[removed for anonymity]

And then somebody again was asking me this morning about what we are going to do with it. So because there isn’t very much information out there about the mental health of carers of adults with learning disabilities, at the beginning we weren’t really sure about who, apart from family carers themselves and the general public, we weren’t really sure about who we needed to tell because we didn’t know who they wanted support the more? who? was ??? But that started to emerge a little bit, but maybe I’ll leave that til you tell me your story and I can tell you who other people say are offering support or not. So that’s how it came about really.

A No I think it’s a really interesting angle on it all. And I am quite surprised that there wasn’t research around because learning disability in its general sense, it’s quite a powerful kind of lobby isn’t it really.

Q Yeah, yeah but it’s usually focused on children though. There’s quite a lot on primarily the parent carers as well, and we were really keen for it not just to be parent carers. So there is quite a lot around that but the whole focus of concern was really around people caring for people with dementia and people in co-caring, older people co-caring situations, which of course includes people with learning disabilities but they were not referenced.

Time 4:40

A Mmm. And you’re quite right, my sister is 70 I think I said in one of the emails and, you know that’s still quite a thing isn’t it really. You know in my lifetime people with learning disability that we knew when [sister’s name] was growing up that to get past 30 would be, you know quite a thing really. And now of course we are seeing people with learning disabilities developing dementia and developing dementia early, so all of a sudden it gets really complicated doesn’t it?

Q Yeah. But you know I think we think that….it’s a tricky one isn’t it because people with learning disabilities are people, we want them to be included in research as people but equally not to be forgotten about. You know sometimes I do think we need to think about people as a group and we need to focus on what’s going on in their lives, understanding that they are not just people with learning disabilities they are brothers and sisters and, you know they have other aspects of their identity. But we do need to focus on that I think.

A You have to hook around something. You know you have to kind of focus it on something don’t you. And people with learning disabilities are such a wide group aren’t they you know in terms of all sorts, everything, in terms of everything really, but you have to angle it around everything. And just going back to the point really was that I think it would be….my position is that I think it would be a real shame if people with learning disabilities and dementia were treated….were addressed, not ‘treated’, treated is the wrong word but addressed in the same way as older people with dementia, because everything about it is different except the condition. But you know the way that you manage people, the way that you would manage an older person with dementia and the kind of techniques that you would use I think are different, or need to be modified substantially for people with learning disability for example, or maybe health issues or whatever. But you know I think it would be a shame if it was all kind of put together under one umbrella. I mean a bit like the learning disability point that you’ve just made really, they’re all people and all different and there will be similarities, so it’s not a throw the baby out with the bath water but I think to look at people with learning disability and dementia I think is quite a…..and I’ll say a bit more about that if you like a bit later but it’s something that I’ve been interested in for a number of years really.

Q Do you want to tell me a little bit about your…well I guess why you wanted to take part in the study – I guess you’ve kind of said that, but what your experiences as a carer have been over the last 7 ???

A Yeah. So I think it’s important to take part in….if there’s an opportunity I’ll always do it, I think it’s right. I think you learn stuff as you go through these things yourself, you learn something about yourself and other things, you just pick things up. But it’s also I think quite validating to talk about it. You know it’s not a secret and I will talk to people about it but you know when I go out with friends they’ll always ask about [sister’s name] and, you know you’ll say. But you don’t want to kind of….well I don’t want to spend a lot of time talking about her – hope that doesn’t sound bad – but when I’m out with friends I want to do what I’m doing, you know it’s that kind of delicate balance. So there’s that aspect, the ability to talk about it. But as I say I think it is quite validating really because you know in life, I mean I’m sure you’ll understand this I guess, you are never quite sure if you’re doing the right thing are you really, you know you do your best and you’re never quite….you know I can certainly do better, you know if I really thought about it, but there are limitations to it. Anyway, so they are the kind of….that’s my context if you like.

Q Yeah.

A And my experience of providing care. Well we’ve always lived together. So I have two sisters, [sister 2’s name] who lives not very far away who is married and is really involved with us, I mean is as involved as she could be and will do anything and everything that she’s asked or not asked, you know she’s very actively involved. In fact it’s just about 10 years ago our mother died, so my mother, [sister’s name] and I lived together all our lives so you can argue that I’ve never left home really, but it didn’t quite feel like that. And so, and I think about this from time to time, not quite a lot but you know I wonder when I knew that I would be a carer really, and I guess probably from quite early on that I realised that…we didn’t have that term but you know I think I knew what was ahead of me really. And there were various stages in my life where I made conscious decisions that, you know I would either do one thing or the other and, you know and I chose this. These are not the best words but you know what I mean, I went down this route.

Time 10:40

And because of [sister’s name]’s level of disability, you know she would be described I suppose as moderately disabled, she’s always fallen pretty much from schooling really, always fallen outside of services. So we’ve never had anything of any substance really to support us. Yeah. And because she can do….yeah so she can do quite a lot for herself, you know she’s got a mind of her own and so on and so forth, you know we kind of….it sounds difficult really but we’ve kind of got through. We got through you know, you’ve got no choice really. She worked, she had a job, because she was born in 1953 you know and when she left school in the 60s you know….I mean (a) when she was born there was nothing really, I mean health visitor I think visited my mum for whatever length of time, but she went to a junior special school which was probably the better school for her. When she got to the time to leave she went to an inappropriate school because there was nothing else for her. Never learnt another thing really, you know. So there’s been no support, no services really that we’ve properly accessed, you know had opportunity to access.

