[0:00:00]

[redacted]

Interviewer: So, [Name of Respondent], can you start by telling me what is your contact with Huntington’s Disease? What is your experience with Huntington’s Disease?

Respondent: Yes. In a nutshell I married into a family and we found out in [1980-1990] that the father and my husband had got Huntington’s. But by then I’d had my children and so the father died a few years later with pneumonia brought on by the Huntington’s, and my husband died in [1990-2000]. Then my children both went off to university; one became [role A], and the other one did [role B]. But since that time the [role B daughter] developed Huntington’s in 2011 when she was about [25-30], and my other daughter developed Huntington’s in 2018 approximately when she was about [35-40]. So, they are at different stages. My eldest daughter is still at home with the family. She’s had to leave work but she’s still doing the housework and looking after the children. Whereas my other daughter because she’s further along the line she’s now in a home.

Interviewer: And do you want to name them? I’ll anonymise the names but it just might be easier? So, your daughter who was [role B] what’s her name?

Respondent: She’s [Name 1].

Interviewer: [Name 1]. It might just make the conversation easier.

Respondent: Yeah.

Interviewer: And your daughter who is a [role A]?

Respondent: That’s [Name 2].

Interviewer: [Name 2], okay. So, [Name 1] is in a nursing home?

Respondent: Well, she’s in a special care home.

Interviewer: Special care; special as in for people with Huntington’s?

Respondent: It’s with people with Huntington’s but it’s also for people that have had brain injuries in one way or another, some neurological problem. But they do specialise in Huntington’s.

Interviewer: And is that close to where you live?

Respondent: It’s 32 miles away.

Interviewer: 32 miles, okay. How long does it take you to visit?

Respondent: Well, it depends on the traffic but it’s between an hour and an hour and a half to get there and usually about an hour to get back because it’s usually later at night.

Interviewer: Was it hard to find a place when she needed care?

[0:03:46]

Respondent: Well, the problem was when she needed care she was going to go to respite but the Social Worker hadn’t organised it, and unfortunately her husband sort of left her – sort of abandoned her – on the one day and rang the Social Worker up and said, “You can look after her now”. I was on holiday at the time so I couldn’t do anything. And so for an emergency a home accepted her but the home was an old people’s home really. It wasn’t for people with any sort of illness of injury sort of thing. And of course they had a zero tolerance policy and when a Huntington’s person is put into a place where they perhaps haven’t got what they want and they don’t know quite where they are they can be a bit upset about it all, and especially if they start telling them to go to bed – do you know what I mean?

Interviewer: Yeah.

Respondent: So anyway I think she didn’t follow their policy of compliance and so they sent her to hospital, and I think that’s why our hospitals are so full because of these people sending people to hospital just because –

Interviewer: Her behaviour was…

Respondent: I mean she wasn’t ill.

Interviewer: No, I understand. So, it was just because they couldn’t cope or she wasn’t fitting in the box.

Respondent: Well, I don’t think they knew how to handle a Huntington’s person you see. There’s a certain way to handle them, and of course they didn’t know. And of course the circumstances at the time: I mean if all of a sudden you’re in your home one day and then you’re not the next it would upset anybody. I think that’s what they forget, the human toll that these things are. But anyway she was in hospital then – well, they did get her this home place but of course a fortnight later she got Covid in the hospital so then she had to be in the hospital for another fortnight until the homme would take her. So, she was in the hospital for a month and then she went into the home after that.

Interviewer: Wow. So, she basically picked up Covid at the hospital where she shouldn’t have been in the first place and then it extended her admission, yeah.

Respondent: I mean fortunately she didn’t get Covid too badly.

Interviewer: But it still it was quite a few weeks then.

Respondent: But of course to her she couldn’t understand why she was then put in a room by herself, if you know what I mean, and that type of thing. And of course then I couldn’t go to see her.

Interviewer: You couldn’t visit.

Respondent: So, it all got a bit messy at that point yeah.

Interviewer: Oh, gosh. And then who found this special home?

Respondent: Well, I don’t know quite who did it exactly because I’d sort of got a bit of a team around me now which is an OT from [location 1] called [Name 3], then I’ve got my Social Worker, and then I’ve got… well, I don’t think it’d got [Name 4] at that time. But there was also an HD Advisor and that would’ve been [Name 5] because at that time we were in [location 6] . So, between the team I think [Name 5] knows which care homes are best for Huntington’s people and the Social Worker would’ve been sort of trying to her there and that type of thing.

Interviewer: So, you were contacting with the same Social Worker throughout this? It was always the same person?

[0:08:23]

Respondent: Yes.

Interviewer: Okay, alright. And how did the Social Worker become involved, at what part? How did she find out that –?

Respondent: Well, the thing is I probably had a Social Worker – I don’t say the same Social Worker but a Social Worker – since about… my daughter came back to me from York when that marriage broke down and I think it was probably about 2014 when I asked for care then, which was like 11 hours a week. And I think that’s when the Social Worker appeared because they seemed to do the working out Carers for you, but they were just domestic Carers.

Interviewer: Okay. So, you applied for CHC, continuing healthcare funding, or does that not ring a bell?

Respondent: Well, the thing was these were just what I call domestic Carers; the ones that go to everybody if you know what I mean whether they are 86 or 30.

Interviewer: Alright. So, they weren’t from a private agency for healthcare?

Respondent: Not the healthcare ones, no. She got those later on, but she got those when she became pregnant.

Interviewer: Okay. When the Social Worker became pregnant or when your daughter became pregnant?

Respondent: No, when my daughter became pregnant.

Interviewer: Your daughter, okay; that makes more sense.

Respondent: Yeah. So, from 2014 to 2018-ish we had the domestic Carers and then because her child became a ward of court before it was born then she went into another special care home to look after her and her unborn child. And that’s when she’d have gone under the National health Payment Scheme.

Interviewer: Okay. And this was [Name 1]?

Respondent: This was [Name 1], yes.

Interviewer: [Name 1], okay; alright. So, how was your experience with Social Care and applying for funding and finding these places?

Respondent: Well, of course when we had the domestic care it is difficult with Huntington’s people because they generally deal with older people and I think they are generally trained to look after older people, so their idea of care is they come in in the morning fairly early, they get the patient up if necessary, they then perhaps dress then, may have a shower, they can feed them breakfast, and then they go again; and then they come, say, at night and do the reverse process of putting them into bed. Now none of that works with a Huntington’s young person because 1) they don’t want to get up early in the morning so that makes difficult, 2) at that stage they probably don’t want to be showered, 3) they really want somebody to be with them, talk with them, get them some food, maybe do some housework and tidying up because by this time they can’t tidy their own house. Because Carers don’t like to do any housework then that becomes difficult. And then if there are other people in the house when you come to tea-time because there are more people in the house than there would be if there was just an elderly gentleman, an elderly woman, then it’s do they cook the dinner for the person separately or do they cook the dinner – you know what I mean? – or how does it work in the kitchen. There are numerous problems with care at that stage. And I’d like to just say when I criticise this care I don’t criticise the Carers because I think the Carers are very underpaid, I think they are not appreciated for what they do, and I think they should have more of a higher status and they should be probably trained a lot better. So, I’m not criticising the Carers; I’m criticising the expectation of a Carer. So, for caring for a person with Huntington’s it’s a package that doesn’t fit the package basically because it’s just different really. And then of course we couldn’t get housing for her because there’s no housing in [location 3] for anybody with a disability under 55, so you’ve got to reach the age of 55 before you can get any housing. So, that doesn’t help Huntington’s people who get it earlier in life either.

