Bad connection

Q …..the problem is it’s just frozen from my end and it says it loading so I’ve got nothing…doesn’t want to go through with it and then for some reason it doesn’t download the recording. So let me just join from a different laptop. Hang there. I’m really sorry for this.

A No you’re alright. I can’t believe I got through.

Q Ah, now it’s telling us it’s recording. OK.

A That’s alright, I’ve consented to being recorded already.

Q OK brilliant. OK let’s leave that then as it is, I can switch off that computer. OK sorry for that terrible start.

A It’s helped me relax well, because it’s not my computing problems.

Q Yeah, however many years into being online and online meetings there’s still always hiccups isn’t there?

A Yes. I did my first degree when you hand wrote it all.

Q Oh, I can’t even imagine.

A All night long. But anyway. ??? so quickly. Right have you got questions, is that how it works?

Q Yeah it’s quite relaxed, I’ve got kind of certain topics to cover but it’s really up to you in terms of what you want to share and you don’t have to answer any questions that you don’t want to. And it’s really just more about you just sharing your experiences really about your sibling and caring for him and how that does or doesn’t impact you life, and what you feel about it really, if that’s OK.

A So would you like a brief history first?

Q Yeah if you don’t mind and just introduce….yeah exactly.

A Not at all. I’m the second of four kids very close in age and [brother] my sibling is the third. He’s just two years younger than me, a little bit less, and the next one is another less than two years younger. So as I grew up it was really like we had two babies, because [sister] the youngest and [brother]. So I can remember a bit helping my mum with bathing the babies and things. But of course my parents didn’t actually know there was anything wrong with [brother] until he was around 2 and they’d just had another baby. He was brain damaged at birth is what we think now but nothing was ever pursued adequately. So he has I suppose you would say mild cerebral palsy, though as he’s now in his 60s he’s creaking a great deal more, but quite a substantial severe learning disability.

So my background is affluent and educated. Our mum stayed at home. [brother] didn’t even go to school when he was 5, so I’m from the era where there was no education before the Warnock Report. And my mother ??? she got a letter to say he wasn’t entitled to a place at school. And then maybe at the age of about 7 he started going to a local-ish school in a minibus, a school for spastics as it was called. And I can remember, we lived in quite a big detached house, you know pushing him. We didn’t have a wheelchair but my mum had a double buggy, so somehow [brother] still fitted in the double buggy because it was one of those tandem ones. So he still fitted in that and getting him down to the drive and putting him on the minibus. And my partner says that was caring, but it was just what family life was you know.

And then I think quite probably my mother had some sort of breakdown and suddenly he went away to a boarding school. If I think about how our life was impacted, I suppose we had the sorts of holidays that was easy to be with [brother], so they were always on a beach. I mean we had very supportive grandparents and my parents also knew how to get [brother] into the [place name] respite care, as it was called. And I use those words sort of because that was absolutely what you grew up with. And my mother still calls him a mentally retarded spastic. Sorry. Obviously I don’t.

Q But that was what it was I suppose.

Time 5:00

A Yeah that’s what the language was, that was all it was. So then he went away to a boarding school, and it’s only kind of quite recently that I realise how awful that was on one level. But we very much grew up, the other three of us then went to uni and did well and left home, we very much always grew up with my parents saying categorically ‘[brother] was not our responsibility’. So from my affluent… and my father’s a very sensible logical man who was really able to get what he wanted out of….you know his rights, thought what was required for [brother] and what [brother] was entitled to from the state, for instance never going to sue the NHS for the birth defect because the state would look after [brother] - and so the state did always look after [brother]. And that was how we grew up. Not that he wasn’t part of our family because he was and he was always there in the holidays. But when I went off to uni and they were just shunting him around various care homes until they found one that was suitable for him for life.

So I came back from uni, I just….[brother] was just always there at Christmas and holidays and I loved him dearly and I have a very, very warm bond with him. He was lovely when my children were born and things like that. But I don’t feel like my life wasn’t when I was growing up and when I was a young adult and my children were young, wasn’t impacted desperately by [brother], like I realise that. I could have gone to live in Australia if I’d wanted to without thinking ‘I can’t do that because of [brother]’ ??? my brother. But I know that lots of people’s whole life is they have to be there, or they had to, and that’s how they almost grew up. Although my partner, who was a special needs teacher for ever says ‘yes you were a sibling carer, yes you did do caring, you were washing? and dressing your brother and pushing him around and stuff’ I don’t feel that that happened, and our parents worked really hard at sheltering us from ever feeling we had responsibility.

Q OK.

A But then probably 15 or so…our dad died 25/26 years ago and he was really good, and indeed by that stage…this is how different we are….he owned the care home my brother lived in. He had a few care homes that he set up in later life and when [brother]’s was going to go bankrupt he bought it.

Q As you do!

A As you do, if you’re affluent, as we are. So actually when dad died we owned the care home [brother] lived in. But things went from bad to worse because there was so many changes. I mean I wasn’t equipped to being on the Board but ended up being. We obviously employed people to run… there were other? care homes, I hadn’t ??? much about this, I think none of my new friends know about the care home business. But ??? which was my job to be on the Board of Care Homes which I did appallingly badly because if I wanted to be on care home boards I would have been wouldn’t I? My dad only owned them. He owned them because he saw it was a business opportunity when he realised how [brother] was cared for, if that makes sense. In later life that became a business opportunity for my dad. So that’s weird isn’t it, I bet you’ve never….

Anyway, the long and the short of it was, maybe 5 or 8 years after dad died and all the new CSCI? regulations which made it all much harder because you couldn’t just be a big friendly warm care home with a cook and a ??? you had to be lots of individual flats all pretending? to be living independently – ha, ha, you know. And of course half your rooms were empty because if you had a 40 bedded house you just couldn’t do it any more. Anyway the long and the short of it was, we sold. And I, you know didn’t think….I thought it was the right thing that these care homes needed to be sold, we and our very aged uncle weren’t able to manage them ???

I took to visiting [brother] a bit more often as my kids were getting older, and I’d turn up on a Monday night thinking I’ll take [brother] to the pub or whatever randomly. And discover that he’d been, quote ‘a good boy and put his pyjamas on early to help out’ and stuff like that. And he started telling me he was pretty unhappy. He’d always been a bit grumpy, he’d always had this crying thing that when he came to see you he cried when he went back, he didn’t want to, you know that. We always put that down to he never wanted to go back to school. Always ??? awful thing of mum being completely wretched when she’d had to get [brother] back to school and he was just weeping and crying and being sick. But that was just something we grew up with and it was the right place for him to be, so….

