[Part 1]

[redacted]

Interviewer: Okay. Alright, so tell me about your Huntington’s Disease experience, how have you come in contact with it?

Respondent: So it’s my husband that’s got Huntington’s, he knew it was in his family when I met him, his dad was obviously suffering symptoms when I first met him. He hadn’t been tested at that stage, but he was always the sort of person that he thought he was going to get it, so we decided to get the test. And then it came back positive. And then that was basically it for a bit, and then he, well, we decided we were going to try for a baby. We had the first one tested while it was in the womb and it was positive, so we aborted. And then I couldn’t bring myself to do it a second time, so we’d gone ahead and had a child, whether that was the right decision, I don’t know yet, until she gets tested. And then [name 2] was great for quite some time, and then the first real symptoms was mental illness, that he started to think he was having conversations with people, he was starting to get paranoid and things like that, and that was really when it started to become a bit more difficult.

Interviewer: How old was he, [name 1]?

Respondent: So he’s what, he’s [50-60] this year, so you’re probably talking about 20 years ago he started with the mental illness, which just kind of got worse and worse. He was self-sectioned, [0-5 times], we managed to convince him that, you know, something was broken in his brain, and if he had a broken bone, he’d go to hospital, so he needed to go to hospital to sort out what was broken in his head, as such. They eventually got him onto some medication which did kind of calm it, we got him a bit calmer. We then had to move house, that kind of tipped him over the edge again. He had, when we moved, we got carers that were through the mental health side of things, so I think we were quite lucky in that respect, I mean, you’re never lucky when you’re dealing with mental health because it was quite stressful. But we got carers with quite long hours; I think we started with, like, 12-4, so it meant I could go out and this and that. He was okay to be left sometimes, but as it’s progressed, he’s now…I wouldn’t trust him at all. He’s had another blip, my daughter had a baby, and although he was happy about that, it was enough to sort of mess with his head again, I think, so we’ve had another bad spate of bad thoughts popping in his head and things like that. And then that’s…I think, he’s very much a fighter, so he’s fought this all along, but this is, yeah, getting a little bit more difficult now.

[00:21:47]

Interviewer: Okay. And he lives with you, [name 1]?

Respondent: He lives with me still, yeah, we’re trying to keep him at home as long as we can, so, like, through Covid, it was, “Right, that’s it, we’re not seeing anybody,” because I was very much aware his sister has equally got HD, and during Covid, her mental health, I suppose, deteriorated a little bit, she wasn’t eating properly and things like that. She ended up getting dehydrated, went into hospital, and they didn’t get her out of bed, so within two weeks, she basically had forgotten how to walk, because she went in walking, and never walked again. So she was put into, like, a rehabilitation unit, but because it was Covid, there wasn’t any physiotherapists going in to do any work with her, so again, she still stayed in bed. So that was it, so she’s been bedbound ever since and she’s younger than my hubby. It’s like it just got her so quickly, it really has, whereas [name 2], I think…I think a lot of it comes down to his mental attitude towards it, you know, he just kept fighting and fighting it, and he’s kept himself going, you know what I mean? Whereas his sister didn’t want to know whether she had it or not and just let it take over, you know?

Interviewer: Where is your sister-in-law now?

Respondent: So she’s in a care home.

Interviewer: Okay.

Respondent: Yeah, she ended up in the care home quite quickly. She doesn’t walk, she doesn’t really communicate very much at all, whereas [name 2], we went through a stage where he didn’t want to know anyone and was a bit, like, you know, a homeless person, like, he didn’t want to shave or anything, didn’t want to talk to anyone. And then we did a 50th birthday party for him, and I don’t know if something just kind of clicked in his head and he was, like, “Yeah, okay, this is alright, I can live here, you know,” that’s when we were in a new house. And then all of a sudden he wanted to talk and he wants to talk now, but now I can’t understand him because his speech is very slurred.

Interviewer: Oh.

Respondent: We play, “Guess what [name 2] is saying,” because it’s, like, he’ll say things like…he likes to smoke, which I think is, on HD, is actually a plus because it’s kept his suck going for longer.

Interviewer: Oh right, there you go, that’s something.

Respondent: Yeah. So he’ll say things like he wants a smoke, and it sounds the same as when he says he wants milk.

Interviewer: Yeah, it’s not…

Respondent: Which is like his staple drink. Yeah, so we do play, you know, “Which one do you want, do you want smoke or do you want milk?” and it’s just, like, so yeah, communication…

Interviewer: Is he getting any speech and language therapy or…?

Respondent: No, because he’s one of those that they offered speech and language right at the very beginning, “Yes, we do have them,” but it almost felt to me like that was a tick box, “We have to offer you speech and language.” He wasn’t the type of man that you could say to, “Well, you need to slow down your eating, you need to think about your eating,” you know, and things like that, “And these are the things you can do to…” He wasn’t that type of person. He was always a, “I’m going to shovel down my dinner as fast as I can.”

Interviewer: “Gobble, gobble.”

[00:25:32]

Respondent: Yeah, so I don’t know how much, how speech and language is with HD, because it does depend on the person, doesn’t it, if they want to help themselves.

Interviewer: Well, I was thinking he could get some assistance on communication, so like, you know, instead of, like, “Is it smoke or is it milk?” you know, there are some…

Respondent: Yeah, so we had one, I think one of the speech and language people gave me a little chart thing that he could point at. He’s never been technology-wise, so things like iPad, but with his (inaudible 00:26:12), I think he’d have trouble clutching something on the screen anyway.