[0:14:40]

Interviewer: Which is the usual.

Respondent: Yeah. So, I mean I know mine probably got it younger than a lot but I know other people that are younger than [Name 1] so it’s not unusual. But then instead of them being able to go to, say, a normal house and live some more years normally they have to end up in these specialist care homes as well because in [Name 1]’s care home there are people that are younger than her and the same age but might not be as far in the progress of their Huntington’s as what [Name 1] is but they are already in a home.

Interviewer: There’s no middle stage; there’s no middle place.

Respondent: Well, there’s no place for them and also if you want them in the home and it’s getting towards more hours then nobody can afford to give you more hours, so you can’t get the hours. Because that was the problem before she ended up in this latest home was that she changed over when she went into the other home, special care home; when she moved into their she moved out of county, they moved her from the house up the road to over the border to [location 7]. And because she moved out of the county of course she got that care whilst she was in the home, then she had the baby and then she carried on having the care until the husband got her back into his house, and then she continued to have that care up to the point where we’d got her a forever home which was a bungalow which she’d moved into a couple of years ago. And when she moved into there of course she’d been in very bad accommodation before that so her health had deteriorated more than it perhaps should have done. And then when she went into the nice bungalow of course her health slightly improved because her conditions had improved, because a lot of the health of a Huntington’s person is their environment so when she was in a better environment and she’d got these NHS Carers who came in, talked to her, did the washing, kept the house tidy and all this sort of thing everything was working quite well for her up to the January. And of course because she was then out of county then of course the person who came in to interview her in January didn’t have anybody else there - no Social Worker, no HD Advisor, I wasn’t there, nobody was invited to the meeting, there was just him and my daughter and her husband – and miraculously after having the disease for [10-15] years my daughter suddenly became well. She didn’t need any care whatsoever; she was deemed to be perfectly healthy and didn’t need any care; and so that package was cancelled.

Interviewer: Oh, goodness.

Respondent: It wasn’t transferred; it wasn’t even said to be transferring. It was cancelled.

Interviewer: And this person doing this assessment do you know who it was, like from where was he?

Respondent: Well, he was the chap in charge of… you said the word of the health –

Interviewer: The continuing healthcare, yeah; the CHC.

Respondent: Yeah. He was the person in charge of those funds and he deemed that she was better. Now in other circumstances I would have been quite pleased with the news, if you know what I mean.

Interviewer: If it was true, yeah.

Respondent: You know, “Miracle!” But as it wasn’t true… I mean, yes, her health had improved because of her conditions, because of where she was living and because of all the help she was getting, because everything was perfect; and then they said, “Well, it’ll finish at the end of January”.

[0:19:51]

Interviewer: Oh my god.

Respondent: So, the end of January comes: of course the help finishes. The Social Worker is put in a difficult situation because she has then got to get domiciliary help in but of course that takes time. So, there was a gap between January and by the time she’d got this help in, but then the hours are reduced. And of course they say, “Oh well, we’ll come in at nine o’clock and then we’ll come in at six”, but the problem was [Name 1] had then in this time reverted to not sleeping a normal pattern. She was up until perhaps five o’clock in the morning, two o’clock in the morning, and wasn’t waking up until at least twelve o’clock the next day. So, then you’d have these domestic Carers coming in at nine o’clock finding her in bed thinking that she’s a lazy young woman who hasn’t got up because they don’t understand Huntington’s, they’ve got no training in Huntington’s whatsoever. So, they’re going straight out back through the door saying, “Well, if she can’t get up I’m not looking after her”; they don’t look around and see that the house is a mess, they don’t look around to see that her seat’s a mess, they don’t look at anything they are just straight out the door because the person isn’t up for them to do anything with.

Interviewer: Yeah, they are not ready. [Name of Respondent], before we move on: up to January how often were the NHS Carers coming in? Do you know what sort of package, how often they were coming in?

Respondent: After January?

Interviewer: No, before they cancelled.

Respondent: Oh, gosh.

Interviewer: How often was she…?

Respondent: Well, they’d come in for the day really. They’d come in later because she didn’t get up until later and then they’d be there sort of… I don’t know; they’re probably get there before she got up, say about twelve, and then they’d be there until about six or something.

Interviewer: Yeah. So, it was more personalised to what she needed then. And so she went from having a Carer with her during her day to being cancelled, to then moved to domestic Carers that had this rigid schedule of, “Okay, we’re going to go in at nine; if you’re not up we’re out of the house again”. So, that’s such a change. And you’re saying it was working well; so, they basically disrupted… We have a saying in Portugal which is, “You don’t touch things if they are working well; just let them be”. If it’s working well just don’t touch it.

Respondent: Yeah. Well, it just seems that every time anything is working well somebody does touch it. And so then it all went wrong you see because she was getting… well, she became quite ill because I think she was not being fed correctly then, and then it was getting a lot for the husband as well and so he was not as good at looking after her, and then because she couldn’t go to sleep at night then they were having arguments and then the neighbours weren’t happy because they could hear the arguments, you know what I mean? It just all fell apart. But of course we were still in Covid times then and it was difficult to get Health to her because they said she wasn’t bed-ridden so she couldn’t get a Doctor to go to her, because she was hallucinating and doing all sorts of peculiar things – Huntington’s people tend to go downhill like that, like a sort of straight line, but if they do that then there’s something else wrong with them. But the trouble is we couldn’t get to have a urine sample because I thought perhaps she’d got a urinary infection, we couldn’t get her to do that; I could occasionally go there but sometimes I couldn’t. And then eventually they seemed to have in [location 6] an Emergency Doctor and Nurse that come out if people keep complaining long enough and they will come out to the home. And of course they found out that she’d got constipation, and what it was causing were these toxins building up in her and that’s why she kept seeing this white dust everywhere and everything else, and that’s why she was ill. So, of course they sorted that out so that was better but, you know what I mean, if she’d have had proper Carers in they should’ve been looking after that. So, eventually that’s when it all fell down: from the January until September the 6th that’s when he left you see.

[0:25:37]

Interviewer: Oh, the husband; yeah.

Respondent: Yeah.

Interviewer: What happened to the baby?

Respondent: Oh, the baby. He was adopted; he was put up for adoption. I mean they were told before they had the baby that that was probably what was going to happen but he wouldn’t listen and he persuaded her that she should have the baby, and so they had the baby. And we had him for five days because of course he was born on a Friday and Social Workers don’t work on a Friday, and then there was the weekend, and then they didn’t get their act together on the Monday. So, he was in the hospital with [Name 1] until the Tuesday afternoon. And then he went into foster care; they were a lovely couple who had him. And then because it was Covid time they had visits to start off with but then of course it went online, and then we had visits towards the end because we saw him until he was almost two and that’s when he was adopted.

Interviewer: Okay. So, [Name 1]’s partner: did he have Huntington’s?

Respondent: No, he didn’t have Huntington’s.

Interviewer: I’m asking because sometimes it happens.