So the long and the short of it was, my partner who I’ve only been with for about 20 years so my second partner not the other parent of the children….

Q Only 20 years!

A Yeah, well yes but my kids are 30 and her kids are 32 so you know we have a bunch of young people that sort of age in our lives.

Q Yeah ???

Time 10:00

A Yeah. I found out about Direct Payments and I found out that [brother] would have a right to Direct Payments. And we had inherited, you know my siblings got a lot of money from dad, and [brother] hadn’t because dad’s idea was if you gave [brother] any money then he’d lose his benefits and not be the state’s responsibility any more. But dad had always said….I’m talking quite a lot, is this alright?

Q No it’s absolutely perfect.

A Dad had always said that he wouldn’t be leaving [brother] money but we would help. Anyway the long and the short of it was that [brother] made it very clear to me, but not to our mum who he saw every few weeks, that he was really unhappy in the care home. And I could see that, and it wasn’t suitable, and they were labelling him as ‘difficult’ because they wanted more money. And they were making their money by putting in more difficult people. [brother] never had? behavioural problems particularly so it became a place with really challenging behaviour because you can charge more if you have more of your rooms full, you know this sort of thing.

Anyway the long and the short of it was, that about 12 years ago with great help from my partner but not from anybody else in my family, we bought a flat near my mum for [brother] to live in. But there was a Catch 22 because the social workers had to hear [brother] say he wanted to live on his own. And [brother] couldn’t possibly conceive of living on his, I mean I was really scared he’d just say ‘I want to live with mum’, couldn’t conceive of living on his own if he hadn’t seen where he could live. And if the social workers took him round to tower blocks to see council houses, that wasn’t going to work because we’re very middle class? and if he wants a home he wants one that looks like his siblings’ home – does that make sense?

Q Yeah.

A Anyway ??? very quickly, I took [brother] to visit it a few times, told him it was his holiday house, because we’re the sort of family that has holiday houses. And then there was some talk of him being moved to another unit in the grounds or whatever. And he told the social worker, amazing, amazing, found the ??? to tell the social worker that he didn’t want to live in this care home any more and he wanted to live in his own home. And it just happened that this, which was absolutely brilliant, [brother] ??? really 12 years ago, and it just so happened that he lived in a care home in East [county], my mother had retired, my parents had retired to East [county] but when he was a child we lived in [county 2] and so [county 2] picked up the tab when he left school for his care home, which was in? [county].

And so [county 2] had paid the tab from the age of 16 to whatever when he left school, to 52 for [brother]. And the [county 2] social workers realised that if he moved into his own flat in East [county] they would lose that. So they were really supportive financially of giving us a budget, which ??? immense trouble moving over to East [county] 6 months later, who actually used the phrase ‘[county 2] has dumped your brother on us’. I’m quite articulate so I fought his corner well, I didn’t quite realise what being a financial appointee would necessitate but ??? had some influential friends so ???

So anyway all that was fine, we got a live-in carer and I managed the budget and really everything went pretty well. I and my partner retired and moved from [town] which was only an hour’s drive from where [brother] was, to [county 3] which is 5 hours away. Then my younger sister, who hadn’t really been in favour of it particularly and mum hadn’t been particularly in favour of it but could see that the point was that [brother] would have his own home when mum died, because he spent ??? he for ever referred to ‘mum’s home’ which was not even where he grew up, as ‘home’, not the one he lived in.

Q Yeah, not where he lived.

A Yeah, so a care home, it’s not your home if you can’t put your own birthday cards on the mantleshelf, or pick your post from the doormat, and you have to lock your bedroom because otherwise someone’s going to trash your bedroom. It’s not home is it? So anyway, we got ??? and that was all absolutely brilliant. But post-COVID things have gone tits up really. We have ??? lost the main carer, but it was probably a good idea because she was maybe a bit more controlling than we realised. And [brother]’s behaviour’s kicked off in completely unexpected ways really, which is difficult to manage. So I would say I didn’t grow up, I haven’t got mental health problems but I do have an enormous guilt. So I can’t make [brother]’s life any better than I’ve tried to but I’ve got enormous guilt. I’ve fallen out with our older brother because he wouldn’t help in any way.

Q OK.

A Mum’s 93 and getting deaf so that [brother] doesn’t even really want to go and see her because the conversation is all too hard. So there we go. So we’ve got a clinical psychologist involved with [brother] now in an attempt to see…. and maybe he’s got a better understanding of what independence is now and wants more of it. Maybe everything just ??? maybe he’s just turned into a grumpy old man. But my sister and I are struggling to manage it, mainly because ??? employ sole workers who he shouts and swears at on a regular basis. And I don’t need to be someone’s employer, I hate being someone’s employer, that’s really awful. You know all the terms and conditions of their work and paying the wages and all that, you know setting up a pension scheme, all that stuff’s a bit ???

Time 15:15

Q Oh it’s a whole job in itself being a Direct Payments employer isn’t it, it’s a whole kind of thing in itself.

A Yes. I mean I don’t know how, you know what’s [brother]’s budget, £1250/£1300 a week, I don’t know whether that’s middling, low or high frankly, it just about does. So that’s it. So poor old [brother], who used to be my lovely warm-hearted great big hug brother, has ??? and refuses to do things. That’s quite hard. I can’t have him come and visit, he just went off on one. At a concert in the village, none of my friends would quite believe it, and everybody goes ‘oh let’s see your brother, how lovely, oh that would be nice, oh we haven’t seen him in ages’, I’m thinking ‘he’s not that nice actually any more’.

Q Yeah ???

A ??? no need to be crying it’s just ‘oh poor old [brother]’, if we could get to the bottom of what it is. I mean it could ??? one other thing is Diverticulitis, you know ??? do you know what I mean? Or just his knees are clicking? or….you know, but he can’t get the medical help. Does that make sense?

Q Yeah. That’s really tough. An interesting thing, when you spoke about the guilt then, that’s something which has come more recently?

A Absolutely.

Q Like you know ??? you were saying you could have gone off to Australia if you’d wanted to and didn’t have any of those feelings, but it’s now that his needs have changed and he’s changed that the guilt has started I guess?