Q Yeah. So she went to school, when did she leave school, how old was she?

A She left school when she was 16, when she was 16/17. And then she went to….my mum was working at that stage – well my mum worked at that stage and my mum found her…do you know [company], they were mail order, they’re now online shopping, and they were in [city], they weren’t very far from where we lived at the time. And my mum worked for them and she got her a job there basically. So first of all she got a job as a, it was like a messenger, and she’s walk round. And you know some of these jobs really worked for her because you know she’s quite sociable and quite task orientated, you know give her a job and she’ll do it properly as best she can. And then she went on to what they called a filing clerk, which was a bit more of a struggle because she doesn’t read or write terribly well, but it was matching numbers basically, you know if you pin it down to what it is it was matching numbers, so she could kind of do that. But she had all sorts of experience. She met some really nice people when she was employed at [company], but she also met with bullying and lack of understanding. And [sister] does stand out, you know there’s no question about it, she doesn’t particularly blend in. So yes, what was the question? Oh when she left school. So yes, so my mum got her a job and then all the time….

Q ??? in that job for, how long was she in employment for?

A I’m sorry, say that again.

Q How long did she work for?

A How long did she work for? She retired 5 years ago, 6 years ago.

Q Oh wow, so she worked the whole time.

A Yeah. [company] closed their [city] offices and moved to [smaller city] or somewhere and she was made redundant, which was horrible because she didn’t understand that. I mean she could have gone to [smaller city] but, you know that was never going to happen. And it was devastating for her because she felt quite rejected and didn’t really understand, all her friends….anyway you can imagine. So we did what we could, we got in touch with the local [borough] [charity] and the [charity], anyway a couple of organisations, and she did get one or two interviews, you know in a group of 200 applicants she was shortlisted. But travel and those kind of things, it was all too….she would never have got to these places, as much as you’d like to think that she could. Travelling is a bit of an issue because she doesn’t read very well so we’ve had all sorts of experiences over the years where we’ve encouraged her to travel independently, but if the bus diverts and she goes down a different road we’re completely stuffed, you know. I mean now we’d have a mobile phone and so on but in those days there was nothing and she’d panic, get off the bus, and then she’d just be wandering round the streets of [city] hoping somebody would find her. Anyway we’ve had all sorts of experiences with that. So travel was an issue. And there was no travel training, and even if there had been you know we can teach her routes but it’s when anything different happens that she couldn’t respond and actually panics, you know she completely panics.

Time 16:00

So she was made redundant, I don’t know, the early 90s, 94 maybe, I can’t remember, that sort of time. And we kind of went round in circles really not getting very far and you know she was getting a bit fed up and it was no good for her sitting at home really. I think our mum had retired by that stage. So we took the bull by the horns really and my other sister had moved, we’re in [town] – well not far from [town] – and our other sister had moved to [town] a year or two before and we just up sticks and moved here, which was a very good move. And we live opposite a huge great [supermarket]s, huge, one of these big superstores.

[removed for anonymity]

A Isn’t it, yeah. So she worked….so we moved here in 97 and she left, what did I say 5 or 6, 6 years ago she said yesterday, 6 years ago. She hated that job I have to say. Hated it. But you know again one or two people were really lovely to her and some of the customers were really nice to her, but some of the customers, you know you work in retail, you know she’s not quick enough and not everybody’s very nice, and not every manager got her, you know understood her and so on and so forth, so she really didn’t like it. But she’s very determined, you know she is determined but sometimes it would be a real struggle to get her there, she’d be crying before she went and, you know you didn’t….you know. And she had to, you know I mean it’s terrible, you know on one hand you can say ‘well resign’ but you know that’s probably….

Q What would she do?

A Exactly, exactly. And you know all the jobs that I’ve had I’ve really liked and I’m sure you have too but not every day is nice is it, not every day you go in with a spring in your step and not everything works out. And you know there’s a reality in life really. So we kind of…and we’re a family with a work ethic so work is quite important to us all, so whether it was the right thing to do, but that was the line we took with her. And she does rely on us to help her make decisions really, you know she can make them, she does speak her own mind but…. So anyway that was her kind of story.

Q And what were you doing all this while? Because you said you never left home. Did you never leave home, were you just….no?

A No.

Q So you left school and got a job too?

A Yes, yes. So I left school at 16, worked for [company] for a couple of years, wasn’t really my ideal job. And then we moved house at that point, 1970. And it felt like a very long way from, you know an extra couple of miles in those days and so I applied for a job in the local authority in what was Welfare Department, Social Care. And so I ended up working for Social Care all my life really, and fell on my feet really, you know loved it. I mean horrible days, bad days you know, but as an idea. And I’m still working, I still work a few hours here and there. So yeah. So I ended up with a career, it wasn’t quite the plan but I ended up with a career. When I left – I took early retirement but continued to work after that – but I was a manager, I was a third tier manager by the time I left so I kind of, you know. But my sister is also in soc….you know is a qualified social worker, you know it’s not surprising is it really, you know we’re kind of in this kind of world really, we kind of understand it. It’s a sort of natural home if you like I suppose. So yeah, so I have worked really hard and enjoyed it really.