Respondent: Yeah. No, he didn’t have Huntington’s but I believe he’s got something wrong with him but he would never go to have anything diagnosed. And, yeah, he wasn’t allowed – like [Name 1] couldn’t have the child because she was classed as not having capacity, so she was ruled out straight away – but he fought to have the child, but he didn’t have the ability to look after the child so that’s why the courts wouldn’t let him have the child. I think they’d have probably let his parents have the child at one point but then even that was ruled out because I said I could have the child at one point because I needed to say that I’d have the child because of my daughter, if you see what I mean? But of course because of my age I haven’t got the support group around me like a 30 year old person would have because all my parents are the same age group and they might be looking after grandchildren but not my grandchildren.

Interviewer: No, I understand. They were looking for a long solution, yeah.

Respondent: Yeah. But also in a way I didn’t want to have the child because then I couldn’t keep the father away from the child. So, it was a bit of a difficult decision to make because 1) you want your grandchild, and then at the same time you’ve got to think what’s best for your grandchild. And I wanted him to have a family that was of his age group, have siblings, and that type of thing. And it has worked out that way because he is now with a family who… he has got a sister that’s like [2-5] years older than him, he’s got a brother that’s [1-4] years older than him, you know what I mean? He’s like the third child sort of thing. And I know he’s looked after and cared for and that type of thing so I haven’t got to worry about him. And also I’ve got to think that I’ve got two children that have got Huntington’s and I’ve got to look after them, so there’s only so much of me to go around.

Interviewer: Of course. Your life is very full and you thought of the child’s best interest, so you were a really good grandma it sounds to me. And this was on top of Covid which was already an extremely hard situation for everyone. I mean this is the stuff that soap operas are made of isn’t it? It shouldn’t be real life.

Respondent: No.

[0:30:31]

Interviewer: It’s a lot to deal with, yeah. Okay, [Name of Respondent], and then I imagine then the partner left; she couldn’t stay by herself, [Name 1] couldn’t stay by herself, and then she went into this special home?

Respondent: Yes.

Interviewer: That’s how it moved, okay. So, this went from everything was fine in January to catastrophe –

Respondent: In September.

Interviewer: Yeah. And by the next year the whole situation was different.

Respondent: Yeah. But strange enough you can seem to get somebody into a home – and, don’t get me wrong, this home I would imagine costs quite a lot of money – and yet you can’t get eight to twelve hours’ care in your home, which I’m sure wouldn’t cost half as much.

Interviewer: Wouldn’t cost as much; yeah. And for me this is a conundrum as well. The same way with the hospital: it was much cheaper to have… Even without speaking of quality it’s much cheaper to keep someone in the nursing home if she had appropriate care than to get her admitted to hospital because her behaviour wasn’t what they expected, and then she gains an infection and then she stays for weeks; that is extremely expensive. So, I’m not quite sure that the decisions made are cost-effective, and that’s what we always say: these are based no funding; why is the funding so stretched and then the care isn’t so good? But then it doesn’t end up being the smartest decision. So, I’m with you; I don’t understand why it wouldn’t be preferable to have the NHS Carers coming in and having those 12 hours’ care and, to the extent that it could be, everything was going well to then removing all of that and then just having this snowball effect of… well, just terrible consequences that shouldn’t have happened. I also don’t quite grasp why.

Respondent: No. I mean the strange thing was that when she did go into the hospital the Nurses loved her because she was in a ward where I think people are put when they’re waiting to get rid of them, if you know what I mean, to get them out of the hospital. So, a lot of them are waiting to go to nursing homes or whatever so of course the ward was full of elderly people, and so I think the Nurses were a bit like a magnet to [Name 1] because they read her books and they sort of did drawings with her and they put films on the TV for her; she had a marvellous time in there, but why couldn’t she have a marvellous time in the nursing home? Because she didn’t fit it; she didn’t fit the criteria of, “Just sit in a chair”.

Interviewer: Stick to our schedule, yeah.

Respondent: “I’ll put you to bed, I’ll feed you, and I’ll get you up; but if you want anything else tough.” Or if you don’t fit into that mould… if you don’t go to bed until two o’clock in the morning: “Well, goodness gracious, we don’t want that”.

Interviewer: Yeah. It disrupts the routine. So, [Name of Respondent], you’ve mentioned as well an Occupational Therapist; at what stage was [Name 3] coming in?

Respondent: Well, [Name 3] I’ve known for a long time because she’s a very HD-orientated OT because she works in [location 1] with [HD consultant] and so in 2014 we did a trial called [trial redacted] so of course we were going in all the time with the trial, and so you get to know her then sort of thing.

Interviewer: Was the trial with [Name 1] or with [Name 2]?

Respondent: No, with [Name 1]. And so she is very good at sorting a lot of things out and if she can’t sort it out then she usually knows somebody who can, if you see what I mean. So, I mean now she’s one of my go-to people; I always keep her informed as to what [Name 1]’s situation is in the present day but then I’ve also got another lady called [Name 4] which is the [Place 1] Trust person and she’s the one that goes into the homes to make sure that Huntington’s people are being looked after properly. So, again if I have problem with [Name 1]’s care at the moment then [Name 4] is involved as well. And then of course back when I was trying to sort out her benefits then I had another lady in [location 6] who helped me sort out her benefits. I’ve got a Dietician’s that do… if I have problems of the salt as well; so, if I’ve got problems with her eating. I’ve still got the Social Worker who again she’s interested in [Name 1]’s health and welfare and also I think she’s now trying to get her back onto the NHS Payment Scheme because at the moment we pay part of her care, but that takes months and months and months. And I’ve also put in for Appointeeship for her benefits now so I’m her Appointee; she helped me with that the Social Worker. And also I’ve gone in for Deputyship; so, I filled in three forms that the Social Worker gave me then they sent me the three forms back again and so I filled more forms in, so I filled the three more forms in. And then I think it went to the court on the [date in Winter] and then they said, “Fill another form in”. But each time because it’s to do with her capacity I have to have the Social Worker come in with me or her go in depending on how we’re doing it and we have to talk to [Name 1] and she has to talk to [Name 1] and be assured that [Name 1] is happy for me to be her Deputy as opposed to me pushing it on her.

[0:38:43]

Interviewer: Yeah; making sure that she doesn’t have the capacity to manage her finances herself.

Respondent: Yes, but at the same time that she’s happy with it.

Interviewer: [Name of Respondent], does [Name 2] have much career, any movements or not?

Respondent: [Name 2]? She has got movement, yes.

Interviewer: Sorry, [Name 1]; sorry, I got –

Respondent: [Name 1]. [Name 1], yes; a lot of movements now. But it’s sort of like you have to be careful if you’re sat close to her that you don’t get hit.

Interviewer: Yeah; very fidgety.

Respondent: Yeah. But she still can walk a bit; she’s got a new walker now that she can still walk from her bedroom to the kitchen sort of thing where they eat.

Interviewer: Whereas now she’s at the special home does she still get someone from the [location 1] team to go in, or is this the Community mental Health Nurse that goes in?

Respondent: Well, a lot of people go in. I mean the Social Worker has to keep an eye on; [Name 3] and [Name 4] both go in occasionally; there’s the SALT team go in. So, yes, they all go in at different times.

Interviewer: Okay. And the home doesn’t present any obstacle to…? So, my point is when they need help are they active in seeking that expert help?