Interviewer: Mm, the fine…

Respondent: Yeah. So yeah, we’ve had the little laminated thing, that he’s meant to point at, but he’s never really been interested in any of those particularly. So you know, I don’t know, we just struggle on by.

Interviewer: So who sees [name 2] at the moment?

Respondent: Sorry, who’s…?

Interviewer: Who’s looking after [name 2], you know, in terms of professionals?

Respondent: So we have a good set of carers, that, like I said, they came through when he was with the mental health, so to start off, we weren’t paying towards his care because it was under the mental health thing, I think that’s why we ended up with a good number of hours. And we kind of stuck with that same agency, they’ve been very good, I’ve been able to say, so right from the beginning it was, like, “Right, you need someone who’s going to be able to speak clearly to him so he’s got a chance to understand what you’re saying, and then you need to be able to understand what he’s saying.” So all the way along, we’ve had people that have been good in that respect, whereas his sister who’s in the care home, the quality of carers that they’ve had is vastly different, you know, the changeover of staff is just crazy. Every time his mum goes to see her, there’s always some new carer and there’s lots of carers that have been brought in from abroad, that [name 3] has not got a chance of understanding what they’re saying to her, you know. So that, to me, is very difficult, I think, for [name 3], whereas [name 2] carers have all been really good, you know, they’ve had the information from the HD Association, they’ve had some training and things like that, and they know how they need to speak to him. It depends on the carer, some of them talk too much, you know, and [name 2] is very much one of those, the first thing he says is, “No,” so you can say, “Right, do you want your breakfast?” “No.” That’s going to be his instant response. But you can also go, “[Name 2], do you want a fag?” “No.” “Well, I know you want a fag, so….”

Interviewer: He just defaults to, “No.”

Respondent: Yeah, he just straight away, it’s, “No.” So they have to check, they aren’t allowed to force things on him, whereas I can go, “Well, yeah, you are having your breakfast, then argue with me,” you know, I’m his wife. So you know, they’re learning, but certain things they can push it a little bit further, just for his own wellbeing, you know. At the moment, he is struggling to eat and I think he’s worrying about eating, so you know, he’s saying no to them more often than not, so then they start worrying, “Oh, he’s not eaten anything today,” and things like that, and you know, it’s just trying to find an even balance on getting stuff into him, you know, “Don’t worry about his not having vegetables today, if all he’s having is cake, that’s fine, just keep the cake and the cream going in, just keep some calories and I’ll worry about the other bits and pieces afterwards.”

Interviewer: So, [name 1], these carers, they’ve been really good, they’ve been trained by the HDA, so is it, like, always the same people coming in, like, more or less the same team coming in?

Respondent: Yeah, yeah. He’s had…they always introduce, if they try to introduce a new carer, they come round and they’ll meet him with somebody else. We’ve had some that haven’t worked, I think his very first carer, he told her to F off quite quickly because he just…she was just the wrong type of person. She was too…he didn’t want to be mollycoddled, you know, all the way along, we’ve tried to give him as much independence as possible, so even down with the cigarette, we still try to make sure he has a cigarette, so he’s got, like, we know he has a broom handle with a hole in the top and the smoke thing goes through so he can do the fag himself, have a smoke himself, you know.

[00:30:55]

Interviewer: Mm hmm.

Respondent: So yeah, so the girls are all sort of…he likes ladies, he likes the ladies to look after him, and so he’s never had a male carer.

Interviewer: Okay.

Respondent: But yeah, they will always introduce, and then if between the carer that’s showing the new person and myself and [name 2], if any of us think, “No, it’s not right,” we get the option to say no.

Interviewer: Okay.

Respondent: And that has been just recently, there was one, she was just a little bit too soft, so she wasn’t going to be able to get [name 2] to do what he needed to do, he was just going to walk all over her, so that was no good, you know.

Interviewer: Okay.

Respondent: So yeah, it…

Interviewer: And how did you…did you ring the agency, you know, and you were, like, “Hmm, it’s not working really.”

Respondent: Yeah, and the last time, it was actually the other carer that said, “No, she’s not going to do it,” and let them know. So I do have a good relationship with his team of carers, which is really good. It does cause problems, so just recently, we had his bathroom redone, and I knew that he couldn’t stay in the house, because it’s his bathroom and there was no way we could work round [name 2] being home. They knew he wouldn’t want to go into respite care, and the danger was if he went into respite care, that they would need to basically drug him up too much to keep him calm. Like I said, because my daughter had a child, that sort of tipped him mentally, he’s a bit more unstable these days, and when he’s at the top level for all of his medication, so the only thing that I’ve got to give him is diazepam, which is touch and go whether it works or not. If he’s too stressed or, you know, too anxious, he doesn’t touch it, so it’s all in the timing. So I knew if he went into respite, that what they would do is give him lots of diazepam, and he’d end up in bed, and then I was worried that he wasn’t going to walk again, yeah, same as his sister. So I actually took him on holiday, and we went in the caravan for two weeks. Unfortunately, the care agency didn’t have enough notice, so whereas I thought he was just going to be able to go on holiday, the carers would go with him, I could stay home and get the jobs done, it didn’t work like that. So the first week, I had carers come into the caravan to stay with him and I was able to come home for a couple of hours each day, and the second week, then I didn’t have any, because it was a mixture of they didn’t have enough carer cover, and there wasn’t enough funding.