Time 20:54

Q But you sort of hinted that there were moments when you could have made a different decision and maybe left home?

A Yes that’s right, yes. So…how best to put it really. So yes at one point a relationship ended and that was a fairly pivotal point, you know I was in my mid 30s and I kind of sat myself down really and I thought ‘there’s one or two directions here’. And I knew – this might sound dramatic doesn’t it – but I knew my destiny, I knew what was going to have to happen and I thought well I’m just going to concentrate on this thing. And it sounds quite grand, and I don’t want it to sound like that because there were benefits and bonuses for me by staying at home, you know I had a ready made family and I did buy the house and so on. But if I’d have moved out I would have had nothing, you know I’d probably have had no social life because I wouldn’t have had money and I’d have still had to provide emotional and financial support I guess to the family. So it kind of made…it was sort of pragmatic really. So yeah I kind of felt that it was the right thing to do. And looking back on it, it was quite an interesting step. I don’t think I would have changed it, I don’t think I would have done anything different, but it was quite….you know sort of 30 something or other it was quite a major decision really.

Q Yeah a really big decision, yeah.

A But I think it had to be really, yeah I think it had to be. You know if I had met someone or got married or whatever, whatever, well then that would have been different. But you know people talk about crossroads don’t they in their life, there was a crossroads and I just had to….you know I felt like I couldn’t tread water really, I had to make a decision, I had to kind of….I wasn’t happy just kind of thinking ‘I don’t know what’s going to happen next’, I thought ‘I’m going to be the architect of my destiny’ really, you know I’m going to make this plan and I’m going to go forward. And it kind of worked out really, you know I mean I’m not….

Q Did your mum encourage you, or how did she feel about your plan?

A She was relieved I think. My mum wasn’t really a coper. And she’d had a tough old time really, her mother died when she was quite young so she hadn’t got really that kind of support behind her. We had no grandparents actually, so there was no other support in the family, there was uncles and aunts but they weren’t really….they didn’t quite understand. You know we are talking about the 50s here, you know there wasn’t quite that understanding. And they were kind, I don’t mean anything different to that but you know there wasn’t…I don’t think anybody said ‘come on [sister’s name] we’ll take you for a month on holiday’ you know I don’t think there was that kind of stuff. So my mum wasn’t a coper, and our dad died when our mum was 49, so very young really. So I was in my early 20s, [sister’s name] was 20, [sister 2’s name] was 14 or something so you know there was quite a big….and that was the other background to all of this really, you know I was the oldest daughter, I am the eldest daughter so you know the oldest kind of takes the lead often. So it was a decision but it wasn’t, do you know what I mean, it was just a set of circumstances all came together really.

Time 24:52

So I think my mum was relieved, she was always a bit….can’t think what the word is….anxious, I don’t want to say that word really, but you know she wasn’t all that thrilled if I had relationships but, you know because I think she wondered what was going to happen really, you know wondered who was going to do what and…. And I mean she was a good mum, it wasn’t that she didn’t look after us and feed us and dress us, you know she did all the right things, you know with the basis of nothing really. You know she had no-one in her life that taught her how to cook or taught her how to sew or taught her how to care for small children, you know just kind of managed really, you know she just came to it. And of course back to the time our dad wasn’t….he was a good dad but you know he wasn’t involved with childcare, that wasn’t what dad’s did. He would do what he had to do but….you know. He worked really hard, worked shift work, was often not here, not at home and so on but only because he was working really hard.

And my mum kind of took the burden of it all but it didn’t wear with her very well, you know she was very worried about it all really and, you know. And the parents, you know your mums and dads worried about letting all their children go, but particularly people like [sister’s name], you know worried about her. So [sister] was very contained by my mum, you know my mum controlled her in some ways, was very resistant to her taking chances really. And I mean you know you can argue it both ways can’t you, but she was well protected, she was well protected. So yeah. So I think my mum also benefitted from me being at home, you know I was earning good money and we could live fairly comfortably and there weren’t money issues. My mum, when she retired she would have been on a state pension and whatever benefits, so we didn’t have to worry about any of those things. So it all kind of worked for everybody really, everybody got something out of it really.

Q You said that your sister was never entitled to formal support. Did you have any support external to family then?

A No, and don’t now. I mean we’ve had… because [sister 2’s name] and I know the routine so we’ve had occupational therapy assessments for aids and stuff, and her physical abilities are declining so we’ve had the full service in. So we’ve had those one-off things but we’ve never had, even in the days when you had social workers allocated, we’ve never had a social worker, we’ve never had any kind of formal support. You know there were no services offered. I mean looking back she probably could have gone to a day centre, I think it wouldn’t have been in her best interest – and I used to run day centres by the way – I don’t think it would have been in her best interest, it wouldn’t have brought out the best in her. And she doesn’t really associate herself with disabled people in some ways. She went to a number of gateway clubs and clubs that again we found for her and connected her to, but she always called herself a helper. So she sort of saw herself as a bit different from other people. But she was very popular, she’s very kind, you know she gets on well with people and people related to her very well. But no I can’t think of any.

Q What about the GP, is she on the GP learning disability register?