Respondent: Well, I mean the home is good; I’m not saying that the home isn’t a good home, but they are on a learning curve because they are wanting to be a Huntington’s home but of course they haven’t always been a Huntington’s home if you know what I mean. And so especially with [Name 1] who is more advanced but not so advanced that she’s just in a chair all the time she does pose problems to them. They’ve just had a new Manager and she’s replaced a lot of people at the home because there were problems at the home, and so it’s improved as in the people that are there now but of course it’s meant that there’s been a huge turnover of staff. So, of course you teach one week and then the next week it changes to somebody else. And so we’ve sort of worked over the last 12 months now. But there are subtle changes that happen to Huntington’s people that perhaps they are not looking for them. I don’t know what it is really. I go in and I see it but I don’t know why they don’t see it; but perhaps I know what I’m looking for and they don’t know what they’re looking for. Just for an example: when her eating went from five to four sort of thing they were feeding her with a spoon like they feed all the other people, but the problem was that she had then changed to the fact that she couldn’t swallow a whole spoonful and also because it was slightly more not mashed up, if you know what I mean. Whereas I’m always pointing out things like, “Now you should feed her with a teaspoon, not a spoon”. So, yes, I mean I’m going in later on today and today we’re going to go through her meals again because she’s not eating her dinners very well. So, we’re going to go through again what she likes to eat and what she doesn’t like to eat. So, even though she’s in a home that’s good you’re always walking on shifting sand so what was good this week won’t be good next week, you know what I mean? So, we’ve put a lot of things in place because one of her big hates is that she doesn’t like her book taken away from her out of the room – just the black book that they write everything in – so of course now it is better that more people know that if they take the book they’ve got to say, “[name 1], I’m taking the book; I’ll bring it back in a minute”, which doesn’t sound very much but people just take the book because they are busy and they’ve got to write it in and all of this sort of thing. And then like her clothes: she doesn’t like her clothes taken away and washed because I think because she moved house so often she lost so many clothes I think she’s a bit nervous about losing her clothes. And so there’s a certain ritual you do for when she has a shower: you first of all look for a pair of socks in the bag that she chooses, not put the socks on the side and say, “These are the ones you’re wearing”; it’s so subtle but the difference it makes is tremendous as to whether she goes off in a mood or not. And then when she’s having the shower you’ll secretly change the pair of dirty pyjamas for exactly the same pyjamas that are now clean so she doesn’t know that the pyjamas have changed but she’s got a clean pair of pyjamas on, do you know what I mean? So, we buy everything in twos; slippers are in twos, clothes are in twos, tops are in twos, everything is in twos, and then she doesn’t have this worry of losing something. So, of course that’s taken a while to get everybody into that way of doing things. But even just having a shower the difference between saying, “The water is on now; I’m just going to put this on the back of your head, have a flannel on your face”, as opposed to going – you know?

[0:46:02]

Interviewer: Yeah, I know what you mean; take them through with you instead of just doing it to them.

Respondent: Yes. And I mean in her bedroom I’ve now put a picture of her going for her degree, her degree photo – the normal one with the scroll in front of her – because she’s sort of perhaps… well, she’s probably better now than she was because she’s being spoon-fed now as opposed to feeding herself, she’s a lot cleaner. But when she’d sort of got food down her and she’d perhaps not washed her hair or whatever people think that you are simple; they don’t think that you can think behind it, plus the fact that when they can’t talk or your talking is a bit slurred then they don’t think you’ve got an IQ to rub together. And that can be a problem, you know what I mean? Because, I don’t know why, but I mean the picture does make a difference to a lot of people.

Interviewer: To see her as a person, as an intelligent woman that she is.

Respondent: Well, yes. So, it’s a matter of getting them – which doesn’t sound a lot – but just talk to her and say exactly what you’re doing, but you’ve got to do it slowly because her brain works slowly in the fact that the message doesn’t get there. And the way I explain it is like years ago when we used to phone Australia if you phoned anybody in Australia you’d have to talk and then you’d have to wait and then they’d talk back to you, and then you’d have to wait and then you’d talk back to them, and that’s how the conversation went. And that’s the conversation you have with a Huntington’s person: you talk to them and then you wait. But, as you can see, any sort of wait is not normal.

Interviewer: Yeah. People are in a different rhythm.

Respondent: And they jump in you see. “Do you want this cup? I can go to the kitchen and get this”, and it’s just no good. And then a new person will come in and then they’ll say, “[Name 1], do you want a cup of tea”, and she’ll say yes and they’ll just take the cup, and so then she’s, “Somebody’s taken my cup”, because she hasn’t sort of caught up with all that’s happened you know?

[0:49:01]

Interviewer: So, [Name of Respondent], I mean it sounds like you spend a long time teaching the Carers how to deal with your daughter?

Respondent: Yes, it’s a full-time job I think. It’s been the same though all the way along because when she had domestic Carers to start off then you were teaching them, and then when she had even the NHS Carers then you’re with them, and then you’ll have good people come in who are very helpful and they know things. And of course I did have the problem because if anybody was exceedingly good at looking after [Name 1] the husband would get rid of them, so that was the added problem I had. Because I don’t know whether it was… well, he was very controlling so I think that was part of it. So, you just get to this stage where you’ve taught them and everything is perfect and then something will get – they’ll leave or… you know what I mean.

Interviewer: They you have to start again.

Respondent: And then you have to start again, and then you’ve got the Social Workers and then they become ill and then they leave or they are on holiday, you know what I mean? So, a lot of these things although you’ve got it all there – and that’s why I have a group of people because when it’s getting on top of me and I sort of can’t… “This isn’t working”, then I send this email off to them all and then hope that somebody will come back to me. And then one or the other will come back and they’ll sort of say, “We’ll do this, that, and the other”, and it’ll be good. But, yeah, I mean there are other people that help. There’s a team in [location 8] which is all together under one roof, and at the beginning that’s quite good because they’ve got a Physio and they’ve got psychological people, they’ve got Dieticians, they’ve got OT, they’ve got a fifth one that I can’t just remember. So, say if they come to your home and they fit all the handrails or whatever you need at the time and then they see you and they think, “Oh, well she could probably do with going to the Physiotherapist”, so then they can refer you direct to the Physiotherapist so then you see the Physio.

Interviewer: And which team is this?

Respondent: It’s a team in [location 8] ?

Interviewer: A rehab community team or…?

Respondent: Gosh, what are they called? Yes, I think they are called a rehab team; yes. But it’s quite good because then if they think you’re not eating right then they can refer you to the Dietician. But then when they’ve finished it’s up to you to go back to them sort of thing.

Interviewer: You have to chase.

Respondent: You have to go back. The problem with Huntington’s: because it’s over 15, 20, years it’s not like six months or a year or two years so you perhaps don’t want a Dietician every day of the year, you just want them perhaps once a year or something; just as things change then you get in touch with them again.

Interviewer: Yeah, alright. So, what would have helped, [Name of Respondent], or what would help to make your experience better and your daughter’s care better?