A Yeah, yeah well the guilt is survivor complex I suppose. I do say to most people ??? I say well it could have happened to any of us. I was born in the same hospital 20 months before [brother], that could have been me you know. So there is that. But also it’s far more time and thought involving than it used to be. [name] my partner and I spend for ever talking about what might it be, what might the problem be, you know is there something we can solve you know. Just sent Vitamin D drops last week in the post because he can’t swallow pills in the hope that maybe a bit more Vitamin D might help. Do you know what I mean and trying to think if there something we’ve all overlooked here.

Q Yeah you’re just trying anything.

A Non-stop he’s on as much Paracetamol as he’s allowed just in case he sneezes and his hips hurt, because he doesn’t tell you if they do. Does that make sense?

Q Yeah it does, very much so. And can I just ask if you don’t mind, like a bit more about then the situation with your siblings?

A Yes.

Q Your sister is involved in [brother]’s care.

A Yes she’s stepped up and is quite involved. She wasn’t sure it was a good idea. To put some perspective, she’s an Evangelical Christian who is a spinster. But actually the thing is that I don’t have a lot in common with her and so we mostly talk about [brother] or mum. The stuff I find difficult is that, in my relationship with her is I am completely dependent on her doing lots because she lives closer. And I’m feeling a bit bad because I moved away, but when I moved away everything was fine.

Q It was fine, yeah.

A My other thing is that I don’t think she has quite such an understanding of [brother]’s rights and learning disability as I have because of my partner as well and her profession. [sister] has no-one to talk it through with. And the other thing that is hardest of all is that I think [sister] thinks our mother is more important than [brother], so whatever mum ??? for [brother] [sister] tries to make happen. So [brother] doesn’t want to go to mum’s, but mum expects to see [brother] three days over Christmas. I’m saying to mum, [sister] that’s far too long. Look, [partner] and I will go down, we will look after [brother] some of Christmas getting to mum’s maybe for one night but make sure we turn up in the morning for the shower and the toileting that’s getting more erratic. Mum several years running has said yes she will allow a carer to turn up, and then cancels them because she doesn’t want them in her home. But [sister] doesn’t want to upset mum.

Q OK.

A [sister] is a very, very good woman. She was never as close to [brother]. He’s a bit ruder to her than he is to me so I feel really bad about it. But yeah she’s great, she’s great. And I barely speak to our older brother. I told him our project, said that I was going to get this home and move [brother] in, and he said ‘you do what you like, I want nothing to do with it’. I went ‘he’s your brother’. He said ???

Time 20:00

Q Sorry you cut out at that point.

A ‘Yes, yes, and he should live in a care home’.

Q Oh.

A And my mum’s very upset about the breakdown between me and my older brother, and she thinks that [brother 2]’s ‘as entitled to his view as you are [participant’s name]’. I go ‘no he’s not frankly, no he’s not’, you know. And [brother] keeps saying ‘I don’t see my brother, I want to see my brother’. And I say ‘you should make [brother 2] see [brother]’. And [sister] says it’s up to [brother 2] to decide. And I think no it’s up to [brother] to decide actually.

Q Yeah, yeah.

A I think when mum dies none of us will see [brother 2] frankly.

Q Yeah OK. So it’s not just you he’s not in touch with or has that fractured relationship, it is with [brother] as well then?

A Yeah, he has a close relationship with mum and he sees [sister] because [sister] chauffeurs mum you know, I don’t think he’d see her for any other reason.

Q Yeah.

A And I don’t know, because I think my older brother feels that his life was blighted because he had to share a bedroom with [brother]. He’s four years older. He went to university when he was 17 and three-quarters, it wasn’t exactly the whole of his life, term-time only he shared a bedroom with [brother]. So maybe he found it hard.

Q Yeah OK.

A ??? how many men have you interviewed compared to women?

Q Yeah I was just saying this to a colleague the other day. Siblings it’s all been females. And I think if they’re interviewing parent carers as well there has been a couple of men. But the majority are women of course.

A So on the ??? 95/98% women. And the only bloke there is, oh he’s written a book about it. He’s become famous, you know. Not all of them but by and large ??? going on at the moment how to find yourself a partner, and I’m thinking well lesbian, it’s a lot easier, women are generally nicer, at least if you’re going to find a man find one who is a nursery teacher who doesn’t need to be number one! Sorry.

Q Yeah, yeah I know, interesting yeah.

A Oh it’s ridiculous, it’s women’s work.

Q Yeah.

A But I wasn’t brought up that it was going to be my work.

Q Yeah OK, it’s something that you’ve taken on out of your love for [brother].

A ??? much later, later life. And basically pretty much when my kids were going, you know.

Q And is that because you had time then I guess, if your kids were leaving home ???

A Well I had money, but I also had the light-bulb thing about understanding about Direct Payments at a time when it was really clear that [brother] wasn’t happy and that he wasn’t being….that they weren’t being fair and honest about him. You know I’d go to annual reviews when he was always down…we never had the social worker it was always just someone called a Care Manager, and she was ??? colluded ??? with whatever the care home managed, the care homes said they needed. And I came out of one meeting, my mother and I were almost in tears, we’d no idea [brother] was so difficult, so moody and the rest. Went over to a member of staff that I’d known since she’d started there in this care home 15/20 years ago, said ‘I had no idea [brother] was so difficult, I’m so, so, sorry’. She said ‘[brother], difficult, he’s the nicest person here, he’s so easy and good natured’. But I guess he learnt this disgusting language and abusiveness there, he must have done – or from watching Eastenders! ???

Q Yeah.

A Well the whole care thing’s difficult, you know you don’t ??? to get. [brother] is surrounded in his family by very middle class classically cultured people, I’m not meaning that as a value judgement just that that is the family ??? he is in. He likes to wear a tie. He wants to be clean-shaven, yeah. You know his favourite things are cuff links and big watches and… you know very middle class.

Q He sounds wonderful.

A Middle class older man. There’s a bit of a culture clash with some of the carers.

Q Yeah, yeah, interesting. Yeah I can see that happening. Is there anything….I mean I know you’ve said yourself that by saying you’ve got time, you’ve got money so your mental health kind of hasn’t been impacted. But is there anything where you do feel you could benefit from, or you could have at certain points benefitted from greater support and what that support would have looked like?

Time 25:00

A What I do realise most of all is that I wished there’d been a [charity] group when I was young. [partner] my partner was running [charity] groups in her special school specifically to give ??? And now when I look back on it I didn’t know anybody who had a disabled or sibling with learning disabilities in particular, might have been a little bit of physical disability. But bear in mind [brother]’s physical disabilities are such that he would have had a mainstream job and a mainstream life probably had he not had a learning disability. And all that the physical disability has done is made it harder for him to fit into other learning disabled areas, like he can’t go and rave on a dance floor or whatever, do you know what I mean?