A Yes. Well I could talk about GPs quite a lot really. I’m not a great fan if I’m absolutely honest at all, I think there’s a lot to be changed in GP services and primary care generally. But I think the Health Service really don’t do very well by people with learning disabilities. And I’m on one of the local carers groups here so I suppose that’s a form of support, but it’s only something that I engaged with, you know it was something that I found and engaged with. And that’s been hugely important because I found out all sorts of things that I didn’t know before. And they’re all mums and dads, going back to the original point really, but they’re all very satisfied, there’s a great level of satisfaction about the GP services for their adult children – and it’s not my experience at all, I don’t find GP services at all supportive of [sister’s name].

I mean they’re not unpleasant, don’t get me wrong and they’ll see her, but she’s treated just like everybody else. And I know that’s an ambition but in this context it’s not, you know she needs more time. They don’t prioritise her. They don’t…you know a range of them when they connect with her they talk to her in ways that you think ‘this is….’ you know you are getting paid for this, you’re being paid as a GP to work with people with learning disabilities, have you not got any other language apart from this.

Q Yeah.

Time 30:52

A And this is an old story now, he’s gone, but I’ll tell you it just as an example. We went for her annual review this particular time and there was a whole range of stuff about this. And this man, a male GP said to her ‘do you check your boobs’ and so she went ‘no, no’. So he said ‘well this is….’ and he doesn’t look at her, he’s typing all the time, he’s not looking at her he’s typing all the time. So he said ‘so [sister’s name], what you have to do [sister’s name] is you have to think of your boob in quartile, so you do this quartile first and this quartile….’ So I kind of put my two-penneth in so I said ‘so think of it as a clock [sister’s name]’. So he looked at me as though I was….he did look at me as though I was completely bonkers. And he still went back to his quartiles. I thought ‘are you kidding, are you kidding, have you not take a clue here?’ And that’s the kind of worst example.

But they keep us waiting, and we’re all kept waiting but she gets agitated, you know she gets worried about being late for something, she does ‘look, look, look, it’s…’ and we always get there early so we are even waiting longer. And then this particular GP we see all the time, and she’s very nice, it’s not that people are not nice it’s just they don’t kind of get it. So she said ‘oh your blood pressure is a bit high [sister’s name]’, I said ‘she’s worried’. She said ‘oh you don’t have to worry about that [sister’s name], we’re not like that here’. And I thought that has no ??? she’s anxious, she’s worried you know. Surely they can work out you know (a) that they’ll need extra time to talk to her, and (b) if she’s on the list, bring her forward. You know others are waiting anyway. So you know I’m kind of mightily unim…. And the other thing that they do is, and I experienced this myself – I’ll talk about myself in a second – am I talking too much? I’m not talking too much am I?

Q No ??? to listen. Sorry.

A I’m on a roll, I’m on a roll.

Q Yeah go for it, it’s great, go for it.

A What was I going to say? Oh yes. So they say ‘[sister’s name] come and see us’, I mean I’m a bit more pedantic about telephone consultations now because I’d rather sit here at home waiting you know, doing other things than sitting in a GP surgery. So they say ‘right [sister’s name] we need to see you for your annual review, your diabetic review’, you need to come in – IO don’t know whatever test it was, oh a urine test. So it’s like ‘how are we going to do this’? So they said ‘well bring it in any bottle’, so…really? Anyway, so we took it into the nurse and the nurse was dismissive, threw it on the window sill, you know looked disgusted that we’d got this bottle of urine. And then she said ‘oh we need another blood test’, that’s right we’d had a blood test before we’d been to the GP. So ‘is there anything else we need’, ‘no just the blood test and you’ll bring us some urine’ that was it, that was it, that was the story. So when we got there she said ‘we need another blood test’. I said ‘you did a blood test’. ‘Ah no we didn’t test for this’. So I said well…..

Q Yes.

A Now it happens to all of us, you know I think GP practices I think generally. But think about this, you know, it’s not that she’s resistant to go because she’ll do what’s required of her but it’s anxiety making. And I’ve got to take time off work, you know it’s not all about me but you know there’s no thinking this thing through really. So I’m very unimpressed really with…. And as I say, in general people are quite nice, it’s not that people are not nice, but that’s the minimum you should expect isn’t it really, it’s not….

Time 35:16

Q Nice doesn’t mean competent does it? No.

A And not thinking through what they’ve got in front of them, you know not thinking through what the issues are and what the issues might be. It’s extraordinary really, extraordinary.

Q Tell me a bit about you and that you said you and the GP, so…

A Yeah. So I generally have good health, I’ve always said I’m fit and….you know I’m healthy but not particularly fit. Oh this is too long a story, I won’t bother with it. I’ve got cataracts and I’ve been trying to have these cataracts done for a number of years actually. [sister]’s had her cataracts done – and that’s another story but… So I got cataracts and in the recent attempt to have it done one appointment was cancelled on the morning, so I was all ready to go and it was cancelled; and then the second one I went and my blood pressure was through the roof – I mean through the roof, 200 and something over….you know I mean through the roof. And I had a similar experience a few years before. And I’ve been on 3 24 hour monitors and it’s alright. So I keep saying ‘I think I’ve got white coat syndrome’, I think. But they can’t quite accept it really. I think GPs are hell bent on treating the condition rather than looking at the big whole. They know that I’m a carer, they don’t think that that might…you know. So the last 12 months I think I’ve been through 3 lots, 4 lots of blood pressure medication, I’ve been on monitors, I’ve recorded my blood pressure. And I get on a blood pressure machine and my blood pressure goes up, you know because I’m now worried about my blood pressure, I’m worried about the reading.