Respondent: Well, you start with the benefits people really because that’s when you start right at the beginning with the benefits people. Because people with Huntington’s are born with Huntington’s but they don’t develop it until later life – like you could have Huntington’s; you don’t look any different to me, do you know what I mean – in the early stages you don’t grow green ears or instantly you can see that you’ve got Huntington’s, so you’ve got that battle to start off. I mean it took me 11 months with [Name 1] to get her benefit; by that time she’d lost her house, she’d lost her husband, she’d lost her job, she couldn’t drive, and she can’t ride a bike. But as far as her Consultant was concerned we were making a big fuss saying that she wasn’t going to be able to do those things. So, you’re fighting Consultants who don’t know; you’re fighting benefits people who don’t want to know. So, then you get to the stage where you’ve got Carers and then the Carers are not made for purpose. I mean I’ve now got with [Name 2] to the stage where she could do with some care. I know it’s not worth getting care in for her because Carers will not care for her how she needs to be cared for. So, to start off with we’re trying to employ a Cleaner. Now I know a Cleaner isn’t supposed to care for somebody but they will clean the house, because she’s getting to the point where the cleaning of the house is probably getting too much for her but she won’t admit to that. So, you’ve got to do it all subtly. So, I could do with a Carer who also cleans. I could do with a Carer who will talk to my daughter because that’s so important at the beginning that they’re talking to somebody as opposed to just isolating and not talking. And I mean I tend to do a lot of the things because with my second daughter I got onto getting a PIP long before she left work and, miracle of miracles, because the HR department after Brexit was all… she didn’t actually finish until the October whereas she should’ve finished probably in the August. But the day that she finished she got her PIP, so that was a miracle, whereas the other one I’d waited and left months whereas this one it was six months but I’d started six months earlier. And so then you have to get the ESA but there’s nobody there to do it so I’m doing that as well.

[0:56:45]

Interviewer: The ESA?

Respondent: The ESA. It’s like if you broke your leg and you couldn’t work then you claim ESA, Employment Support Allowance. But there are two sides of ESA: there is where you’ve broken your leg, you need support at the moment but in six months’ time you’ll be going back to work, or there’s the type which is for Huntington’s which is for life basically because there’s no cure. But with ESA if you don’t claim it within two years of you leaving work you then cannot claim it.

Interviewer: So, who is helping you with navigating this bureaucracy with the benefits?

Respondent: Nobody; nobody really because that’s my expertise.

Interviewer: Oh, alright.

Respondent: Just because I’ve done it before.

Interviewer: What is your background then, [Name of Respondent]?

Respondent: Well, no; it’s what I’ve learnt.

Interviewer: Oh, you mean your expertise because you’ve been learning throughout your whole life?

Respondent: Yeah.

Interviewer: Oh, I thought you were professionally like an [financial roles] .

Respondent: No. But the finance for these people is not… I can’t find anybody that’s sort of – I know I’ve got this [Name 6] in [location 6] which has helped me behind the scenes of me getting the money so I can pay [Name 1]’s bills and all that sort of stuff, but there isn’t anything. There’s no leaflet that says, “You’ve just had Huntington’s; these are the benefits that you need to apply for, this is when you’ve got to apply for them, this is what you’ve got to do”. I mean my daughter because she has a good pension from the NHS she didn’t qualify in having any money from the ESA so it sounds a bit peculiar that I’ve claimed it and she’s not getting any money, but I’ve claimed it because you can get other benefits because you get an ESA although you’re not actually getting any money. So, it’s all very complicated. And now because the ESA is going up in April and because her pension isn’t going up she’s now getting a tiny little bit of money; so, she wouldn’t have got that if I hadn’t have gone for it – I didn’t even think of that one. So, you’ve got that problem of getting money for their family because you’ve gone from a specialist [role A] getting a lot of money to getting your pension, which is not the same money. And you’ve got to keep the house going, keep the kids going, you know what I mean?

[1:00:01]

Interviewer: Yeah; the bills need to be paid.

Respondent: You’ve got to get something to replace that. And then with the care: well, then that’s not made for Huntington’s people as I’ve said so you’re forever fighting against… It’s a bit like, I don’t know, asking a Bricklayer to put plaster on the wall: it’s the same sort of thing, you’re still spreading stuff but a Bricklayer wouldn’t know how to plaster a wall necessarily do you know what I mean?

Interviewer: Yeah; each monkey needs a tree.

Respondent: Well, that’s it. And then there’s no training… well, I mean the Advisors do train the Carers but I think that’s sort of voluntary so I don’t think they’ve all got to turn up. And then of course next week you’ve got somebody that’s left and somebody that’s come, and that’s the big problem with care: you’ve got this big turnover of staff all the time so you just about get to know somebody and they are getting to know [Name 1] and all her little foibles and everything and then that’s gone and then you start again. And that’s the problem: there’s no consistency in care. I mean, yes, I should probably go down the PA route; I don’t really know a lot about it but from what I know I think you have to employ them directly, you have to then do all the wages for that person and all the stuff that goes with the wages.

Interviewer: A PA is a Personal Assistant?

Respondent: Yes. And then who is going to pay for the PA? You’ve just lost your job, you’ve just got less money if you’ve managed to get even the benefits, and then you’re supposed to pay. They sort of say, “Oh, well, we’re paying you money so that you can pay for Carers”, but the money you get won’t pay for a PA, not every day, you know what I mean? It’s like fitting a square peg into a round hole.

Interviewer: So, you mentioned [Name 5] earlier as in the Advisor; I was under the impression the Advisors could help on applying for benefits?

Respondent: Well, yes. I must admit we did have an exceedingly good Advisor in [location 3] called [Name 7] and I mean it sounds funny but because I had to fill in so many forms for my husband saying the worst scenario – and at that time if you were having Disability Benefit you had to fill in a form every six months or so and it would be a different form, and it would be about 45 pages long and you’d have to fill it all in, it would take two days; and you’d put the worst scenario, but I didn’t really know what the worst scenario was; but anyway after doing that I became… I don’t know what it was; when it came to doing the form for [Name 1] in the February I had great difficulty filling the form in because I think it just brought it all back from the time before, if you know what I mean. So, I must admit [Name 7] was very experienced and she did help me fill in the form because there are certain words you’ve got to use, you’ve got to be always negative, you can never say anything positive; if you say one positive word that’s it, you can’t have it. So, she was very helpful in filling the forms in then but unfortunately due to circumstances we’ve lost her now so we’ve now got a new one, and of course now I’m training him as well as him going on these courses and things. It’s just like you’re starting again really with a new person.

Interviewer: With a new Advisor you mean?

Respondent: Yeah.

Interviewer: Okay, yeah.

[1:04:46]

Respondent: So, we’ve got a new Advisor for us and then the Advisor for Wales has also left and she’s actually working for the home where [Name 1] lives now. But anyway she’s left so now we’ve got a new one there, a brand new one, so she’s just going through the start of all the stuff that you have to do to start a new job. So, we haven’t got her up and running yet. So, it takes a while to get an Advisor up and running.

Interviewer: With enough experience.

Respondent: Yeah.

Interviewer: So, [Name of Respondent], did you get any support after your husband passed?

Respondent: Well, no, I didn’t really but I didn’t sort of think I needed it at the time. And also I’d got one child that was just doing her GCSEs, another one [1-5] years younger, so of course I had to retain because I’d lost my income as well. Of course in those days the benefits stopped they day they die so you’ve just built up this money so that you can afford to live, and then they die and nothing.

Interviewer: And you had stopped earning to care for him?