Q Yeah.

A So I wish I’d known people, and I never did. I mean I remember my teachers knowing about it, and so from my girls’ grammar school when I was going on the languages exchange I’m sure they made sure that the family that I went to was understanding and that whoever came back would be fine about [brother] – not that he was ever seen as difficult or any sort of blight I mean. And in later life, I have a friend in my village now who had a sibling, she’s in her 70s, he died 16 years ago of a sudden heart attack, but when I look back on what [friend’s sibling] was like I think that [friend’s sibling] really probably had severe autism and tunnel vision and some…. Because he could read and he could recite bus timetables. [brother] can’t read, you know. So I think that’s what was wrong with [friend’s sibling]. My friend doesn’t really quite see it that way, but then she was 8 years older. And about 5 years ago I met her younger sister, who was [friend’s sibling]’s twin, that was great because then I really knew that I’d found someone who knew. Because if you’re already at grammar school when your sibling of 5 is diagnosed with something you barely notice I think. But the twin, so that was good to meet her.

And the bit I found ??? is sometimes I talk to people in my WI about ‘oh problems with the carers again, I’ve got to go down….’ Oh yes, and they go off on one about finding carers for their elderly mother. And I’m thinking ‘this is not the same’. This is not the same. And I find myself getting really angry with the sprouting of blue badges and, you know free cars for people who have always managed perfectly well to buy a car and just got gammy hips now. Do you know what I mean?

Q Yeah, yeah.

A ??? the disability. Old people have taken over disabled as their right. Does that make sense?

Q Yeah ???

A I’m also rather intrigued as to what’s going to happen when [brother] hits 66 or 66 and a half, what’s going to happen to his benefits when he suddenly becomes retired. I don’t even know, I don’t even know. Because although I’m officially in charge of it all I don’t really know how it works, the money just keeps coming. And every so often I write to the ??? saying ‘look, minimum wage has gone up 10% you’ve got to give me a 10% rise’. You know most years I haven’t done much. So what were you asking? I wish there had been [charity], I wish there were [charity] to talk to. But I tried through the [charity] network and I did a couple of zoom meetings with people in [city]. But I just felt like I couldn’t contribute anything and that I was very out of place because I was so much richer, better educated, and less ground down than any of them, that that wasn’t a space for me there really. Does that make sense?

Q OK.

A So that’s why I’m not even sure that you need my story or whatever. Because I think the only thing I would say is that obviously mental health is mental health and so as I said I am sometimes very anxious from it and stressed, although how much that is to do with other aspects in my life I don’t know, and that it is quite time consuming. But I believe that if you grew up in a family where it was well dealt with – well not dealt with but do you know what I mean, our father was able to get what was needed and it was [brother]’s rights so he’s always been financed. If you always had adequate housing, if you never had to think ‘actually if we need to we can buy a flat for [brother] to live in’. I mean how many people can I say that to, ‘I just bought a flat for my brother to live in’, do you see what I mean?

Q Yeah. ??? But I mean from our perspective, like I said, the range of experiences is what we are interested in and I think everyone does have something to contribute. And like you say, you say there are still feelings of guilt and there’s still that.

Time 30:00

A Oh yes I mean feelings of guilt, and there’s responsibility. And quite frankly [partner] and I are now talking about much longer we can keep this going and whether or not it’s what [brother] thinks he wants we might need to move him back into in the next 5 years or so, probably not until after mum dies, might need to move him into….well if we could find a community, even if we buy our way into a community. Do you know what I mean, like actually I’ve done my best and I can’t beat myself up. I can’t actually make [brother] a happy man at the moment. And you know if he was one of my other siblings I wouldn’t even be thinking about having any responsibility to make them happy.

Q Yeah. Yeah I kind of understand what you are saying. And I think what you said about kind of your friends is really interesting, or mentioning it to people at the WI and them just not having any comprehension, and comparing it to just someone who is older is really interesting, and potentially quite isolating if you don’t have anyone perhaps to share that with. I don’t know how you feel about…

A Yes, I mean meeting my friend’s sister, the twin of the guy with learning disabilities was wonderful because she completely knew. She told a story about how she used to take [friend’s sibling] on holiday, and he had such poor spatial awareness he was always falling over things. And she’d be coming down the stairs of the pub for the breakfast and all the staff would be there trying to kind of help him, you know. My previous partner and I, when the kids were little [brother] and mum, after dad died, [brother] and mum often came on holiday with us. You know [brother] had this thing of going to reception and asking who was on duty and needing a little list of what was happening and things, you know ??? Because he always wanted to talk to people, and that’s fine, but he gets grumpy now. You can’t move him away from talking to people. I mean it’s not my responsibility, if you don’t want to talk to him any more you’ll have to leave, because it’s really obvious that he’s not going to be able to end this conversation. But there being slight elements of being embarrassed now with some of how he is because he gets cross so quickly, and that’s quite difficult. Not to say that I’m not a grumpy old woman, you know.

Q Yeah. And it sounds like the future then as well is quite a big thing at the moment, thinking about what’s going to happen in the future and how you’re going to manage that, or ??? manage that.

A Well yes, if we lost….we’ve got two main live in carers, one week, one weekends, if we lost one of them it would be a disaster. If we lost them both we could buy agency care, but you can’t buy agency care for 4 days and 3 days, which we thought was a really good idea to split it like that. Because if push comes to shove I can afford to buy more care even if the state doesn’t give me all the money. And I am prepared to do that, I’ve sort of ring-fenced some of my inheritance for that. And actually when mum dies I think I will fight my older brother for a share for [brother], even it just means him ??? benefits, just for the recognition of it. Which is all kind of like I’ve got this fight going to happen. And it’s awful, mum hasn’t died yet. ???

Q Yeah but you’re kind of preparing.

A Yeah I know.

Q But you’re preparing for it.

A Preparing for it because I’m angry.

Q Have you looked into Trusts and stuff like that for financial help?