Q Yeah, yeah I’ve had the same thing. I’ve had exactly the same thing, yeah.

A And I’m animated now but actually I’m a calm person, you know I am animated that doesn’t make me calm, but in a crisis, in a decision making, you know I’ve been used to making lots of decisions about people and things and organizing things. And so I am pragmatic, I mean I’m now nervous about the cataract operation, which I never was before, but I was no more nervous about…I was probably more nervous about going to the dentist than I was about having these cataracts done. But now it’s become this huge, huge thing in my life really. And my eyesight is deteriorating, really, really deteriorating, I’m no longer….I’ll drive to the supermarket, I’ll drive to the dentist, but I mean I won’t drive more than a mile or two because I don’t think it’s right. So it’s completely impacting on my life. And they know that [sister]’s in my life because we both had our cataract procedures scheduled on the same day, we organized it so that [sister 2’s name] could take us and you know she could look after us. So they knew, they know, but they don’t think either, they don’t….

Q No, no.

A Awful, awful. So whether I’ve got high blood pressure or not is anybody’s guess really, but when it’s monitored it is.

Q It’s fine.

A It’s fine. And then when I’ve had these cataracts done I’m stopping it all, I’m not taking any more ??? But you know I’ve been through 4 lots of medication, and 3 of them have really had horrible side effects really. But the last one, I had palpitations, you know I mean…oh for crying out loud. The time before I thought I was becoming doubly incontinent because….and I think oh for crying out loud this is the last thing. And I keep these things from [sister’s name], you know I keep them from her for obvious reasons. So you know so I have to organize these things in a way that she doesn’t latch on it because she would be really worried. You know I sometimes say ‘I’m going for a blood test’ and she’s really worried about it ‘what’s that about, what’s going on, are you alright, are you alright’ you know. So it’s all….anyway, that’s sort of me really in terms of my health. But I think I’m healthy enough really, I just think this….and if I….

Time 40:33

Q What would you say about mental health in particular, because our focus is on mental health.

A Yes, and I think it’s quite interesting. I think in general terms I think I’m very upbeat, the cataract thing is getting on my nerves frankly. And there’s something else, we had two deaths in the family and I’m Executor and I can’t get….you know now it’s over 2 years and we can’t get Probate, you know it’s just getting caught up. So that and the cataracts is making me feel a bit....if I think about it it makes me fed up. But in general terms, you know mentally, amazingly really I think my mental health is good and I don’t quite know why because….yes I don’t quite know why. I think for some people it would be quite debilitating and so on, but I do try and rise above these things and I am upbeat and I do….you know my way of tackling all, you know in work and anything really my way of tackling things is to not quite get ahead of it but to try and embrace these things. I try not to let these things bring me down.

And it’s not every day, I mean some days I think ‘oh for goodness sake’ you know when she’s having a wobbly and so on and I don’t know what to do next and so on and so forth. But in general terms I cope…well ‘cope’s not the right word’ you know I consider myself to be quite well and you know I look for the positives in life. And there are lots of positives about living with her, you know she’s quite…she doesn’t mean to be but she’s quite funny and you know engaging, and she’s got a kindness about her, and so on and so on. So it’s not all bad. But I think surprisingly really, given the story, it could be quite negative.

But because I keep saying I’ve kind of known what was going to be, I made sure that really all the way through my adult life really, I made sure that I had plenty of things to do and had good experiences. I travelled a lot. I had, as I say, an interesting job, I had a good social life. But at that time that deal with myself was really ‘I don’t want to get to the end of my life and be miserable’ you know I don’t want to look back and think I’ve missed opportunities. You know we all do to a certain extent don’t we, but you know I missed those opportunities, I made sure that I had plenty of things to occupy me – and still do, that’s why I work now is because it gives me…it uses my brain, you know it makes me engage with things. So there we are.

Q Could you go on holiday? If you wanted to go on holiday?

A Not any more, no not any more. I travelled extensively up until about, I don’t know more than 10 years ago now and several times a year, was away all the time. That was a benefit of living at home, you know I could go really. But…and I don’t know what happened but all of a sudden I thought ‘I don’t want to be going to ??? any more, I don’t want to be sitting at Heathrow for 2 hours’. And that may be negative and I do miss it, I mean I did do some amazing things, did some very lovely things, but I kind of don’t want to in a way. Whether that’s because I think the idea of going and trying to plan to go is too much – I think there might be a bit of that. And I realised that recently, some friends of mine have asked me to go to France with them next year. And that’s a big step, you know it’s very sweet of them really, lovely of them, but I think ‘oh God, what are we going to do here, will [sister 2’s name] come across and stay’ but that might not be… you know I can’t quite….the organisation of it is sort of out of my head really. But I will do my best to go, I will do my best to go, but it will be a test.

Time 45:19

Q Yeah. If you could have any support that you wanted to have now, if you could wave a magic wand and put something in place, how would you like life to be if you could change things? Maybe you wouldn’t change anything?