Respondent: Well, I used to go out for cleaning jobs because those were the only jobs I could do for three hours; do breakfast, go out for a cleaning job, come back for his tea, that type of stuff. Because I didn’t have any help at all looking after him. So, of course I did that but of course that wasn’t going to then cover the benefits that I’d lost. So, fortunately he had got some insurance so we sort of lived hand to mouth until I could do the probate, and then I did that and then we got the insurance and I was able to retain then, and I did then [redacted] and I became an [FINANCIAL ROLE] . So, then I could work in [redacted] and keep the family then.

Interviewer: You were an [financial roles] . I thought so. Alright, so aside from life you also then… well, you went on with what life gave you and you thought, “Well, let’s better capitalise on this then and make it professional”; well done you.

Respondent: Because the problem is I’d looked after the shop and I’d looked after the family business for the last few years but when you go for a job you’ve got to fill in what your qualifications are; well, a qualification isn’t, “I’ve looked after a failing business because all the family went sick”, so you can’t put a qualification down. And then of course when I got the qualification then I couldn’t put anything in, “What’s your latest experience in the last two years?” because I hadn’t been to work. So, then I went to one of these agencies just to sort of go to a job so then I could put a job down saying, “I’ve done this in the last few weeks”, and then you can get the job then. But, yeah, it’s not easy really.

Interviewer: Yeah. I mean as a Carer you are limited in if you can do any work and then you’re limited in the sort of work you can do to fit the flexibility you need because you are caring for someone full-time, and then when they die they stop the benefits but also you have no income and you have no experience to put down. So, yes, that’s not a great position to be in. And with children to raise; bills to pay.

Respondent: Yeah. And also I hadn’t really got a car. I hadn’t read the instructions on that bit so I did have a car for two months and I don’t think it had any insurance or anything because I didn’t realise that that stopped. The mobility stopped overnight as well on the car. But I didn’t quite catch up with that for a couple of months, yeah.

Interviewer: But you didn’t think you needed any help because you don’t know what you don’t know.

Respondent: Well, I mean I should’ve had help really and I probably should’ve had some money from somewhere but there weren’t food banks or anything that you have now. I mean a lot of that time we were eating out the shop of anything that had gone out of date; I mean that’s what I survived on. But, no, it wasn’t the same back then even to what it is now. I mean you think it’s bad now but there wasn’t anything then at all. I mean the only thing: there were two Neurologists that came in the yard once because my husband was trying to kill himself and I said, “What shall I do?” and they said, “Just keep an eye on him”, you know? That was your full help.

[1:10:51]

Interviewer: And this was the Neurologists?

Respondent: Yes. “Just keep an eye on him.” I’ve got two kids to look after and all these other things going on but I’ve just got to keep an eye on him but I couldn’t keep an eye on him 24 hours a day, it’s just impossible.

Interviewer: Do you feel the Neurologists are better now? I mean do your daughters see a Neurologist even?

Respondent: Well, I don’t think the majority of Neurologists are very good. I mean [HD consultant] at [location 1] they specialise in it, they are excellent; but anybody that doesn’t specialise in it – you see most of them all they deal with are strokes and that type of thing or brain injury from an accident, you know what I mean?

Interviewer: Yeah. There’s no mental health problems associated.

Respondent: That’s their biggest, I should think, bread and butter sort of thing. But of course, like the Neurologist we saw in Leeds: I mean [Name 7] had written him a letter saying what was going to happen over the next 12 months and he basically wanted to, if he could, be struck off because she was sort of scaremongering.

Interviewer: What was that, sorry?

Respondent: Scaremongering.

Interviewer: Oh gosh, you’re going to have to…

Respondent: Sorry. She was making out that things were worse than what they would be.

Interviewer: The Neurologist?

Respondent: No, the HD Advisor wrote a letter to the Neurologist to say what was going to happen in the next 12 months but he just said that she was –

Interviewer: Oh, he thought she was exaggerating.

Respondent: Exaggerating what was going to happen in the next 12 months. But instead of keeping that information to himself he then read that letter to my daughter and her husband so then the husband he’d gone off on one, so it didn’t do them any good. Then he just put Huntington’s as what was wrong with her on the form so that means nothing, so that didn’t help the benefits. When [Name 1] came back to my house we went around a lot of Neurologists; all they seemed to want to know was your life story, “See me again in six months’ time”, what is the use of that?

Interviewer: There was no actual plan to help now.

Respondent: [Name 1] did have some brain x-rays and I definitely know she hasn’t got dementia. We went to find out what was what and he said, “Well, she’s definitely not got dementia”, and I thought, “Well, that’s very good; that’s not really what I’m” –

Interviewer: She had Huntington’s already; why did she need it? I mean to be honest Huntington’s is a dementia syndrome by itself as it evolves, she didn’t need another.

[1:14:30]

Respondent: Well, you know, I’m thinking, “Yeah, okay”.

Interviewer: So, it’s like the Neurologist didn’t think the… so, they were still looking for something else aside from the Huntington’s or was she not diagnosed then?

Respondent: Yes. I mean she was diagnosed then but I think probably his speciality was dementia, you know what I mean, not Huntington’s so all he could say was she hadn’t got dementia. But he didn’t have any knowledge really of Huntington’s. And that’s what I find: it’s a waste of time going to a Neurologist; it’s just not worth it. And the problem is as well with Huntington’s that in the beginning they don’t have any medication because there isn’t any medication at the moment so of course when you fill in a form for benefits or anything and you say, “No medication”, “Nothing wrong with them; they’re not having any medication, they are perfectly alright. What do they need any help for?” And as well because a lot of people don’t know how… forms don’t fit Huntington’s either so when you’re filling in the ESA the ESA are a law unto themselves so although my eldest daughter [Name 2] had been through the NHS system to say that she needed to finish work, she’d got all the medical people saying that she could not continue etc. so the NHS don’t retire you under sick health unless you’re really sick, do you know what I mean?

Interviewer: Yeah.

Respondent: And yet when you filled in the form for the ESA and you filled it all in then they come back and they say, “You must fill in this medical form because we don’t take anything from anybody else’s sources”, so then you fill in this medical form but the medical form isn’t really directed at Huntington’s so you have to manipulate it a bit like, “Yes, she can use household equipment but if she’s got anything new like a set of blinds and nobody has taught her over and over again on how to open the blinds she cannot open her blinds because she can’t remember how to open them; is this normal for a 30s…?”

Interviewer: Yeah. So, for these forms then what you’ve learnt is there’s a language and you need to speak their language otherwise you don’t get any funds.

Respondent: Yeah. Because if you sort of just say, “Yes, she can use the washer and the dishwasher”, “There’s nothing wrong with her”.

Interviewer: Yeah. But if you change the dishwasher then she can’t use it.

Respondent: But if she had to change the dishwasher… new learning is difficult. They know old learning. Because that’s where you fall down: with [Name 1] when we were trying to get that she hadn’t got capacity with her finances then the Social Workers would come in and they’d say something like, “[Name 1], do you know that you’ve got a bank account?” and she’s say yes, and, “Do you know anything about cheque books or have you got any BACS payments?” and all this sort of thing, and she’d say, “Yes, I’ve got BACS payments” – well, she’d just say yes but anyway – and so they’d ask them these questions and they’d say, “Oh well, she’s got capacity; she knows all about bank accounts, she knows all about money and the household bills have got to be paid; so, she’s got capacity”. And then you sort of say, “Well, did you ask her what her pin number was on her card?” “No.” “Does she know her pin number? No. How can she pay her bills if she doesn’t know her pin number? Does she know what bills she’s got coming in? Does she know if they’ve been paid?”