A Well my problem….yeah, not massively. Partly because my father who was really astute always told us that Trust Funds didn’t work, and also because I’m not actually sure that it’s alright for someone to continue to claim benefits when they’ve just inherited a large amount of money. If that was white van man down the council estate doing it you’d be furious, so why should [brother] continue to have benefits if he has money? So actually I think his money should be used. I don’t think that I should have to pay for my brother. And when care managers and sometimes social workers have said ‘yes but don’t you sometimes look after your brother’ I always say ‘and do you look after your brother?’ It’s not a normal relationship to do intimate care and sleepovers with your brother is it?

Q No, no.

A I don’t know what your family situation is, that’s not what it’s about, but… And actually I’m at the stage now with [partner]’s support of saying ‘well obviously if there’s an emergency I will go down, but if we can’t can we find somebody else to pay’, can we just pay someone to do the nights and I’ll spend the afternoon taking [brother] somewhere. I don’t need to have the row with nicking him shaving him in the morning, you know I don’t ??? in my life, he doesn’t want his sister wiping his bum does he frankly?

Time 35:00

Q Yes so having a more kind of conventional sibling relationship where you can.

A Yes I think that’s quite important. And recently my son got married, it’s the first marriage of that generation, and my son wanted to invite [brother] to the wedding. And we thought it would happen but we had changes in carers, we hadn’t anyone that we could trust to do it and [brother]’s behaviour, the ??? terribly in the year and a half ??? engagement and the wedding. And in the end we weren’t even sure if we got him there, it was a long way, 6 hours from where he lives, that it would be manageable and what we would do if he kicked off and things. And in the end we organized something completely different for him to meet with his nephew and fiancée and her mother and our mum, somewhere that he liked going to celebrations ??? for afternoon tea. But the day before he absolutely….he woke up in the morning adamantly said he wasn’t going to do it. So he shouted he just wasn’t going to do it. And in the end, in the end my partner, who is slightly embarrassed about it, used every single trick in the book from all her years of experience – and a little bit of emotional blackmail – got him ready to go. And actually he loved it. But it’s so difficult.

Q Yeah, yeah.

A He’d just cancel everything. So I’m just saying, you know and I do feel guilty, I do feel guilty. Because I used to be furious that there would be other people who would invite us to family things and they never invited [brother], I used to be furious ‘how could they not invite [brother]’. ??? being invited as a cousin, why is he not there? But now I myself think ‘well it wasn’t a suitable…’ he wouldn’t have survived it in tact ??? invited him, I suppose how I put it now. That he would have let himself down.

Q Yeah.

A So that was a thing, yeah.

Q Yeah OK. It sounds like your partner is a huge source of support then and kind of fully understanding.

A Huge support. And that’s why I worry about my sister because she’s not got anyone except God to talk to about all this. You know how it is.

Q Yeah ???

A And I have huge support. And there’s a long going….there’s a thing at the moment on [charity] saying, you know people are having trouble finding partners what would you say. And it’s like…yeah. And I know when we got together the important thing for us was that we were OK about each other’s kids, not about [brother], he didn’t feature in one of the things that was actually more important than your relationship.

Q Yeah it’s interesting ???

A But I know it bothers people, a lot of people out there, because I read the [charity] thing and I read it. And there’s a lot of young-ish women, young women out there, up to women hitting 60 I suppose, who are like ‘I can’t get my mum to let go’, ‘I don’t know what we’re going to do when mum dies’, ‘mum’s had a stroke’, ‘I’m fed up because actually I can’t live my own life because I have to do all this stuff, I want to do it but….where’s my life in all this and I can’t survive’. And I suppose why I was uncertain about being interviewed by you is that I don’t have a story that helps those people in any way at all get what they need. You know if I want counselling I can buy it frankly.

Q Yeah.

A And I know that that is an enormous privilege, added to which my social circle is highly educated left-leaning. Most of those people are going to be OK about [brother]. It just makes sense. So I think that our very good fortune of the class and background we were born into and our financial affluence has made a terrific difference, and I can’t say it otherwise, you know it’s an unfair society.

Q Yeah. I guess that’s like anything across society isn’t it, it is. Any areas where people struggle, being kind of middle class or affluent, it does help doesn’t it, it helps in every situation really.

A Yeah, yeah. So we had a Prime Minister who had a severely disabled son who went to the school that my partner had taught in. And at that school, that is the only environment in which as a highly affluent middle class parent you are likely to meet people from other classes. Because your son would have gone to Eton, only he didn’t, he just went to [special school] along with all the other people with severe cerebral palsy, because that was actually the best place.

Q Yeah.

A But that Prime Minister promised to make packages portable – and didn’t. So there’s my big anxiety too. My sister says ‘oh well when mum dies I’ll move [brother] to live opposite me, I’ll take prime responsibility’. I said ‘yeah, and some, we won’t get the budget off [county 2]’. [county 2] will never give us that budget if we move [brother]. And [brother] has to say he wants to do it. And then we’ll be fighting over the budget. You know that budgets aren’t portable. It’s appalling.

Time 40:12

Q Yeah it’s this big issue, yeah trying to get other councils to take on so to speak responsibility of people.

A So say you work for the….with cerebral palsy you work for the BBC in London, you get transferred to Salford and Salford won’t pay for your care to allow you to continue to work. It’s not just people who aren’t in work who suffer.

Q And it stops kind of just natural relationships and progression and that life dynamics happening if you can’t just move house can you to live closer to family or to…you know to suit your situation at that time. Yeah it’s another way I guess disabled people are treated differently.

A So here’s how it affects me. If [brother] needs to move I have to pay full capital gains tax on the profit on his house, and then I have to pay second home stamp duty on buying a new house for him. Isn’t that bonkers. Because somebody somewhere along the line abused that you can buy a property for a disabled relative. So we know that’s not ??? with anybody else with that problem but, you know it’s going to cost me….what £50,000-£100,000 in tax if [brother] needs to move.

Q And you’re actually saving the state a lot of money by having that property aren’t you?

A Yeah, yeah, yeah, because he can’t get housing benefit because I’m his sister, you know.

Q Yeah but you’re saving them about ??? aren’t you?

A Like that’s my stress. I mean really it’s not a stress is it, I’ve always thought if you can solve it by money it’s not a stress. If you’ve got the money and you can pay for whatever it is, it’s not a problem. Sorry. So that’s sort of ???

Q No, no it’s a different set of injustices isn’t it, yeah.

A Yeah. I bet David Cameron got every single one of his houses disabled ??? immediately. And [partner] said at the same school there was a child who couldn’t come to school if his dad wasn’t at home – and his dad was a taxi driver, because his dad was the one who had to carry him down the stairs to the school bus. But the Cameron’s will have had….