A Well it is interesting because….this isn’t a direct answer to your question but I think this might be the answer. I was thinking about, you know we are both getting older and [sister’s name] is becoming frailer and her memory is not as good as it was so there’s always that kind of ‘what’s going to happen next’. And to all intents and purposes I’m fine you know but anything could happen, if the pressure’s a real thing I could have a stroke, you know everything could tumble down really, really quickly. And so I’m always trying to think ahead, we always try and think ahead really and I decided that probably what we’d have to do if one or both of us got past a certain stage of coping, that I think we’d have to have a live-in carer because I don’t think [sister] would cope terribly well in any kind of institution. She might cope in a shared life service but her abilities are on that cusp of not maybe working, you know it may not work, she may not qualify any more. I don’t think she’d cope even in a small group home, so then she would live in a house by herself or with one or two people – well she might as well stay here and pay for a live-in carer here.

And [sister’s name]’s got assets, [sister’s name] because she’s lived at home her money’s been well protected and she has got assets, so she could afford a live-in carer for the amount of time that it was possible for her to live here. So I think that would be the route really. And if I was unable to care for her then we would have a live-in carer together really, I think that would be the answer. Which is a bit extreme but I think that would probably be the thing that would work for us really.

Q It sounds to be like it makes sense and that you are very lucky that you’ve got the financial resources to make it happen, because it would be difficult to get social services to make it all happen for you I think.

A Yeah. They’ve offered me a little bit of respite, which we don’t need because [sister] pays for companions, so that’s where she’s out today….whoops, what have I don?

Q Are you still there?

A Oh yeah, I’ve lost….sorry what’s happened, I’ve lost the camera. Ah there we are, sorry, something happened. So once [sister] retired we found a number of people to come and take her out, do activities with her so that she wasn’t just sitting around in retirement. This is all about money. So yeah so she pays for somebody to come on a Thursday afternoon, she has somebody come on a Tuesday morning. Anyway. So we’ve always protected her money, you know she’s accrued money, you know she worked all her life and obviously she makes contribution to the house but it doesn’t really make a dent in her…she doesn’t take a private pension but she put money in so that she’s got money, yeah she’s got money behind her. Because we know at some point there’s going to be some kind of care option necessary and we wanted to feel that there was some control at our end, that it wasn’t just going to be local authority funded and decided really. So we are lucky, we are lucky. But it’s been hard work to get there, you know it’s not just dropped on her lap, you know she’s had to work from the time she was 16 or 17 until she was 62 or something, anyway, but she’s worked all her life for that so it’s reasonable really.

Time 50:00

Q So is there anything else that I should have asked you about that we haven’t talked about do you think?

A No I don’t think so. I suppose the only other aspect is…actually it might be relevant to the general point that is about friends really, my friends. And I think it’s been quite an interesting experience. I mean some of my friends, particularly friends have been friends for 50 years and it’s a sign of their own advancing years, but really once mum died and more of my focus was on [sister’s name] I was quite surprised that some people just walked away really after all that time. And it’s partly to do with our own age, you know they’re of this age too and a little bit older than me but I think they were….and it may have been to do with them seeing themselves, you know facing their own reality if you know what I mean. But I have been surprised about who has kept up relationships and who hasn’t. And that’s probably been the shock really if anything would have affected my mental health, and sometimes when I think about it I’m quite distressed about it really and think these are friends that I’ve been very good friends with, loyal, supported them through quite difficult times, and when the time came to give me a bit of whatever then they can’t face it really. And I don’t know whether I should criticize them or not but it’s a bit of a blow, it is a bit of a blow to….

Q I feel very intolerant towards people who don’t reciprocate ??? get out, ??? are not available ???

A Sorry this is going off on a tangent, but there was one particular set of friends and I was firstly friends with the wife and then I became very….you know the husband, you know they are proper friends. She was a little bit older than me and I think she was an older child and I think I was more regarded almost like a younger sister really. Very engaged, you know I can’t say enough, there all the time, you know they knew mum, they know Di and my mum. And they started a new business and Kay died within a year. And I was at home and everything was tickatiboo at home and I couldn’t have been more supportive. You know I don’t normally talk about myself in this way but I couldn’t have been more supportive, you know I was on hand all the time to get them through it. And I don’t mean that it’s like a, you know income and expenditure account, you know you don’t put in and expect to get something out, but I did. I never thought it wasn’t….

Q I don’t expect it to be like the same amount, if you know what I mean, but like vary. But I think I probably do do that, yeah.

A It wouldn’t be in the front of my mind, you know it would just be something that I would assume from them, you know would assume from them. And as I said I don’t particularly want to talk about my situation, it’s not like when we would meet up that I would just be spilling out what has been going on, I mean I would expect them to ask about [sister’s name] and I’d be cross if they didn’t but you know I wouldn’t talk endlessly about it. And at first I didn’t believe it, I just thought I’m misjudging it, you know I’m misjudging this. But no, no, no. This particular situation they just dropped me, just dropped me, just dropped me, which was….yeah not pleasant really, but….