Interviewer: Yeah; how much money she’s spending a month on electricity.

Respondent: Yeah. They ask broad questions which she knows. Well, she kept a house in York, she used to pay the bills, she knows all that because she’s an intelligent person; but she didn’t at the time know her pin number, she didn’t know what money she’d got in the bank. Her husband was paying the bills supposedly – but he wasn’t – but they didn’t ask specific questions. And so one minute she’d be having capacity and then the next minute she wasn’t having capacity, and then the next minute she was having capacity; it just sort of change with each Social Worker that she had. So, you’ve got that in the background going on. So, I find that the finances are the one bit that nobody will take on even now with [Name 1]. I mean it’s me that’s doing the Deputyship; it should probably be the Social Worker, but the problem with the Social Worker: you get one Social Worker to get the Deputyship and then she’d leave, do you know what I mean?

[1:20:38]

Interviewer: Yeah. There’s no continuity.

Respondent: And of course with her husband a husband trumps everything and the old people now: people are sort of having people go to their homes and marry them and do all sorts of things with them and then they’ve taken all their money and everything. But nobody will listen to you; they won’t listen to me because I’m not her husband, do you know what I mean?

Interviewer: I see; yeah.

Respondent: I think I can go into the bank and I can sort of say, “I’m worried about this account”, but I haven’t got the pin number, I can’t get into the account, “Will somebody help me?” “Well, you’re only third party. We’ll send you a pin number”, but then you still haven’t got the pin number and you can’t understand why you haven’t got the pin number. And then eventually you get into the account and then you find that all the money is gone. You then tell the bank all the money is gone, “Freeze the account”, so then they freeze the account and then won’t let you in again, won’t let you see the statements, won’t let you do anything because I haven’t got power of attorney, and then they give the money back again and then he takes the money again, but I can’t see it because I’m not allowed in the account. So, people are allowed to do all this stuff but because of data protection – data protection only protects thieves, it doesn’t protect the person at all that has got Huntington’s. So, you’ve got all of that going on as well.

Interviewer: Yeah. I was wondering: who can check that these things are in the best interests of the person with Huntington’s? Who should be responsible to see that the husband isn’t fit?

Respondent: So, with the last Social Worker that we had at the home, just for an example, I mean these people lie you see and they don’t consider that they are going to lie. And so he was asked if he’d got any debts, the Social Worker does this thing, “Have you got any debts?” and he said, “No, we’ve got no debts”, so then they’ve got to believe that he’s got no debts. But at the time he hadn’t paid any of [Name 1]’s care money and he hadn’t paid any TV thing, he hadn’t paid the electric, he hadn’t paid the gas, he hadn’t paid the water, he hadn’t paid any of the bills. But you see the problem is as well with [location 6] Council they’ll send a bill out saying, “£250 for your care”, or whatever it is but they don’t put, “But you owe last month’s and you owe the month’s before and you owe the last month before”, so even if you pick up a bill you still can’t see that anybody has got any outstanding money. Do you know what I mean?

Interviewer: Yeah. You need to see the trail, like is there a trail.

Respondent: So, of course when I ring up and I sort of say, “Oh, do I need to pay this £250?” they say, “It’s not £250, it’s £1,800”. And that’s the first you hear of it. But all this data protection: you see I don’t suppose they can tell the Social Worker, do you know what I mean?

Interviewer: So, actually there is a gap here with the finances and the care as well. So, what you’re saying is the Social Worker is taking his word for it without really checking because the systems aren’t communicating because of data protection.

Respondent: Well, yes. And with data protection they probably can’t check you see. It’s like their hands are tied like my hands are tied. And that’s why I’m waiting for the Deputyship because until I get the Deputyship then I can’t divorce the husband. Because I’ve done a will for my daughter in [2015-2017] when he married her in [2017-2020] it made the will obsolete because once you marry you’ve got no will; that’s a killer. Why is that in place? Why should your will suddenly not become valid because you’ve got married?

[1:26:04]

Interviewer: I didn’t know that. I mean, yeah, people should know these things. Someone should tell… well, yeah, I see the problem I just don’t know the solution to this.

Respondent: No, I know.

Interviewer: Because that’s not just Huntington’s is it that’s mental health.

Respondent: Yeah, because lots of people are living in their homes now with dementia; a man will come in, he’ll marry her, and unless the registry office notice that the person hasn’t got capacity then they get married; once they are married then everything that that person has got is theirs when they die. And the relatives even can’t get hold of the body at the funeral because that belongs to the husband – or the wife, it depends which way around it is – that’s just wrong.

Interviewer: Yeah. So, [Name of respondent], we’re nearly done. I wanted to ask you: if you picture your daughter’s care as excellent what do you see for it? At the moment you think, “Oh, her care is excellent”; how should that look?

Respondent: With [Name 1]?

Interviewer: With whichever you want to speak about; or both.

Respondent: Well, with [Name 1] I’d like just that everybody is working from the same sheet and everybody that goes to see [Name 1] knows what [Name 1]’s likes and dislikes are. Because if a person is kept in a perfect way then that is so beneficial to her Huntington’s health. They need some exercise, they need fed properly, they need to be looked after correctly in their own way whatever that is. They need stimulation, say watch the rugby or watch the racing, perhaps go out, perhaps have their hair done, have their feet done. And just remember that they are a human being. So, if they become ill then it’s probably because they’ve become ill not because they’ve got Huntington’s. So, it’s that type of thing. And it’s the same with my daughter really. The trouble is there’s nothing in place really that’s perfect for a Huntington’s person – a young person. There are probably things in place if you are 60, 70, over 55, do you know what I mean? But there’s nothing in place for a young – there are even things in place for a child and there are things in place for an elderly person, but there’s nothing really established for disabled people that are in their middle age. And of course with a lot of things – and I mean it’s worse now with the internet – Huntington’s people tend to spend more, they don’t think about spending, whereas before they’d got to go to the shop to buy it whereas of course now they are –

Interviewer: Now it’s easier to…

Respondent: They can do things on the internet. So, I don’t really know quite what the answer is to be honest, I just know if there was somebody there that could be sort of assigned to the person that would be there forever that would be perfect, but it’s never going to happen. Do you know what I mean?

Interviewer: So, I often think about with children the nurseries have a Key Worker; they have someone that is responsible for the child and as a parent you know that that professional is the main person that should know your child, and if you have a question you to go to that person or you schedule a meeting with that person. And with Huntington’s I feel there isn’t such a person that you know who to go to, who is the professional that should know your daughter the best. And of course we can’t keep them always, people move, but there should be a way of passing on the information of what she likes or what she dislikes, the way she likes to be treated, who are the relatives that are worthy, which are the ones that you should flag. That sort of thing would be good; even if the person changes in a few years that information can be passed on instead of just having to start from the beginning and learn with the same mistakes.

[1:31:49]

Respondent: Yeah.

Interviewer: [Name of Respondent], I’m going to do a couple of boring questions that I need to ask everybody. How old are you?

