[redacted]

[0:00:00]

Interviewer: So [name 2], can I start by asking you what is your experience of HD? You have started telling me but…

Respondent: Yeah, I cared for my mother-in-law alongside working, and bringing up our sons as well, but back then there wasn’t really any care, we had to fight for a social workers, she was at a home, my father in law had passed away. There were no carers to home care or anything like that. It was only the social worker, when it came, we were being called in the middle of the night by her because she’d fallen out of bed. My two sister-in-laws didn’t want to know. You know, they turned their phones off and everything. And then when we had to fight for a social worker and it came to the point where it was far too unsafe for her to live at home any more. We had no room in our house so she went in… the social worker did fight to get her, my mother-in-law, into a specialist HD unit in [Location 1], and the staff and the care for her was absolutely fantastic.

Interviewer: Where was this unit again, sorry?

Respondent: It was in [location1], just outside [location 2]. It’s [name 1] it’s called. It’s still there and still has a HD unit there. The staff there were fantastic. They couldn’t do enough to help us and explain things and that, and she was there until she passed away.

Interviewer: How long was that, [name 2]?

Respondent: She as in there for, I think, two years.

Interviewer: Two years, okay.

Respondent: Yeah.

Interviewer: And you were happy then with how she was being treated there? You felt…?

Respondent: Oh, yeah, yeah, yeah. They weren’t… you hear of nursing homes where people say, “Oh, they just put on a show, the carers, when you’re there”. They don’t. you could tell that they understood. They were all trained in Huntington’s disease, so they knew how to handle, how to speak, the problems with Huntington’s, you know. It affects different people differently. I mean I’ve noticed that with my husband now, his symptoms are completely different to his mum.

Interviewer: Okay. Was she more… what sort of… well, how was she with her?

Respondent: Yeah. He has a lot of anger issues. I don’t know if that’s just from being a man or what, but he has an extremely short temper and the… I don’t… some things are the same, but I mean [name 3] just let it go over her head. I don’t know if that’s because she’s a woman and he’s a man. Men tend to not deal with things better, but it just seems different. Like with the anger, the reasoning, trying to understand, and if he sys black and white you try to say, “No, black is black,” he’s right, you’re wrong. So, I’ve just learnt to agree and walk away, so to speak.

Interviewer: And your mother-in-law wasn’t like that?

Respondent: No, [name 3] wasn’t like that at all.

Interviewer: Okay. And the nurse at this institution, this home, do you know if she has access to any therapies or was it nurses or do you know what she had?

Respondent: There were nurses and there were carers. They could go for hydrotherapy. They had like specialist equipment, you know, not gym equipment, as such, but specialist stuff to help them try to strengthen the bit of muscles that they had. They were trained in the feeding, who could eat what, you know, from different stages. Things like that.

Interviewer: And you say that it was the social worker that really fought really hard to find a suitable place for [name 3]?

Respondent: Yeah, yeah. I mean this is going back, oh, about 15 years ago. So, I’m hoping it’s still as good.

[0:05:07]

Interviewer: Okay, and now, so tell me a bit about your husband’s experience with Huntington’s.

Respondent: So, he’s not had the genetic test. He woke up… I woke him up for work one morning and he was very confused and his memory had regressed about 20 years. He was talking about a friend and this friend had died 20 years ago. So, my older son was still at home and I shouted [name 4] in to the bedroom. The dog got and jumped on the bed, and [name 5] just said, “doggy”. So, I asked him what the dog’s name was and he looked at me with a look of, “Are you being stupid?” and he said, “It’s doggy”. So, [name 4] then got a picture of his daughter, our granddaughter on the phone, and he said, “Dad, who’s this?” and he went, “I don’t know”. So, we dialled, rang for the ambulance, and the ambulance came. They suspected a stroke initially, but when they got him into A&E, they did some scans and the scans showed the difference, you know the brain with the Huntington’s, with the… is it some cortex or something?

Interviewer: Yeah, it’s like the… there’s like plates of proteins that accumulate on the brain and it just totally intoxicates the brain.

Respondent: Yeah. So, I mean they’ve said he’s got manifest Huntington’s, because the neurologist has asked [name 5] a couple of times if he’s thought about taking the test, but [name 5] doesn’t want to. He doesn’t want to. He says, “What’s the point, I know I’ve got it?”

Interviewer: Okay. So, he was seeing a neurologist then even though he wasn’t tested?