Interviewer: Okay.

Respondent: So if the council had put him into respite, they’d have paid that, but because I didn’t want him to go in respite and I needed extra hours for the carers, there was a limit on it, which was a bit…a bit frustrating.

[00:34:23]

Interviewer: Yeah, it would still be cheaper to have the carers, yeah.

Respondent: Yeah, you know, so we only have so much money, but they were still very good, and they came out and I was able to get home at least once the second week in the end, mainly because the two ladies from the office came out and supported [name 2]. One of them was a normal carer and one was just the office lady, you know. So they did what they could, and we got the bathroom done, and that’s sorted.

Interviewer: Okay.

Respondent: But yeah, so I’m happy with the carers I’ve got. I worry every so often because [name 2] takes a dip and they start worrying about being able to support him anymore. So that is at the back of my mind all the time that, you know, eventually, are they going to actually say, “We can’t help you anymore,” you know, and we’ll have to change everything, which is not good. But so far, we’ve got past most of the problems that HD throws.

Interviewer: [Name 1], when this started with the carers, I mean, you said, you know, he had the mental health issues and he self-sectioned, and then care was arranged. Who arranged for the carers to start coming in for his mental health?

Respondent: So I think it was done through the mental health service, so he had a care coordinator at that point, that arranged it. And it was all, yeah, I’m not sure exactly who, but it was something to do with the mental health service.

Interviewer: But he was admitted to a unit then?

Respondent: He was, yeah, he self-sectioned a couple of times to get his meds right, and then I suppose the care co-ordinator at that point was appointed to him, and then I had to find the care agency.

Interviewer: Okay. Have you seen this care co-ordinator again after?

Respondent: So the care co-ordinators is within the mental health service are in high demand, there’s a real shortage of them. So over the years, they’ve changed many times. [Name 2] has a [antipsychotic treatment injection] every fortnight, so someone from the mental health service comes out and does that. So he still has a care co-ordinator, but we went, I think it was about 18 months without one, because there just wasn’t anybody to take on the role. And the last one he’s got at the moment, I don’t rate her that much, I’m afraid, not nearly as good as the ones that we’ve had in the past. I think the demands on their service, you know, are quite high and it…they’ve been good, and the psychiatrist that he has has been good, he’s getting towards retirement, so again, I worry what we’ll end up with if that changes.

Interviewer: Is the psychiatrist in the NHS?

Respondent: Yeah. So he’s based at [location 3] in [location 2]. So he’s been there, the first psychiatrist we went to see, [name 2] didn’t like. He prescribed [name 2] olanzapine, basically [name 2] went from a 34 waist size to a 38 waist size, and I went back to him and said, “Look, [name 2] just is eating all the time.” He said, “No, no, it’s not the drugs,” and I went, “Okay.” He says, “[Name 2] just needs to eat salads.” Now, if you’ve got HD, you don’t need lettuce, I’m sorry, you don’t need lettuce. So he was just, like, “You just don’t know what you’re talking about.” And I knew, because he came off the olanzapine and his weight dropped. He was on the olanzapine, his weight goes on. So at one point, [name 2] got pneumonia and ended up in hospital, his weight just dropped severely. So I said to the psychiatrist, or the doctor, I said, “Can he have some olanzapine,” he had some olanzapine, his weight went back on. So I know it’s not a side effect he puts on weight, it’s something to do with you always feel like you’re hungry or something.

Interviewer: Yeah, his appetite.

[00:39:22]

Respondent: But for the psychiatrist to tell me it wasn’t anything to do with the olanzapine while he put on weight, you just think…and then tell him to eat salads, it’s just, like, “You don’t know what you’re talking about, mate, go away.” So I’ve always refused to go back to him, so now we have…I think it’s Dr [name 4], he understands, he’s very good. But yeah, and then his normal GP is very good as well, and she wants to help. How much she knows about HD, I don’t know, but she does at least get things done when I need things done, if you know what I mean.

Interviewer: She provides a facilitator, yeah.

Respondent: Yeah, definitely.

Interviewer: Does he have a neurologist, [name 2]?

Respondent: He did, we used to go to…we went to [location 4] at one point, but that became a bit difficult. Then we did a spate of a couple of trips up to [location 5], and then I’m not sure how long ago that was, and then [location 5] was getting difficult to go to as well, so we stopped, and then I did ask if he could see Dr [name 5] in [location 2], and we had to go through [name 6], I don’t like her, I’m sorry. I’m quite glad you’re going to anonymise this, because I don’t like the woman. I asked if he could see Dr [name 5] because he’d never seen Dr [name 5] in [location 2]. He’d seen another lady, I can’t remember what she was…I don’t know what her title was. And I said, “Look, he’s not been seen by anybody for ages, I’d just like him to be seen by Dr [name 5], just to find out if there’s any new that he could do for him, or whatever.” And we ended up, we never saw Dr [name 5], she booked us an appointment with probably one of his other doctors, and it was a fairly useless appointment really, because they came round and said, “Oh well, you could try adding…” increasing one of the antidepressants that we’d been given, but a letter never got wrote to the doctor. So in the end, that took a couple of months before that happened.

So you know, I haven’t ben that impressed, as I say, with… And she came out to see us one time, and she was saying about how good the care home was that [name 2] sister was in, and she said, “Oh, the carers are fine there,” she said, “Because I trained them,” and I pointed out to her, “Well, all of those carers have gone because of the high turnover of staff.” I said, “If you ask me, that care home’s not that great.” But she was, like, “Oh no, I trained them.” So I don’t like her. I didn’t find her that useful, considering she’s supposed to be the HD specialist nurse, you know, she doesn’t seem that interested in helping. But that’s my opinion. I’m sure she’s a very nice lady.