[redacted]

Interviewer: If there is anything feel free to let me know. If there is anything you want to add honestly just go ahead.

[1:34:02]

Respondent: Yeah. No, I think we’ve covered most of it. It’s just mainly I now work for a university and they are doing things with Social Workers but I still don’t think they see the difference between domestic care and NHS care, I don’t think they see that there’s a difference whereas domestic care is really… well, they are lower paid to start off with whereas NHS Carers are more highly paid. And the domiciliary care is more for just getting people out of bed, feeding them a sandwich, and disappearing again whereas the NHS care is more interlinked with what is wrong with the person and how they can help that situation; they will clean and they will keep them in a tidy state and all the rest of it. But they’ve also got more… like just for an example: I don’t think if I’d have not had the NHS Carers that I’d have known how to look after [Name 1]’s teeth because the specialist Dentists in the country that are for people with Huntington’s, and so I was able to get the right care there for her after Covid. And it was other things that they did that they knew about. I mean I learn as I go along but I still don’t know as much as people that went to university to be trained.

Interviewer: Yeah; Nurses and things like that; yeah, of course. I mean I don’t even quite understand why [Name 1] was sent domestic Carers to begin with. It would be interesting to see how is it that they make that decision of sending domestic Carers or NHS-qualified workers.

Respondent: Well, the thing is with the NHS you have to apply. And I mean the Social Worker at the moment is in the process of applying for NHS cover for the home. And when we’d lost the NHS cover – because of course when she went into the home the NHS cover was really for the unborn child, it just happened to be inside [Name 1] do you know what I mean?

Interviewer: Yeah.

Respondent: But that is why. Because he was a ward of court it was a protection for him. So, that’s why she got it then but of course once he’d said that she was better and she’d lost it then you’ve got to go through this whole procedure again of you’ve got to get Neurologists and different people to say that, “This person has got that”. It takes months to actually succeed. And you fill one form – and it’s a bit like the Deputyship – you’ve then got to fill another form in, and then there are more questions to be answered and, “Is she covered by this type of cover or is she covered by that?” So, you can’t have that in the beginning because you’re really not covered by all those things because it’s only when you’re going along that you pick up all these people along the way.

Interviewer: It’s a full-time job. Yeah, I don’t understand how Carers are supposed to be doing it all with caring and then doing all this bureaucracy and chasing people. You guys really do it all.

Respondent: And also it’s knowing who does what you see. Because like the Social Worker with the Deputyship: I fill in the forms but then she’s got to fill in the form for capacity, but that’s her only role is the capacity form because then I have to fill in and send off the form and everything. So, everybody has a little part in it but unless somebody else is doing the management of it all… I mean to be honest I don’t know how people do cope without a person like me, do you know what I mean? And I don’t think they do. And I think those are the people that kill themselves because I mean they can’t do it themselves. I mean the Huntington’s Society: there is a group of people we meet in [location 8] and I’m the [role] and somebody else is Secretary and we meet every other month. And people come that have got Huntington’s and they glean this information off us, you know? We’ve also got the Advisors going in there so that they can see the Advisors. But that’s as good a thing that a lot of them have got to sort of find this information out almost from ourselves if you know what I mean. And also we supply things that they can’t get from anywhere else, which can be just on a small scale; it could be that they’ve gone down to eating just soup so they need a soup maker. Well, you can’t ask anybody for a soup maker; you can’t ask the benefits people for a soup maker. At the moment we’re working on putting something towards a fence in somebody’s garden because they’ve been taken out of one house, put into a council house, and the dog is going over the fence that’s broken. But it’s 12 months until the council will come and mend that fence, so we jump in doing all these different things that they just aren’t available anywhere else for Huntington’s people. And the trouble is with Huntington’s people whatever they need they need it now, do you know what I mean?

[1:41:16]

Interviewer: Yeah; it’s more urgent, yeah.

Respondent: Not next week or next month.

Interviewer: Yeah. [Name of Respondent], would it be helpful to have the process clearly laid out? Like as you were saying earlier, “I wish someone had told me”, when your husband died… like the car, as you were saying that the benefits were immediately closed, so that the person can prepare a bit in advance and then know. I mean a situation like that – and again with two children your head is racing – so would it be nicer to have some sort of roadmap; “Okay, do this and then that”?

Respondent: Well, yes, I mean it would be nice to have a roadmap. But the trouble is these roadmaps are forever changing because if somebody died now I think they have four weeks before the money disappears if you know what I mean, so that has improved. But, yeah, it would be nice to have some sort of guide to all the different – because the thing is with Huntington’s being physical… so, it’s a physical thing so you’re going into wheelchairs, you’re going into handrails, you’ve gone into walk-in showers, you’ve gone into sitting-in showers, all that that entails; you’ve also got the mental of, “They look alright but they are going down the shop and they’re spending loads of money”. So, you’ve got the monetary side of things that could be going wrong and then you’ve got the physical thing of them not being able to do what they used to be able to do. And because they are young there are certain expectations. Like when my daughter was married to her first husband he expected her to go out and get the shopping, come home, and make the tea, which I know sounds a bit old-fashioned but that’s what some people are like. But when she was sleeping all day… do you know what I mean?

Interviewer: Yeah. Because they are young it’s even harder for other people to understand that they are sick so it doesn’t quite click with them.

Respondent: Well, yes. I mean even children when you’re sort of saying, “Oh, can you mash the potatoes tonight? Get the hot pan off the stove and pour the water away, mash the potatoes, make the gravy”, then, “Why isn’t mother doing that?”

Interviewer: Okay. [Name of Respondent], is there anything you would advise me to do differently next time to do better with other participants?

Respondent: Well, no. I think your questions are quite good and they are pointed in the right –

Interviewer: That’s because you are a good participant.

Respondent: Well, I just hope that you can have a little think about what I’ve said and come up with one or two –

Interviewer: No, it’s been really useful [Name of Respondent]. And although I can see that there are common things with other people that I’ve interviewed before it just gives always such a different perspective with people’s experiences, and I think putting it all together is going to be really good I hope. And it’s amazing how people have great suggestions in what could be done differently and better. So, I thank you very much for your time. I want to ask you if you know other people that could potentially take part feel free to pass them on my email and my number because you’re the only person in [location 3] that I have interviewed so far. I’ve had professionals but not people with lived experience of Huntington’s Disease. So, I am struggling to reach people there both in [location 3] and in [location 2] .

Respondent: We’d probably put you forward at our meeting. We’ve got one this month – the last Thursday in the month. But would you have any objection for us to… we’ve now got a WhatsApp site.

Interviewer: Oh please, yeah.

[redacted]

Interviewer: Thank you so much, [Name of Respondent]. I really appreciate your time and your experience, and I wish I could squeeze more your brain. I can see you know so much and, as you’re saying, it’s sort of like, “Believe the Carers”, because you really know better.

Respondent: Well, yes; because although I criticise Carers I’m not criticising them personally.

Interviewer: No. I mean you guys; relatives as in informal Carers. Yeah, sorry, we tend to refer to you relatives as Carers and then the other ones are formal Carers. But I mean you; you know your daughters best.

Respondent: Yeah.

Interviewer: Thank you so much for your time. And if you have any questions after this feel free to drop me an email as well, alright?

Respondent: Okay, then; will do.

[redacted]

[End of Transcript]