Respondent: Yeah, yeah. I think it was about three to five years prior to that, we did think that he had, you know, like a bit of movement issues, so we did go see [name 6], who was the Huntington’s guy at [location 2]. And he did the motor tests, you know like with your hands and touch your nose and things, and he said he was confident at that time that he wasn’t showing any symptoms. He did mention the genetic test, but [name 5] said no. And he just said, you know, “If you’ve got any worries or anything in the future, come back and see us”. But then after he’d been in the hospital this time, [name 5] did say that a couple of junior doctors came and did the tests on him again, you know, the motor tests, he said, and they kept walking past and looking at him, you know, watching him in the bed and the chair and doing a lot of observations. And then he told me that they’d told him that he’d got it, but nobody told me. It was when he was discharged, one of our friend’s daughters is a nurse and she was reading… because I just looked at, you know, the discharge notes and I just said, [name 7], can you translate that into something I understand?” and she read it, and she did say, she says, “It is indicating Huntington’s with the changes”. Because of it being in the family, [name 7] had looked up, read up on it as well. Then when we went to go see [name 6], he did say, it is, they class it as manifest Huntington’s because he’s not had the genetic test. But even now, [name 5] does not want the genetic test.

Interviewer: So, they did the test on him while he was at the hospital?

Respondent: I’m assuming that, yes.

Interviewer: Yeah, okay.

Respondent: But neither of our sons want to have the test done.

Interviewer: You have two sons?

Respondent: I’ve got, yeah, two adult sons.

Interviewer: They don’t want to do the test, okay.

Respondent: No, they don’t. They don’t because they’d rather wait and see.

[0:09:59]

Interviewer: So, [name 2], I’m intrigued because in a lot of areas in the country, people can’t access a neurologist unless they’ve had the test. So, I’m curious into how did your husband get to see a neurologist? Was it like the GP that asked?

Respondent: Yeah, yes, it was a GP referral. At the time there was a GP that had been there since [name 5] was little, and she’d acted for his mum, you know, for when she needed anything when she was suffering with Huntington’s. And it was actually [name 8], the GP, that referred [name 5] the first time to the neurologist.

Interviewer: Okay.

Respondent: So, it was with help from our GP, family GP that knew his mum, you know, that had treated his mum as well.

Interviewer: Okay, so she already knew there was… I mean it was like an hereditary disease and she had…

Respondent: Yeah, yeah.

Interviewer: Cared for his mother and so she was alert to… what’s your husband’s name, sorry?

Respondent: [name 5].

Interviewer: [name 5], so she was alert to [name 5]’s, yeah, possible diagnosis.

Respondent: Yeah, she’d also looked… she was the GP for two of [name 3]’s sisters, who had HD as well.

Interviewer: Okay, so it was a proper family GP, so she was looking after different members of the family affected.

Respondent: Yeah, yeah.

Interviewer: Okay. Do you know if this GP still practises, [name 2]?

Respondent: She’s retired, unfortunately.

Interviewer: She’s retired, okay, yeah. I was curious to speak to her but as she’s… yeah, alright, but it’s good to know that this was… I mean it certainly sounds helpful that she was looking over the family, after the family.

Respondent: Yeah, she was absolutely amazing.

Interviewer: Okay. Alright. So, [name 5] as at the hospital. It sounds like they did the genetic test on him, possibly, without even [name 5] realising.

Respondent: Yeah.

Interviewer: Okay. He was discharged. You didn’t know he was actually diagnosed like formally with Huntington’s until the exams were reviewed by the neurologist and that you had asked your nurse friend to translate it for you.

Respondent: Yeah. I mean at this time, we were still coming out Covid, so I couldn’t go and visit him in hospital, so he was in there ten days on his own.

Interviewer: Oh, okay, so this was during Covid. Yeah, alright.

[0:12:51]

Respondent: Yeah.

Interviewer: Okay. And then he was discharged back home.

Respondent: Yeah.

Interviewer: And you saw then the neurologist at the clinic appointment, is that…?

Respondent: Yeah, yeah.

Interviewer: Okay. So, what happened after that?

Respondent: He just said that there was clinical trials, if he was interested in going into them. [name 5], at that time, [name 5] was still dealing with the diagnosis and he said, “I don’t want to do anything”. So, he just sees him every 12 months just to check on how he’s doing. He’s gone in last year and he’d lost a little bit of weight. We do have help. We have like the speech and swallow team and the psychologist and the… I can’t remember what it’s called, occupational therapist. I can just call them and ask for re-referrals for different things. We’ve had extra handrails put in the house, you know, from the occupational therapist. She came and did a survey of the house. We’ve had a wet floor shower room put in instead of the bath. The speech and swallow team have been out three times, three separate times, you know, blocks of so many visits, and the psychologist, she’s also been out. He is on the list for a tablet, you know with the (?) to help him with his speech because he does lose his speech, or his speech, days, some days he can wake up and there’s no speech or very little speech.

Interviewer: Okay, so is he going to… is it a voice work or something that you’re doing?