Interviewer: Which is why I’m speaking to you, yeah, to capture your opinion. You know, you’re supposed to voice your opinion, that’s why, so don’t hold yourself.

Respondent: I found her, considering what HD is like, I didn’t like the way she also kind of slagged off the HDA. Now, I know it’s a charity, but they’ve got people in place that are there to support people with HD, and I haven’t used them a tremendous lot. I did go to a carers training thing one time, and it was [name 7] that was running that, and I found that really useful. I’ve done another thing that was a Zoom meeting that was all about supporting parents with children at risk. That was really good. I got some bits and pieces from that. And I just found that [name 6] view of the HDA was, “Well, they weren’t any good.” So when I said to her the care agency that we’ve got, [name 7] had done the training session for the carers, “Oh well, you know, that wouldn’t have been any good.” And you’re just, like, “You should be working together, you know, you should be a good team, because there’s not many people handling HD, so start bloody working together and you may…not slagging each other off.”

Interviewer: That’s a very good point, you know, and you’re the client, so if you see, you know, with any service really, you don’t like going to a restaurant and having people serving you food saying, “Oh, the chef is extremely like he’s not on a good day today,” you know, we don’t expect this, you know.

[00:44:53]

Respondent: No.

Interviewer: Especially not with health, you know, as you’re saying, there’s such few people either way that know about Huntington’s, you want to see them, you want to think at least that they’re working together.

Respondent: Yeah, yeah. And you know, I know the number of people with HD probably is going up, because you know, you hear about it more and more, but you know, we had that appointment, there was no…she didn’t phone afterward, or email, you know, just to check how it went, nothing. Nothing at all, and there’s been no contact since. So unless I push for contact with her, I don’t…no, you don’t get anything. So you’re kind of, like, you feel a bit like you’re just left to it. Yeah, you’ve got your diagnosis, now go and sort it out, you know. And it does sort of feel like…whereas before when he used to go to [location 4], we got a regular appointment, there isn’t anything… there’s no regular appointment for [name 2] to see anybody at all, he’s just, you know, “We’ll just leave him.”

Interviewer: And does he get seen, I mean, you’ve spoken about the injections with the mental health team, but is that it? Is that the only regular thing he gets?

Respondent: That is the only regular thing he gets now. And that changed, like I said, that’s changed, because it used to be his care co-ordinator that would come out and do the injection, she or he would check how I’m doing, how [name 2] is doing. And then, because we went…it must have been a good 18 months without anybody, you know, and now they’ve appointed this new lady, I’m still not sure what her…what she understands of HD, I don’t know whether she’s looked into it or anything. So you know, it’s…you udo kind of feel like you’re just left. I think if it wasn’t for the actual care agency that I’m using, they’re always asking, you know, “What can we do?” And they’ll say to me, “Do you want me to contact the dietician?” and I’ll go, “Yes please, go on,” and they’ll do it for me, you know. They’ve kind of gone above and beyond, I suppose, what their normal route is, and they’re very… I’m always trying to work ahead, so what’s the next stage going to bring up, you know, what do we need to do to try and…and they’re very much the same, and they know how the system kind of works, I suppose. So [name 2] has needed more and more care, so the hours have gone up, and it’s normally them going, “Right, [name 1], we think we need to put in for some more hours,” and initially it was a bit of reluctance from me, because it is weird when you’ve got carers in your house, your house is not your own, or it doesn’t feel like it’s your own.

Interviewer: It’s like you’re always on…yeah.

Respondent: Yeah, that’s it, and I tend to not be at home with them, when they’re there, I go out, which, you know, I get work, keep myself sane as such. So you know, the more hours they are there, the less I’m at home, the less I feel like I’m at home. But he needs the support. And then they’ve changed the way the funding works now as well, that, say, like, I said to them, “Okay, I don’t want anybody on Christmas Day,” so those four hours, they used to bank those four hours, and they knew if I said, “Okay, I want to go up to see my family in [location 6], can I have a carer extra…” “Yeah, you’ve got four hours banked, we can do that.” Now they’ve changed it, I think there were some other care agencies that weren’t, they were banking hours, charging the council the money, and then not giving the hours out. So now they have to charge exactly what they’ve used each week, there’s no flexibility. So now if I want to do anything for myself, I now have to say, “Okay, well, I’ll look after [name 1] Wednesday morning, just so I can have Wednesday evening instead.” You know, which messes with his routine a little bit, but that’s the only way we can do it now. So when we used to be able to bank, it was a lot easier.

Interviewer: I understand. And when you go to the GP, you said, you know, that she was quite nice and she’s trying to help, is she the person looking after your health, or you know, yourself as an individual, who looks after you?

Respondent: Me? So yeah, we do have the same GP, yeah, it is what it is, isn’t it?

[00:50:24]

Interviewer: Is, like, the mental health, even if the care co-ordinator is not always showing up, I mean, I’m just trying to figure who, you know, if you need…

Respondent: So at different times, I have been offered support through different services. I’ve always kind of just said no, but I did take it up at one point, but it kind of felt like I was just going and moaning, a bit like I’m doing now, I’m just having a moan to you really.

Interviewer: No, but I need your moans, because I need to put it together.