Well so they didn’t quite drop me, there was a little bit of contact but no invitations to go out, no phone calls, nothing, even when they knew my mum was dying, not a follow-up, not anything you know just ‘anything we can do?’ you know, nothing. And at that point I thought ‘do you know what, this is too difficult for me to engage with, I’m just not going to…I’m going to stop sending Christmas cards, I’m not doing all the…’ there was no running really but I’m not doing it, I can’t hold your hand through my situation, you know, this is the time. All I wanted was a phone call you know, all I wanted was ‘come down…’ you know which I used to do ‘come down for dinner’ or ‘come down and spend the afternoon’ or whatever. But nothing. So it is quite…

Time 55:27

Q I don’t know if it helps to say, you know this isn’t only from me. So people have talked about this, and about family members as well. Cutting ties with family members because they’ve just not helped, or treated their member differently from, you know another grandchild, that kind of stuff. So it does happen.

A Yeah I completely get that. We are really a small family. So my dad was one of 6 and only 2 of them were married – we had 2 nuns in the family. And the other brother than had one son, and his son died in his 40s, so there’s no family on my father’s side at all. And then on my mother’s side, she had a brother and a sister. The sister had no children, the brother had one daughter, I think she’s got long term mental health problems, but we don’t have any….you know the minimal contact, you know Christmas cards and birthday cards but there’s no real contact with her. We supported her father and his second wife. He would come to us for support, so he wouldn’t go to her. But that’s our family. And another distant cousin that we were very close to died as I said 2 years age and his partner. So there’s no-one, there isn’t anybody. And that’s fine, you know that’s the nature of our family, but there isn’t anybody to… I mean there’s [sister 2’s name] my lovely sister, but it’s the three of us really and her husband, but there’s the three of us, we have to be kind of self-supporting really. You know there’s no option really, there’s no option. But yeah and it is very sad isn’t it really when families just kind of….they don’t know what to do do they, that’s what they do, they don’t know what to do.

Q No, no I think they just…. And I think for something, although that’s sad in one way, in another way there’s something so special about that connection between us. So I think that’s what you’re describing with your sisters that, you know.

A Somebody said we were like meerkats here. You know how meerkats, there’s always one that looks up and is checking, and the others are….

Q Yeah.

A And that’s how we were described at one point.

Q Well I think it’s quite difficult to describe it to people who don’t experience it, because it is a bit difficult to articulate isn’t it that there is something about us that I think is really different because of, you know what’s happened to us really.

A Yeah definitely. And my brother-in-law says we are quite impenetrable. You know you insult one you insult the three of us.

…

A You never know, you never quite know, you never quite know what’s going to happen really. And yeah that’s one of the pleasures really isn’t it, you know. And being part of a close knit family is….you know we’re lucky aren’t we really, you know some families are just so disparate. You know friends I’ve got you know, some of my friends are always falling out with them and I’m like I can’t imagine, you know I’ve never….somebody said ‘yeah I’ve not spoken to my brother for 30 years’ and I think….I can’t imagine. I can’t imagine falling out with either of my sisters. I don’t think we’ve ever, ever fallen out. If we’ve got differences of opinion then we’ll give way to the person that’s got the strongest thoughts really. You know if somebody wants to do something then we’ll just go along with that because they think it’s the right thing to do. I mean we’ll talk it through but you know we’ll give way to the person that’s got the most definite view. Does that make sort of sense?

Q Yes it does.

A If somebody says ‘I feel really strongly about this’ well then we’ll do that then, you know. We don’t even have to say that, we don’t even have to have that kind of debate about it all, you know we just kind of work something out together really. So yeah it’s a funny old business. But yeah I suppose that…anyway I don’t know whether that’s part of your research or not but that was the only other aspect that I was thinking about.

Q Absolutely. Because we are interested in who supports people. And I think…you know when I talked about at the beginning about the general public, they are, we need to communicate with the general public because I don’t understand why people do that. And maybe they don’t know that’s what they’re doing, I don’t know, but they do do it, you know you are not the only person telling us that ??? and the impact that it has, of course it has on people when that happens. That’s why there are these specific people, like the bloody GP you know, we need to tell them. And the whole social worker thing. So everybody is saying ‘I don’t have a social worker’ or ‘I do have a social worker but I never see them and they’re no use’. And I think we’d really like to take the research to social workers and say ‘can we have a conversation about what’s going on here’ because they must have….you know they must have a set of reasons. What’s going on for them that means they’re doing that? I think we really need that conversation.

A Yeah. I think what’s going on for social workers is that all their time now is being dealt with on emergencies and safeguarding. And I think the amount of old fashioned traditional kind of social work is a luxury. You know I think as soon as they’ve got a case load it will be full of emergencies and high priority and safeguarding investigations. That will be what they’re doing. And I think finding the next generation of social workers is getting increasingly hard actually because, you know who wants to be…. You know I’m a qualified social worker but I’ve always been in management, I’ve always run things rather than….you know I manage social work teams really well but my side is I’m a kind of provider, whereas [sister 2’s name] is a case worker, social worker. But who would want to just be in that fire fighting. And all you get is families just phoning up and moaning at you because you’re not funding care, and you know there’s no money and…

Q That’s what I’m going to be doing tomorrow morning by the way!

A Well it’s awful, it’s awful.

Q I mean from my point of view – my husband dies when I say this – but I say to them ‘under the Care Act 2014….’

A Yes.

…….

Time 1:05:00

A I mean that Care Act was remarkable in many senses wasn’t it because it recognised carers, you know it recognised the full life for people with disabilities or whatever. But there was nothing behind it, you know there’s….