Q Yeah, the inequality.

A Right. But what my dad got ??? I suppose, pretty much. Sorry. So you know, bit of a…. So my mental health now, I don’t feel like I’m spinning plates particularly. A little bit but that’s to do with just trying to get the best for [brother] at the moment when he’s going through a tricky patch emotionally, mental health wise I suppose. He must be very angry at stuff. But also because he’s got a learning disability he can’t snap out of it very quickly.

Q Yeah and it’s tricky to ???

A But ??? have said to me, I said I lose my temper too easily. They say ‘well what does [partner] say to you when you lose your temper [participant’s name], does she say ‘now go and sit quietly in the lounge [brother] and I’ll leave you alone’. No, I say ‘no, she tells me to go for a walk up the hill and I go’. Because you can’t do that [brother], nobody tells you to go out for a walk. And people are just there all the time. And have you heard of that sort of phrase, a sort of velcro’d PA, someone who kind of has to feel stuck to your shoulder because they’re not earning their money unless they are there with you all the time? You know people feel really weird just sitting on their own in another room being paid. You know.

Q Yeah. So much comes down to how good the carers are though doesn’t it, you know in terms of….

A But it’s very hard to see that as your job isn’t it?

Q Yeah.

A So he has to really lose his temper and be rude before you’ll leave him alone. And my sister and I find it quite hard to suggest to people that there might be a different way of doing it, because after all they’re there all the time. I think they love it, I think they love it when they come back and they see I’ve failed to shave him properly because he threw a wobbly. I think they love it you know.

Q Yeah.

A Just like ‘you can’t do it either’ you know. It’s like, no.

Q Is there anything else in terms of kind of what you do find supportive and useful? So obviously there’s your background I guess and the money aspect, and your partner, and meeting the twin. Is there anything else which has kind of really helped you found, or really kind of helped you navigate I guess the system, or made it easier for you?

Time 45:10

A Give me some suggestions, because no I’m not finding that particularly. I read the stuff on [charity] network and there are a couple of people I think ‘oh I want to meet you’, you sound like you’ve got it more. And then there are some people I feel sorry for. I’m not even able to give particularly good advice because I can’t even remember how I became [brother]’s financial appointee, I mean I was just in the care home and somebody said ‘could you just sign this [participant’s name]’ because it was always the manager and we’re not supposed to have a manager any more so can you do it? I haven’t got any ??? as I am. You know it isn’t….I don’t know. I think growing up being absolutely told he was not my responsibility on one level made life easier. I’m angry now with my parents for that because I think he is my responsibility.

Q Oh.

A I am angry about that. Because actually my older brother had a child that they knew was severely disabled in the womb and then he was stillborn. And I feel like saying to my brother ‘yeah and if he had lived you wouldn’t have expected your kids to have embraced him’.

Q Yeah, you would have wanted them to have their….

A ??? upset my sister-in-law too much so can’t be saying it, you know. But my parents really did pretty well I think. And I wasn’t envisaging dealing with [brother] being so angry and only….occasionally out of control. But we are getting help from a clinical psychologist. I think, again part of me thinks we are getting quite a lot of help first because when they met [brother] he was very engaging, because he can be really engaging and gregarious he is, loves meeting with people. And so of course I think she thinks [brother]’s so lovely, he’s got this wonderful supportive family and so she’s got somebody she feels she can work with. Does that make sense?

Q Yeah.

A So again I think we are privileged, you know. By and large [brother]’s a really likeable man, he just flips every day once or ??? But he’s a really likeable person, which helps us as well so ??? you know. He’s even got a look that people say ‘oh he’s handsome’ do you know what I mean, not in like weird ways but actually….I can’t explain. So I think we’ve been really privileged in all sorts of ways – well we’ve all been privileged, [brother] hasn’t obviously. But sometimes [partner] brings me back down to earth and says ‘but look, what do the men his age in the village do’, well really most of them just sit and watch telly don’t they and moan a bit, you know. ??? No so I can’t. Tell me something else that might be. I can’t, you know. I do feel guilty. I do feel guilty and upset on his behalf but there’s nothing to do. And I do feel that learning disability, people with learning disabilities aren’t represented, ??? speak for yourself is difficult. ??? sometimes.

Q Yeah. What was it then, because you said kind of you weren’t sure about taking part in the research, and you said again that you’re not….you don’t feel you can help perhaps because your mental health doesn’t perhaps suffer in the same way as other people’s. What was it then that made you want, or made you kind of follow through and did get in touch and…

A Well I sent the email saying I wasn’t sure that this would be particularly for you in your research but I was happy to do it. And ??? said it was completely up to you and explained what it was. And then I got a prompt yesterday – day before – so I thought you must…you know you need to interview a certain number of people. But I’m not sure that my story is going to help in getting more support for people who are siblings is it, for live in carers, I haven’t got anything to say that’s going to get more support there, so ??? a story I think you can use in that respect. I suppose the only thing I reiterate time and again is that affluence, good fortune and education, and we have good fortune in health all the rest of us for instance, makes a difference.

Q But you know that’s something in itself, just getting evidence for that I guess and in terms of then it’s….

A But ??? I feel like ??? you know I don’t know how it works. But I’d like to meet other people in my situation. I tried with [charity] and I haven’t really got there so….

Time 50:00

Q Yeah. And you know that’s really interesting as well, how you kind of perhaps don’t feel that you fit in in those situations because you are very fortunate in lots of ways. So you don’t have the struggles that other people do.

A Yeah. And I didn’t have that whole thing about, you know can I even go to university, I’ve got to go and live at home now because I’m a central part of the care package. That’s never, ever been it. And I suppose suddenly now [sister] and I are a central part of the care package and one of the difficulties is finding staff frankly, you know, which is just hard. So you know that’s not the same is it as people ??? who are completely under-housed with very difficult siblings and sons very often. You know because if you’ve got quite severe autism in your family it does tend to go down doesn’t it, it does tend to ???

Q Yeah.

A So you’ve got that problem. There’s autism for sure in your family, and you don’t as a woman massively necessarily, you just about manage. But your brother’s severely autistic, dad was hopeless and now your son is, you know.

Q Yeah.

A And actually you’re not coping that well. So I can sort of see.

Q Yeah. It’s different though isn’t it, and it’s all relative. You have a different relationship with your brother than many other people have with their siblings, and you know.