Respondent: Well, hopefully, in my moans, you’ll get stuff that’s relevant.

Interviewer: It’s a very positive moan.

Respondent: So yes, I have had carer support at different times, but I just find I’d rather come and moan to my mother-in-law, you know, or my sister or something instead.

Interviewer: So when you moan to professionals, is it not…the moan doesn’t develop from being just a moan, is there no plan or action?

[subject had a cough attack, paused interview to recover]

[Part 2]

[00:00:00]

[redacted, subject had a cough attack]

Interviewer: I was asking you in terms of you, who looks after you, you were saying you look after yourself basically.

Respondent: Yeah.

Interviewer: Okay, is there anything that you think would be helpful in terms of, like, for you personally to get more support?

Respondent: No, I can’t think of anything particularly. It just…sometimes it feels in the evening, that it’s just me and [name 2] and you know you just think, “Is this…this is my life?” It is what it is at the end of the day, like, it could be an easier life, I could try and put him in a home, but that doesn’t seem fair on him, he don’t want to be, so you know, we do what we can do. Even if just now he’s not under the mental health, he’s under adult social care, but there doesn’t seem to be…I suppose it’s their understanding of what it’s like to be looking after him, but I think that’s carers across the board, isn’t it, that, you know, you are just stuck. But before I could say to [name 2], “Right, I’m going to just nip to the shop or something, I’ll be back in an hour,” now I don’t think I could trust him at all. He starts getting anxious, and if you’re caring for somebody else, you could probably say to them, “Look, just stay in your bed, you’re safe in your bed, don’t move,” and as soon as I walk out the door, he’s up out of his bed, and he starts…he worries that I haven’t left him cigarettes, and he’s going in parts of the house that he knows he shouldn’t go in. Like, I treated myself to a nice vase a long time ago, and I said, “That’s on the mantelpiece, you do not go near the mantelpiece,” because you’ve got the arms and legs and everything going, haven’t you? And yeah, so he’ll go and he…he’s not knocked the vase off yet, but he knocked a tealight off instead, because he was searching for cigarettes. I’m, like, [name 2], why are you searching for cigarettes?” I said, “You can’t light it,” I said, “The door’s locked, you can’t go out, you know you’ve got to go outside for cigarettes, so why are you searching?” and he’s got no answer. So you know, when it comes to…

[00:05:06]

Interviewer: He’s just fixated on it?

Respondent: Yeah, he’s fixated, he’s got to find his fags, and he just… So HD is just not logical, you know, anyone else you could say to them, “Just stay in your bed, because you’re safe, the carer will be here in 20 minutes,” or whatever, and the logic just goes out the window.

Interviewer: Which you don’t think social services get that perspective?

Respondent: I don’t think so, but you know, then I suppose, that’s not their job to, I suppose, I don’t know. So it’s just this business of if I want to do something, I’ve got to then try and work out how I can do it, you know, so like, I’ve got a party for my nephew’s little boy, his birthday party, I’ve got to then try and work out how I can cover [name 2] at another time, so this affects my work, you know, because the cover I get at the moment allows me to go to work, so you know, I’ve got to miss a couple of hours of work so that I can look after [name 2] so that I can go out at a weekend and…

Interviewer: Yeah, it sounds like the shift from banking hours to have this more rigid…it’s really messing up your, yeah, there’s no flexibility as you said.

Respondent: Yeah, there’s no flexibility, so then that kind of feels like it’s restricting me even more, you know, living with someone with HD restricts you anyway, because you’ve always got to think about them first, but now it’s, like, “Okay,” I can’t just say, phone up, whereas before, I could just email and say, “Can I get a couple of hours here and there,” you know, but I can’t do it now.

Interviewer: Is your daughter in [location 1]?

Respondent: Yeah, so my daughter still lives at home.

Interviewer: Okay.

Respondent: So yeah, and my granddaughter as well.

Interviewer: The baby, yeah, I thought…

Respondent: Yeah, so her husband to be is in [redacted institution], so they made the decision it was better for her to stay at home, than to actually move out, he was in [country away] when she was first born, and it was, like, “No, that’s not going to work for you going to [country away] , stay at home.” So yeah, the house has changed and that’s what…

Interviewer: That’s why it’s unsettling, okay, yeah.

Respondent: Yeah.

Interviewer: I mean, it’s really, yeah…

Respondent: Yeah.

Interviewer: I hadn’t picked up that she was with you, yeah.

Respondent: Yeah, so you know, so if I haven’t got carers, like, my daughter will go, “Oh, can I go out for a drink with work friends,” and I went, “Yeah, okay, I can look after [name 8] but if your dad’s not playing ball, you’re going to have to come home,” you know, because I can say to [name 2], I’ve got [name 8], she’s only a baby, I’ve just got to look after her, and he’ll be going, “I want a fag,” “Well, you’re going to have to wait until I can actually put [name 8] down and she’s safe first.”

[00:08:25]

Interviewer: Yeah, you only have one pair of hands.

Respondent: Yeah, that’s it, but he doesn’t understand that.

Interviewer: Yes, of course, yeah.

Respondent: He’s just fixated on what he needs, you know, so then I have to say to my daughter, “Okay, as soon as I need to, if he starts getting difficult, you’re going to have to come straight home,” which she’s had to do in the past.

Interviewer: She’s not been tested?