Q Yeah. ‘Will you promise me’. I’m fixated on the promise. I want you to deliver on that promise. So I…

A Well you’ve only got to look at success of governments, they’ve avoided the funding discussion.

Q So I think I’d like to talk to them. I think people have talked about access to mental health services and them not feeling that what’s offered meets their needs. Or you know people…I spoke to somebody who….the woman kept saying ‘why are you late’ and it was because of her caring responsibilities and she was like ‘what, what?’.

…

So that takes us back to the digital story telling. So I did this on another project that Patty ran and I had no clue what I was doing. I had no clue how to use the technology. I had no clue what my story was about even, you know I just knew I’d had some experiences and I did manage to make a film. So my pitch is that I did it even though I didn’t know what I wanted to do. And so when I did it it was actually face to face but during the pandemic Patty shifted it online, and they are based in Canada so thanks to the joys of Zoom we are able to do the digital story telling workshops.

So the first one is a kind of ‘let’s think about your story’. And she’s encouraging me to ask people is there one story that stands out for you. But I think you’ve told me so many different stories you might want to have a think about that question. So when I went to the workshops some people clearly had a story that stood out for them because they arrived with a script – I was like ‘God, what’s a script?’ and a real clear idea in their head of ‘I want this image and I want this music’ and I thought ‘oh, I don’t have anything in my head’. But we all managed to make something, and it was really in that conversation. And you work with film makers and artists who have done this work before, and the thing I loved about them was that they are super talented, you know in their little worlds they have won prizes or whatever it is and they could so easily have said ‘well what we need here is a….’ you know, and they never, ever did that, everything they did was in conversation with you so it felt like your film at the end.

So that’s what we’re going to try and do. And the first one is on the 7th of October in the afternoon and then there will be follow-up workshops. But if the group thing is not for you we can do things outside of group, because one of the things that we wanted to be was flexible, not like the counsellor saying ‘what do you mean you’re late, I can only fit you in on a Saturday afternoon and if you can’t come then you can’t participate’.

A Too bad, yeah, yeah.

Q We do not want to do that. So there will be opportunities to do it really across the month I suppose at the time that would suit you to do it.

A I’m still not sure if I’m honest about whether I want to do this. Maybe it’s just the thing that you said, I don’t know what my story is really. Yeah I don’t know what I have to say.

Time 1:10:12

Q And yet you’ve said so much.

A I know, I know, I can’t stop talking. I know it’s ridiculous really.

Q Oh sorry, I’m really sorry, it’s not the 7th of October because you’re a sibling. Sorry, the parents one is the 7th. This one will be after Christmas so you’ve got a bit more time to think about it.

A OK, alright, well can I think about it a little bit more because I’ll reflect on my gabbling here today, you know I’ll reflect on what….

Q Would you like to see an example of a film?

A That would be nice, yeah.

Q I’ll send you a film. And I’ll send you….there’s a really lovely one made by a sibling actually that you might like. It’s not all bells and whistles-y, there’s a kind of…she has got a script and she reads it over, and then there are images and sounds and stuff that go with the script. So that might make you think ‘oh it’s not so bad’. And I know it’s easy for me to say, but not knowing what the story is I don’t think is a barrier because I think in conversation you will come up with a story. And if you go to the first workshop and you think ‘oh no really I don’t have one’, you know that’s absolutely fine.

A OK. So send me an example, that would be lovely to see anyway, that would be lovely to see. But it will kind of focus my mind really about….

Q OK.

A Yeah, if that’s alright.

Q Absolutely. So what will happen in the meantime is that we’ll be back in touch with you with the transcript. So somebody transcribes it and then I will anonymise it. Sometimes people are really happy with the way I’ve done it, other times people aren’t. So we had somebody who just said ‘no, no, no you’ve not taken enough out’. You know you might want to take more out than I have taken out, you might just decide ‘I don’t want that bit ???’ you know it’s absolutely fine. If you just want to leave us with little bits that would be fine, it’s completely up to you, it’s your transcript and it’s completely up to you with what to do. So we’ll be in touch about that. And I’ll send you an example of the story and Martina will be in touch about when the workshops might be, and if you wanted to have another chat about that any time that would be OK as well.

A Right, thank you [name]

Q No thank you, it’s been an absolute pleasure to meet you and thank you so much for sharing….

A And you.

Q …so many stories. They’re amazing stories.

A Sorry. Once I get on a roll, once I get on a roll.

Q It’s been really lovely to hear them, and that’s why you’re here, I wanted to hear them.

A Oh it’s my pleasure. It’s good to participate, it genuinely is very good to participate in something like this. And I think my stories, you know my experience is probably quite different from a number of people. And I did go to one of the [charity] groups, you know the organisation, and I was the older person because they were all young adult men and women, and I didn’t quite fit. I mean it was lovely to see but it didn’t quite fit really. And yeah, they all had their issues of wanting to help their parents and didn’t know how, and so on. And I’d been through all that and in that example it didn’t really help them you know, somebody else telling them what they’d done wasn’t particularly useful, they’d need to work that out for themselves I think. So anyway, off I go again! Anyway [name]I’ll let you go.

Q Thank you. OK take care, thank you again.

A Nice for talking. Thanks for your time.

Q Thank you. Bye bye.

A Bye now.