood that I…. Because my brother got on really well with my dad and, you know I didn’t want them to miss him. All my thoughts and feelings were put on to their thoughts and feelings. So I wasn’t able to grieve. So that’s when I ended up having my panic attacks because of it. So yeah I didn’t know how I would work with it, and I didn’t know there was any plans out there to help you, to help people with disabilities to understand about dying. Because there’s things now that I know about dying, but at that time I didn’t know anything. So I did what I thought was right by taking them to visit my dad, being there at my dad’s funeral, getting them to see that my dad was cold and he wasn’t awake and, you know.

Even when my dad wasn’t there any more and my mum ended up going back to Pakistan for a while, my brothers wanted to go to my parents house. How do I explain to them that no-one’s going to be there? So I had to physically take them and they’d both come out of the car, stand and knock at the door, and then nobody would open. So we stood there for about 5 minutes or 10 minutes to physically knock, and then when they realised that no-one was opening the door and I’m saying ‘well no-one’s home, no-one’s here’ and then trying to tell them that dad had died and my mum was in Pakistan, and then bringing them back. And then they’d cry, you know they’d ??? I was the one that felt that and saw that. So you know my siblings haven’t seen that, they’ve not got that ??? And yeah.

And when my mum were ill I tried to do my best, but then none of us went to my mum’s funeral because they wouldn’t allow us. So I thought well I’m not letting my brothers go on their own. My in-laws didn’t go either. So they sided with me. But yeah. So that’s how I fell out with my family. And like I say small steps. But if my brother came and said he wanted to meet up and talk, you know I’d be more than happy. You know I wouldn’t shun him or anything, I’d be really content that he’s making the effort. If he’d made one effort I’d make about 10 to get close to him.

Time 1:20:00

Q Yeah, yeah you wouldn’t….yeah.

A But I don’t know. I can pray that day comes but we’ll see, we’ll see.

Q Oh it’s so difficult for you, and another layer of complexity on top of all your caring roles and responsibilities as well, it’s additional things for you to have to navigate and manage.

A But that’s where my faith comes in. It’s a real strength for me to have that belief.

Q Where your what sorry comes in?

A My belief.

Q OK, yeah.

A Because I feel that since I’ve had my brothers I’ve been able to do things I don’t think I’d have….You know when I was working and I had my young children and we hadn’t thought of my brothers coming to live with me, I had already made plans of being a deputy and owning my own nursery and what have you. But then….you know when you’ve already thought ‘this is how…when I get….’ My husband and I decided that we would retire at 50 and we were going to enjoy life and stuff. Work really hard and then get to 50 and retire. But it’s not happened. I mean he’s still working at 62. So yeah things didn’t work out the way…. But then again, like I say I’ve done things that I don’t think I’d have ever been able to achieve if I’d been on that path, so things happen for a reason don’t they?

Q Yeah.

A I’ve been to a Pilgrimage as well, so I’m really honoured to have had that, you know to have been able to. Because it’s really expensive now, people can’t afford to go it’s so expensive. So yeah. So yeah lots of things have happened that I think, and think ‘wow would this have happened if I….’ But yeah. So yeah I’ve got challenges and stresses on one hand, and I do get some beautiful stuff that come my way in the other hands, I’m really honoured and blessed in a way.

Q Yeah, lovely. Honestly I don’t….yeah, hats off to you. I’m struggling with two children let alone your three children, two brothers, work, in-laws, everything else – and now grandchildren as well, caring. Incredible, absolutely incredible. Thank you so much, I think, yeah there’s been so much there, it’s been really, really lovely and a privilege really to listen to you share your story, so thank you.

A So when you get the results of whatever you’re collecting, will you be sharing the outcomes?

Q Yeah. So first of all what will happen is, we’ll get your interview transcribed and Martina will share a copy of the transcript with you just in case you want to go through it or if you want to have a look, or if you change about you know what you want included or not included or anything like that. So she’ll do that with you. As well there is a voucher for taking part today and a demographic form so we can collect that kind of information. There’s also, did you see on the information sheet stuff about digital story telling and making a digital story? Is that something you’d be interested in?

A Yeah.

Q Yeah, brilliant, so Martina, I’ll tell her that and she’ll share information with you about that and the next step. And definitely when kind of all the findings and analysis, when we have it together, it’s very much we’d share it back with participants. But also it’s thinking about who would benefit from learning about your experiences and who needs to know about this. So people, you know like you mentioned like GPs understanding and social services and therapists, and wider family members as well, about understanding what it’s like to be a carer. You know like you said, your sisters don’t know, they don’t understand. So it’s about sharing the findings with those wider kind of groups of people so that they can hopefully get an understanding and, yeah make things easier ???

A So how long do you think it’s going to take to get it all to that stage then?

Q Hang on a minute, I’ve just realised we’re still recording aren’t we. I can just stop.