Respondent: She’s not been tested, not yet, no. I think they have decided that they won’t have any more children until she’s been tested. I think when they had this baby, they kind of rushed into it a little bit and weren’t fully understanding, you know. She only knew so much, but I don’t think partner was as aware. He was aware, it’s not like they didn’t know, but they’ve not…

Interviewer: Well, it’s one of those things, you never know until…

Respondent: Yeah, the same as I did, do you know what I mean? When I decided, “Okay, I’m just going to have her,” it was, like, “Well, surely they’ll come up with a cure before it affects her,” you know, you just hope, don’t you, that something will change.

Interviewer: [Name 2] is not doing any trials?

Respondent: No, no, he probably would have done originally and then it gets to that stage where it becomes too difficult for him to do it, you know, and like, that lumbar puncture and things like that that was going on, there’s no way he’s going to keep still long enough for someone to do that.

Interviewer: Yeah, yeah.

Respondent: And because his mental health was not good, asking him questions, he’s not going to get a real answer, you know.

Interviewer: It sounds like it’s a little bit too advanced for this.

Respondent: Yeah. But you’d have meetings with the psychiatrist and they’d be asking [name 2] stuff, and I’m going, “But that’s not true,” you know, I mean, at one point, he totally decided I was having an affair with someone, it was, like, “I haven’t got time to have an affair, I’m trying to hold it all together.” But in his head, that was true, and you just think…and he’s telling the psychiatrist this, and they’re believing what he’s saying, it’s just, like, “Hmm, this is not quite right here.”

Interviewer: When that happens, do you say something or sort of, like, do you wait until he’s out, until [name 2], they take [name 2] to do some walking or whatever, and then…

Respondent: Yeah, and then I’ll put them straight basically. Yeah, you know, but of course, their first thing is to the patient, isn’t it, so you know, they’ll be asking [name 2] sort of questions and luckily I’ve been in all the meetings, but if I wasn’t, then who knows what they would be coming up with, you know. “Yeah, it’s safe for him to go home.” It wasn’t safe for him to go home because he was still having the wrong thoughts in his head.

Interviewer: Yeah, so sort of, like, they ask [name 2] the questions because [name 2] is the patient, and then [name 2] gives his version, you know, what he sees as the truth, you know, in his head.

[00:12:00]

Respondent: Yeah.

Interviewer: And then you have to find a way of getting the right information to the professionals in a more diplomatic way, and not to upset [name 2] because you’re going home with him.

Respondent: Yeah, that’s it, it’s me that’s got to deal with it. You know, at one point when we were trying to move house and I asked, he was getting quite aggressive and not wanting to move, and he actually… I said to him, “Right, I’m going to take you to your mum’s for the night,” he got in the car and then he decided, no, he didn’t want to go to his mum’s and actually pulled the handbrake up when I was driving, to stop the car. So you know, there was things that he did that just he wouldn’t normally do, and I ended up, I called the police, and they just said there was nothing they could do. Nothing they could do to actually get him to go to his mum’s for me, you know, so I’m trying to pack all the stuff for the house while I’ve still got [name 2] there, not wanting to move, and it’s, “Ah, this is just…” But there was nothing, nothing I could get, no sort of help at all at that point. But definitely when the mental health was going, that was the real, real awful time, you know, I think at one point I literally walked into my doctor’s surgery and just burst into tears and said, “Someone’s got to see me,” and then they did, luckily the doctor did see me. But you know you just…you get to a stage, the crisis point, and the system just doesn’t work, they don’t understand HD, you know. When he was sectioned, he was in the hospital with lots of people with mental health issues, and they’re nothing like HD, you know, there were people that had drug addictions and things like that. I didn’t feel he was safe. And now, like, I did actually say to that [name ], I turned round and I said, “Look, where would he go now when his mental health’s not fantastic, and he now can’t look after himself, he couldn’t go the place he went initially, because he was able to feed himself and things like that. Now he can’t do that, so where do they send him now?” She said, “Well, there’s nowhere in [location 1].” He’d have to be sent off God knows where to some hospital.

Interviewer: Yeah, and as you were saying, you are always thinking about what’s next then, like, you want to know, “If this happens, this is what I need to do, and if this happens…” In your head you want to have that map for when…because in crisis, I mean, it’s not the best moment to think through as well, it’s not when you…you should make the decisions with a clear head. [Name 1], is there any social worker coming, reviewing…?

Respondent: No. At one point, I don’t know how it happened, but there was, like, an emergency one (social worker) put in place at one point, and she actually got all of the relevant people together, it was on a Zoom meeting, so she got the GP and she got the care agency involved, I was there, and the psychiatrist, and they actually all got to talk. And that was quite good, it was the first time that had ever happened, you know, everyone sort of got together and the GP was talking to the psychiatrist and they were discussing, and you know, as soon as the psychiatrist said, “Oh, we could try this,” and literally the GP, I could almost hear her typing as she was doing the prescription up straight away, and it all just happened. And that as the first time I actually felt like, “Hey, this has just worked,” and that was because however this lady was, someone in social services, I don’t know, kind of arranged the meeting. And then I think at that point, we were able to access, we got a couple of extra hours a day, straight away. But then that person’s gone.

Interviewer: Oh.

Respondent: And now we’re back to, you know, nobody kind of co-ordinates it all together.

Interviewer: So that was one time?

Respondent: Yeah, yeah.

[00:17:05]

Interviewer: By magic, it’s almost like a blink of an eye, you don’t even know if it happened or if it’s part of your imagination.