A Yeah. And it’s not as close as it could be, but it’s far closer than many. You know sometimes I can’t….it’s too late now because mum’s sort of past being able to talk about it, but I do wonder if he had been born obviously severely disabled or with Down’s Syndrome, whether we would have seen much of him at all. But he was already so much part of our family before any diagnosis happened.

Q OK.

A But I might be wrong, and I don’t mean to belittle my family because I think other middle class families didn’t bring home children with Down’s Syndrome, and he doesn’t have that.

Q Yeah, it was the time.

A Yeah.

Q Very much the time.

A Watch Call the Midwife to find that out don’t you?

Q I do like Call the Midwife.

A It’s about women. But yeah I mean obviously, but….

Q And it sounds very…just going back to thinking about women and thinking about your partner, it sounds like her career has actually been very helpful in terms of giving you massive support, her career it sounds like has been very helpful at some point.

A Massively. She’s always producing ideas for what we could do with [brother]. And then we look at the care staff and we have to manage that with all of them. They all work separately. And I know that [partner]’s biggest piece of work ever at work was dealing with 5 classroom assistants and getting them all doing what she wanted. It wasn’t the ??? kids, it was the other adults. So whatever bright ideas we bring up for [brother], you know managing it. I can get myself pretty irate over….you know [brother] put on quite a lot of weight in the last couple of years, his main carers are severely overweight if not obese, you know. And it was not until we were told his cholesterol was too high that I thought ‘well I can step in now, he’s not going on statins, that’s ridiculous, this is ridiculous he’s just got to lose some weight’. But you know I give a very, very, very clear dietary guidelines that it is a piece of fish or chicken with a small amount of carbohydrate and a great deal of vegetables, and back I come ‘we’ve had lasagna for dinner with garlic bread’, they’re just not getting it. They’re not getting ??? But I mustn’t criticize because that’s the cooking. ‘Oh he likes lasagna, and I did make it only half with milk and half with water’. It’s like ‘no that’s not what I’m talking about’, no wheat, no dairy in the evening. But do you see what I mean?

Q Yeah, it’s really tricky. It’s their different lifestyle isn’t it and their reputation there. Yeah.

A They’re working really hard, they’re working really hard – too hard.

Q Yeah but replicating their lifestyle or what’s normal or OK for them I guess when it comes to health and things like that, when actually….

A Yeah, yeah. I’d look skin and bones if I lost any more weight to a woman who weighs 16 stone, I’m thinking ??? They all say ‘not overweight’, yes he is.

Q Tricky, it’s a tricky one.

A Well it’s just a silly little example but, you know. So managing as gently as possible. I mean as you can probably tell I’m a kind of fairly blunt sort of a person, I don’t have very good soft skills, I sort of know that about myself. So you know managing someone who is spending four and a half days living in [brother]’s house with 4 hours off a day to go and do something else, and dealing with his moods and his intimate care and feeding him and keeping the house clean and tidy…you know.

Time 55:10

Q Yeah, and it’s difficult because I guess you don’t want to upset them do you, and you don’t want to….

A And they do actually ??? they know him better than I know him. Perhaps they do because I’m not there all the time. Get people to write down for the clinical psychologist, I must get them to write down exactly what he said and what he did, and what had happened before, you know the A, B, C ???

Q Yeah the antecedents and…yeah.

A Yeah. And that’s interesting because I didn’t know he was called them fucking bitches all the time until then, nobody actually said that. ??? I mean I’m the employer of sole female workers – argh!

Q Yeah.

A You know it’s funny and it isn’t. I don’t know.

Q And again it’s something which, you know you never intended to be. But I guess you did because you took on the Direct Payments, but you know you never intended to be an employer.

A No, no I didn’t. No I didn’t expect it to be like this post-COVID. And he didn’t catch COVID but post-COVID I think he thought his mum was going to die ??? He thought his mum was going to die, he wasn’t allowed to hug her for however many months, you know it was all face masks, he hated it. Two key people in his team left and all his activities closed down. You try getting hydro, most of the hydro pools have closed. So it’s just really hard. And we ??? I’m not sure ??? So why did I take part in the project? Well basically because you guys prompted me and I thought oh well you must need to talk to someone different. Do you know what I mean? So I hope it hasn’t wasted your time.

Q Oh my gosh not at all, no.

A ??? most of them are supportive in this you know.

Q Yeah. No it’s been really, really fascinating talking to you. No honestly, you laugh, it has been. Everyone’s experiences are so different, but there are and there still are feelings of guilt or feelings of that responsibility and stuff, there is still stuff there. And it’s interesting knowing about what does make it easier. So having that contact, having a partner who understands the system or has been a special needs teacher for 20 odd years, however long she was, you know. And it’s things like that and about kind of….

A When I was negotiating, you won’t believe this, when I was negotiating getting [brother] out of the care home and into his own home, our sons both played in a youth orchestra and a few of the parents came round for a drink afterwards. And one guy said ‘I’m really hungry, have you got anything to eat mum’, I found him the sausage rolls and we sat down and nattered. And I discovered that he was a special advisor to Cameron on disability.

Q Oh wow.

A He sat on…they weren’t Zoom they were just on hearing meetings with social workers, he sat in on them to make sure that we got what we were entitled to.

Q Wow.

A ??? [brother]. [brother] loved him because he was smart and….

Q What a fantastic connection to have then.

A Yeah. And it was just like he was the parent of one of my son’s friends. And he visited [brother] and then he was able to say to all the social workers, you know as a special advisor on disability in the Cabinet Office or whatever it was, that he’d met [brother] and this is what [brother] wanted and he didn’t quite know why they didn’t think it was.

Q Wow,

A You know.

Q Yeah.

A I didn’t know about that, that was just one of those fortunate things. But it does smooth your path if you….

Q Yeah. And it’s interesting, in other research I’ve done and speaking to family members and what’s always helped are those kind of random connections which get made that people can draw on. Whether it’s having a friend of a friend who is a lawyer or knows about Human Rights and things like this.

A Of course it is, of course it is. It’s that sort of thing which you’re more likely to have if you move in better educated….I don’t think the money is quite to do with it so much as highly middle class, you know, clearly middle class background.

Q And a sign of where the system is failing, if it comes to just relying on those random fortunate encounters. ???

A Well [brother] hasn’t got any more than he’s entitled to, I’m certain of that.

Q Yeah but he’s got what he’s entitled to because of….

A Yeah. And they won’t cut his money easily because….

Q Yeah, not without a fight.