Respondent: Yeah, so what they’re doing is we’re on the waiting list. The lady will come out and she’ll tailor make one of these tablets for [name 5]’s interest, things like that, so that he can use that when his speech isn’t working, he can use that and the tablet will ask the questions for him.

Interviewer: Okay, okay, so it’s like to assist his speech.

Respondent: Yeah.

Interviewer: And [name 2], all these teams, like they’re coming from [location 2], is that right?

Respondent: Yeah, yeah. Yeah, the [location 2] teaching hospitals.

Interviewer: The what, sorry?

Respondent: Is it [location 2] teaching hospitals, it’s a trust.

Interviewer: Okay, okay. The appointment [name 5] has at the neurologist every year, how does that go? What happens at the appointment?

Respondent: He just asks him how he’s getting on. He’ll test his motor skills, do his weight, his height. I think it’s just really a check-up to see what’s changed in the last year. He does suggest trials, but [name 5] is not interested in anything like that.

Interviewer: So, do you find these appointments helpful?

Respondent: Yes, they are. I mean sometimes, you know, he says things that I’m unsure about, I can ask [name 6] and he’ll point me in the right direction.

[0:16:52]

Interviewer: Okay, so it’s an opportunity for you to ask questions?

Respondent: Yeah, yeah.

Interviewer: Okay. And when you need something in between because you have this appointment once a year, when you need help, who do you contact?

Respondent: If it’s medical, the GP. If it’s speech, to do with his speech and swallow or getting, you know, help in the house, moving about, I just phone… it’s neuro rehab. I’ve got the number direct to them, so like speech and swallow, physio, psychology. And then they’ll put me on… they have actually told me that Huntington’s is… if you’ve got Huntington’s, you’re pushed up the list, up the waiting list.

Interviewer: Okay, for the rehab?

Respondent: Yeah, yeah.

Interviewer: Okay. And are these people from the same team? Do they speak to each other? I mean do you seem to… how’s their communication?

Respondent: I think it goes onto a central database, I assume. I’ve never really asked them.

Interviewer: But do they seem to know…

Respondent: (overspeaking) his records, I’m assuming, goes onto his records so they can see who’s been and when and what’s happened.

Interviewer: So, when they come and see [name 5], they seem to be informed about what has happened, you know, with previous appointments…

Respondent: Yeah, yeah.

Interviewer: Previous professionals.

Respondent: Yeah, yeah.

Interviewer: Okay, that’s good. And with the GP, does he… is he informed or you just go to them with a very specific sort of like, you know, [name 5] is getting more agitated or is it more direct things?

Respondent: There’s no direct. He goes to the GP for his asthma and his repeat prescriptions. The psychologist changes his antidepressant. He was on fluoxetine and the psychologist said that mirtazapine would work better to settle him at night if he took it at night. So, then they sent him to the GP and then the GP did the prescription.

Interviewer: But you wouldn’t go then to the GP for Huntington’s-related concerns?

Respondent: If it was something different to speech and swallow or… I know if it’s something to do with physio, it’s better to ring [location 3], and they’ve told me to ring them direct rather than go to the GP to get a referral on. Anything else is just for the GPs, or even if I’m unsure, if he suddenly develops this new symptom, I’ll speak to the GP. We have an online consultation, so I’ll just put a message on in there and then one of the GPs will ring me.

Interviewer: Do you prefer these online consultations to face to face?

Respondent: If they need to see him face to face, they will ask me to take him up to surgery. I would prefer that rather than having to get him up then to sit and wait in the waiting room.

[0:20:44]

Interviewer: Yeah, I understand.

Respondent: Yeah. And it’s easier doing this online consultation rather than ringing and trying to get through on the phone as well. I think if [name 5] was on his own, he would struggle to manage that.

Interviewer: Yeah, okay, it sounds like you’re managing his care.

Respondent: Yeah.

Interviewer: So, is the GP also aware of these appointments with the other professionals, or do you tend to do a summary for them?

Respondent: Yeah, he does. When we’ve been to see the neurologist, he sends us a copy of the letter that he sends to the GP, which goes on [name 5]’s GP notes. The GP that he’s registered under at the practice is aware of Huntington’s as well.

Interviewer: Okay, and is he the one now seeing you usually, or is it random?

Respondent: It can be random, but I mean we don’t really go to see the GP. The only time he goes up to the practice is for his asthma review every year.

Interviewer: Okay, yeah, for other chronic conditions he has.

Respondent: Yeah, yeah. The Huntington’s tends to be managed through the neurologist.

Interviewer: Can you ring the neurologist if you’re struggling with something?