Respondent: Yeah. So again, I’m lucky that the care agency, [name 8] that is in charge there, she sort of, like, thought ahead, “Look, we’re going to need the extra hours.” She’s found out how to deal with adult social care, and it’s gone…and we’ve actually got the hours, I don’t know how because I didn’t think we would, but it has happened. And they’re very good at recording…they record everything, so every time [name 2] bumps one of the girls, it gets recorded, which, you know, he’s not doing on purpose, it is his movements, but they record everything. So when they went to panel for the hours, they had a big file of reasons why he needed the support, so I think that’s why they got the hours, and that’s down to the efficiency of that care agency. If you’re with a different care agency, would you get the same sort of support, you know?

Interviewer: Was it like a big file, a proper…

Respondent: Yeah, probably not paper, it probably was…

Interviewer: When they come in to see [name 2], do they bring something with them?

Respondent: So they record everything while they’re working, they write down exactly what they do each time, they record all his medication that they give and everything, and then they have body maps for whenever he’s got, I mean, he’s always hurting himself.

Interviewer: Yeah, he bruises.

Respondent: Yeah, so they have all of that, so you know, because they record all of that and when I think of his sister in the care home, I know damn well they’re not recorded all the things that happen there, because his mum might find out a couple of weeks later, “Oh yeah, something happened with [name 3], she nearly choked,” or whatever, you know, sometimes they tell her and sometimes they don’t. So with this care agency, at least I know that they are recording everything. Sometimes it might be a bit silly, you know, “Oh yeah, he hit me with his hands in my stomach,” but because they’ve logged all those, it mean when they’ve needed to go for the extra hours, and eventually I think they may need to say, “Well, we need two carers at certain times,” they’re going to have all that information ready.

Interviewer: Yeah.

Respondent: I suppose eventually you’ve got this this CHC funding thing as well, now, I know when trying to do it for [name 3], the form that they sent was…it just was crazy what you had to, the person has to be like to get CHC funding. Whenever they’ve mentioned it for [name 2], I just say, “I’ve seen the form, he ain’t going to get it,” you know, you’ve got to be aggressive all the time and really difficult, you know, to tick all the boxes to get it. But at least this care agency are recording everything, so eventually, yeah, he might be able to get CHC, he might not.

Interviewer: When the time comes, [name 1], you know, just as a suggestion, I’m not here to give you clinical advice, although I’ve worked, you know, in the… So when it comes to CHC, it would be good to speak back to [name 7], because she’ll know what to do about the forms. There’s a language that you need to speak to, and it’s not about lying, okay, it’s not the case, it’s about painting the right picture basically.

Respondent: Yeah. I think I learnt that quite quickly when they first did [name 2] disability forms. His doctor actually, when she filled in the forms, did the worst case scenario for it, and he got straight onto the high mobility. Now, she could have not done worst case scenario and then he wouldn’t have…we would have had to keep fighting and fighting for the next step. But because she did, you know, and when I was filling it in, the woman, actually, I don’t know where this woman came from either, she came out and had to fill in the form, she advised me, you know, “You’ve got to do worst case scenario, what is he like at his worst.”

[00:21:53]

Interviewer: Yeah.

Respondent: “Not on a good day.”

Interviewer: And if you’re not home, what happens.

Respondent: Yeah, that’s it, so you know, all those things, luckily got sorted.

Interviewer: Okay. [Name 1], what would you say…what would make a real difference to you, right now? To you or to [name 2], like…

Respondent: I don’t know. I don’t know, you know…yeah.

Interviewer: If you think about, you know, your care is excellent, what does that look like?

Respondent: What do you mean? I think it’s just…no.

Interviewer: It doesn’t matter if it’s like that will never happen, like, what would it look like? Already, you know, this is a bit of a more direct question, you already gave me some pointers, you know, you said you went to the appointment and then after that, there was nothing, you know, there was no-one checking, you know, you’re saying if you don’t do the chasing, then nothing happens.

Respondent: Yeah, and I just think it just feels like [name 2] is kind of forgotten, when it actually comes to the HD side of things. You’ve got all these other departments helping, so, like, the mental health side of things, the GP helping where she can, but the HD actual specialist clinic, he’s not getting anything from. And it does just feel like you’re just left to it. And you know, every day there’s something new that gets thrown at you, you know, it’s like the other day, we try and keep him as independent as possible, so he’s got a drink holder thing, that has holes in it, that he can put his drink bottle in and he just leans over and he drinks from it. So nobody’s holding this bottle for him, he can do it himself. So he’s had…when he smokes a cigarette, he kneels on the floor, and he’s been coming down heavy on his knees to have his cigarette, so he’s ended up with housemaid’s knee, with his legs being really swollen, and it possibly has got infected, so they’ve been dealing with that. That has meant that he’s stayed in bed more because he’s more wobbly on his feet. I don’t know whether it’s the pain, because pain threshold-wise, they don’t feel pain the same, do they?