A Yeah because we know what to say. And when they want to cut it by 20% I’ll be saying ‘and what 20% of the time would you like me to leave [brother] on his own’. Do you know what I mean? And maybe those are simplistic things but… And anyway if push comes to shove we’ll pay it ourselves. We haven’t got enough if he lives to the same age as mum but, you know my kids aren’t bad about that. My kids aren’t bad about that too you know, it was [brother]’s dad’s money, [brother] can have it, you know.

Time 1:00:20

Q Yeah you’ve got that security blanket I guess, which you hopefully don’t need to use but you have got it there.

A We’ve got it, and secure housing. And all those things that so many people haven’t got. Personally I think secure housing is the biggest need of anybody. I think people can’t address people’s mental health problems until you’ve given them secure housing.

Q Yeah.

A And I’m really pleased, you know not big like on the Party but I’m really pleased that Starmer is talking about housing as the number one. Sorry. I’m not sure how much I’ve got to help you out.

Q No just a couple of questions. Does it make it easier knowing that say he does have that secure housing I guess and that you have ultimately got money. Does that make it easier thinking about the future does it for him?

A Absolutely and categorically yes. Yes it does. I own his home and so he can live there for ever. And in my Will I’ll leave it to my sister you know so that he can live there. And if we lost all our carers we would have to find….I think the money we get we would be about 30-40% down on what it would cost to use non-stop agency care, and I could finance that for a number of years today. My biggest concern actually is that my sister and I die before him. That’s my biggest concern. Because there’s nothing to suggest that he won’t have longevity, nothing at all in his conditions.

Q Do you talk about that with your sister or put anything in place?

A Not yet because she’s still terribly, terribly concerned about mum dying. Because her primary life relationship is with our mother. Obviously mine is with my partner and our four children and then with [brother], they are all more important to me than my mum frankly, who is 93. And no I have to have the bullet of having some bigger conversations with my sister, but it’s not easy. When I once said to her I’d rather go to Dignitas than expect my kids to look after me, she said ‘I’ll look after you’. I’m thinking no you won’t. No I’ll go to Dignitas

Q Yeah my mum’s made it very clear she wants to go to Dignitas, so.

A Excellent. You know I really think that certainly….you know I might be your mum’s generation you know that our generation will be looking at how our parents live to nearly 100 and drain the health service for no good reason and didn’t contribute any more. And think actually when I can’t contribute I don’t want to be there.

Q Yeah, it’s exactly that. Looking at mum’s quality of life and stuff before she passed away and….yeah.

A Yeah. So I don’t think longevity is quite what it’s cracked up to be.

Q Yeah. But if your sister’s an Evangelical Christian that’s a tough conversation to be having.

[Section deleted as requested in the interview]

Q No it’s fine. And it will…

A But I did hear of the difficulty of non-stop treatment. And yeah. So I suppose that would be a long term issue in which my sister and I may disagree actually as to what level of treatment possibly [brother] should or shouldn’t have. Although I think the health service makes it for you because I don’t think people with learning disabilities get much treatment too.

Time 1:05:06

Q And I guess COVID kind of….I mean it was challenging for everyone but additional challenges when you have got someone who is kind of more vulnerable and depending on carers, and having to have those conversations about [brother] and for [brother], yeah really difficult.

A Yes I think my sister had a grumpy week of it when somebody went off with a cold thinking it might be COVID and had to wait til they got ??? before they could come back. [brother] told her he didn’t want her there.

Q Yeah. Fantastic. Thank you so much.

A Well it’s been a great pleasure talking to you. Not many people understand, not many people let me talk as much as this.

Q No I’ve really enjoyed it, thank you.

A If there’s anything that needs clarifying send me an email ???

Q And if you do on reflection think of anything else that we might not have covered which you think is important or anything, please do get in touch as well. We will follow up with the transcript, you know if you want to look at it you can, if you don’t you don’t think you need to do that that’s absolutely fine. And also information about the digital storytelling workshops if you did want to think about it.

A I think that wouldn’t quite be something I’d feel terribly comfortable or useful in, sorry.

Q No that’s absolutely fine, I can pass that on if you like.

A Yeah I think you don’t need any more of my stories.

Q No that’s absolutely fine. If you want to we’re welcome to everyone taking part.

A No it’s ??? nice, I’d never seen before about click that thing to hear my name. So where does your surname come from?

Q My dad is Swedish, so Sweden, yeah.

A Yeah, yeah so it’s just a different….I would have pronounced it completely differently. I’ve never seen that ???

Q Yeah exactly. It’s really interesting, because I’ve got two kids, one a 5 year old, he’s just started school and I’m really curious because his speech is quite unclear and he can’t say his surname, which is double-barrelled, ??? and I’m really curious as to how his teachers pronounce it – because he can’t pronounce it himself. And so I’m really interested. Because it just doesn’t come up, it’s a tiny school so you don’t need to say your surname at all and I’m really curious what he is getting called at school.

A Yeah, yeah. Well I used to be a teacher and I can tell you the registers when you were a supply teacher was always a terribly interesting thing.

Q But yeah my dad’s Swedish so that’s where it comes from. But yeah thank you so much, it’s been lovely.

A It’s been a lovely way to spend the afternoon, thank you very much. What an amazing job you have.

Q Oh do you know I really love it, and it does feel a real privilege being able to just talk to people about their experiences. And people are just so honest and it’s lovely.

A Are you doing a PhD at the moment?

Q I did a PhD yeah, I finished it a couple of years ago. So I work as a researcher.

A Oh was it quite awful?

Q Pardon.

A To do that much studying.

Q Well yeah. Luckily I kind of enjoyed it. Well I did at the start, towards the end. But I love just being able to talk to people and hear people’s experiences.

A You did it with a baby?

Q Yeah, yeah, that was tough. But we got there. We got through the….

A Of course you’ve got the Swedish jumper on haven’t you?

Q Yeah! It’s a real privilege just being able to listen to people’s stories and people just share and being so generous with their time sharing.

A ??? pouring with rain yet again as it always does in [county]. Is it for you?

Q Yeah, yeah.

A ??? oh hasn’t it been awful.

Q Yeah. Oh I’m just so fed up, yeah just so fed up of the rain. Anyway.

A So I just press my screen to find out how to leave, because I think we….you know are we done?

Q Yes we are, thank you so much, been lovely to speak to you.

A Oh no I’ve had a great time. Thank you for listening. OK, nice to meet you.

Q Bye.