So we’ve had to adapt the way he drinks his drinks, so we’re always trying to think of different ways to change things to help him. You know, he’s now eating his food and drinking his drinks laid on his bed, it’s not ideal, because you know, I suppose it’s more of a choking hazard, he’s laid down, he should be sat up. But we can’t get him to sit up. He cannot sit up, he just slides down, you know, and you just always think, “Well, there’s never…” Is there any help for that kind of thing? But we just end up trying to fix it ourselves and work out how we can do it. He’s always had, well, we had to fight for it but we managed to get him a wheelchair. He doesn’t want to use the wheelchair, because he’s stubborn, and we got this wheelchair. Whenever I have had to use it, its’ not suitable. He slides out of the wheelchair. So they put a strap around the waist of him and he slides, and the strap cuts into him, yeah? I had to take him, he dropped a heavy brass ornament on his toe, he broke the bone in his toe, right, and he didn’t really notice, but it was very swollen. So I had to take him to the casualty, so I took him in the wheelchair because I didn’t know how long we were going to have to wait. Luckily, they rushed us through quite quickly, but at one point, he slid in his wheelchair so far down that he couldn’t pull himself back him, he got stuck. So then I had to get a couple of the nurses to, like, pull him back up in his wheelchair. And I’m now sort of, like, saying to the wheelchair people, “No, he’s not using it that much, but it isn’t fit for purpose.”

Interviewer: It isn’t fit for him.

[00:27:00]

Respondent: Yeah, you know, and the woman phoned me the other day and she says, “Can you get him to clinic?” and I said, “No, he can’t get to clinic, how do you think I’m going to get him to clinic.”

Interviewer: Which clinic?

Respondent: Well, they didn’t tell me what clinic it was for the wheelchair.

Interviewer: Oh, for the wheelchair, yeah.

Respondent: So they’re now going to come out, but it was just, like, I’ve been waiting months and months, and you know, then when they come out, [name 2] won’t want to sit in the bloody wheelchair anyway. But I need that, I need to know that I’ve got a wheelchair there, because if I do need to move him, you know…

Interviewer: Well, yeah, you need to know you can move him if you have to.

Respondent: Yeah, that’s it, and it’s, like, just to get him out so that he can have a cigarette, that’s the only pleasure he has these days is to go outside and have a fag, and now it’s getting difficult for him to walk, we have the wheelchair there, but it wasn’t even worth asking him to sit in it, because it wasn’t going to do the job.

Interviewer: Yeah, and creating a hazard, more than anything, it sounds like.

Respondent: Yeah, that’s it. And so often, he just ends up on the floor, so we’ve got to try and lift him up.

Interviewer: It would be good if you, yeah, I don’t know if he’s ever been seen by an occupational therapist?

Respondent: Yeah, we did have an OT, she came out, and we’ve now got one of these camel things, so last resort, if he was to fall and be on the floor, and we needed to get him up, we’ve got this pump thing that will lift him up.

Interviewer: No suggestion in terms of the chair, I guess, what would be appropriate?

Respondent: No.

Interviewer: Okay, that’s what I was thinking, yeah.

Respondent: Yeah, so we’ll wait and see whether we get the chair, now, the wheelchair. And the chairs that he’s had over the years for him to just sit in, have never been really fit for purpose. They tilt back but he still manages to slide.

Interviewer: Yeah, and they’re very rigid sort of movements, you can’t really bend.

Respondent: Yeah.

Interviewer: I see, so it’s bit like, okay, so who do you talk to about these things, who helps you make a plan.

Respondent: Yeah.

Interviewer: Because you have the problems, you don’t want to have to come up with all the solutions, I guess.

Respondent: No, but it does always feel like we’re having to…

Interviewer: Be creative.

[00:29:32]

Respondent: Yeah, and come up with the solutions every time.

Interviewer: Okay, [name 1]. Alright, we’re nearly at the end.

Respondent: Have you had enough of my moaning?

Interviewer: No, it’s just because I said I would take a maximum of 90 minutes, and we’re approaching it. How old are you, [name 1]?

[redacted]

Interviewer: (…) [name 1], is there anything that we haven’t covered today that you’d like to add to our chat? I like to leave, like, the five minutes before this ends, you know, if there’s anything else, something you thought I would ask you that I didn’t ask you? Or…

Respondent: I don’t think so, no.

Interviewer: You don’t have a big, like, “What we need is…”

Respondent: Yeah…no, I can’t think of anything, no.

Interviewer: You were saying it would reassure you if you had someone from the, like, Huntington’s Disease side reviewing [name 2], and…

Respondent: Yeah.

Interviewer: And knowing that that part is being looked after?

Respondent: Yeah.

Interviewer: Okay.

Respondent: Yeah, possibly just so I don’t feel like he is totally forgotten, you know, it just seems crazy that he doesn’t have contact with the specialist doctor in [location 2] in some way.

Interviewer: And who adjusts his medication? It’s the mental health team and the GP, I’m assuming?

Respondent: Yeah.

Interviewer: yeah, okay.

[00:31:59]

Respondent: Yeah.

Interviewer: So if the carers from the agency come in, and they’re, like, “Oh, maybe…” I’m not sure if they give you suggestions of, like, “Oh, maybe we should contact the GP because he might need, you know, diazepam or…” Like, they would ask you to contact the GP or they would contact them?

Respondent: So when it comes to the diazepam, we’ve had to kind of…we trust them because they know him, if you know what I mean, so they were a bit wary of giving him diazepam, but they’ve now got enough symptoms, or you know, signs that they use to think, “Okay, maybe he needs the diazepam.” But he’s no good if he doesn’t have it soon enough, so as soon as he starts to show some agitation or as soon as he’s…normally his teeth start grinding, lots, then they know, “Now’s the time to give him a diazepam.”

Interviewer: That’s, as you say, because they know him well enough to see those changes, the triggers?

Respondent: Yeah.

Interviewer: Okay, alright.

[redacted]

[End of Transcript]