Respondent: I do have his secretary’s number and the neurology admin number So, you know, if I need… if I have any concerns, I can. I also, rather than bother the neurologist or the secretary, I can email [name 9]. She’s the specialist Huntington’s advisor through the Huntington’s Association for [county in England]. I can email her as well and she can point me in the right direction for things.

Interviewer: Okay. Yeah, that’s really good. And so are you happy with the support you’re getting?

Respondent: Yeah. Yeah, I know where to go and who to contact things, and if I’m unsure of who to contact, I can either get in touch with [name 9] from the HD Association, or I can just contact my GP, and failing that, if it’s physio that he needs, I’ll ring the neuro rehab, same with speech and swallow, I’ll just ring the neuro rehab and ask for a referral.

Interviewer: Okay, yeah. It sounds like you’ve mapped out quite well who are your people and who can help you with what.

Respondent: Yeah.

Interviewer: Was it easy to get your head around this?

Respondent: I think because I looked after his mum, I know more of what to expect. It’s not come as a big shock of what’s coming. I know more of what to expect, even though the symptoms have manifested completely different.

Interviewer: Yeah, you’ve been through it once, yeah.

[0:24:40]

Respondent: Yeah.

Interviewer: Okay. So, right now, what’s the most important thing about [name 5]’s care?

Respondent: Making sure he’s happy and relaxed so he doesn’t get in a bad mood.

Interviewer: Yeah, you’ve mentioned he can have a bit of a temper.

Respondent: Yeah, yeah. But I have got coping mechanisms with the help of the psychologist. We’ve got these coping mechanisms for him to follow to, you know, calm him down. And if that fails, I just walk out of the room and leave it rather than stay there and try and reason.

Interviewer: Yeah, you have strategies. Okay.

Respondent: Mmm, yeah.

Interviewer: So, [name 2], who checks on you as a carer?

Respondent: Nobody. There’s nothing for carers. I have been in touch with Carers UK. I did have some counselling sessions at first and then our next-door neighbour both sides, we tend to, one morning every four weeks or so, we’ll just go out, have a coffee and we’ll moan about our other halves.

Interviewer: So, you have a friend that you can…

Respondent: Yeah, yeah.

Interviewer: Okay, that’s really good. The counselling with Carers UK, you reached out to the charity?

Respondent: Yeah, my mum told me to get in contact with them.

Interviewer: Did you find the counselling helpful?

Respondent: Yes, it did make… it helps talking to somebody that didn’t know me.

Interviewer: Yeah. And why did the sessions stop?

Respondent: You only have so many sessions. They only give you so many sessions. I mean she did say if I needed them again just to get back in touch.

Interviewer: Okay. So, from a carer point of view, is there anything you need? I mean do you feel is there something that should be in place to support carers?

Respondent: Yeah, I mean like time to themselves, but with [name 5]’s Huntington’s, he doesn’t like anybody else looking after him, whereas [name 3], his mum, would have anybody and anybody. I mean he doesn’t have a really good relationship with his sisters. One really over-fusses and overcompensates, but she overcompensates for mistakes she made towards him earlier on in their lives. And [name 10] next door, I mean she’s been on holiday with us when the boys were little and everything, she’ll come in and chat with him, but he’s very… he’s a man’s man and I think when it comes to it, when he does need to have carers in the house, I don’t think he’d let them shower him.

Interviewer: So, you haven’t had carers yet?

Respondent: No, we don’t need them yet.

Interviewer: You don’t need them, yeah, okay. But you worry that when you do need, well, if you do need carers that you think he won’t react well at having strange people…

[0:29:24]

Respondent: No, that’s right, yeah. I don’t think he’d… yeah.

Interviewer: Even in the house, does he accept that his sons help, or does it have to be you?

Respondent: Me with his personal hygiene. They do… I mean they take him out for a ride in the car, things like that. They can help him, you know, move about the house, but with his personal hygiene, I don’t think he’d let them do it. He’s a proud man.

Interviewer: Okay, so basically it feels like it has to be you.

Respondent: Yeah. And I mean at the moment, while he’s still able to, I just stand there and… might sound awful, I just stand there and I make him wash himself. He’s still capable of doing it, so I will tell him. He’ll say, “Can you do this?” I’ll say, “No, you can do it”.

Interviewer: So, when you go see your friend, for example, does [name 5] stay at home by himself or does he stay with company?

Respondent: He’ll stay at home by himself, it’s just we’re not out long and he knows that if he needs anything, to ring. I’m not far away. I don’t go… I’m literally just five minutes’ drive away.

Interviewer: And he knows how to ring you and…

Respondent: Yeah, yeah, he can still use his phone. He can still use social media and things.

Interviewer: Okay, so it’s more like as the disease progresses and you see that he’s quite attached to you caring for him…

Respondent: Yeah.

Interviewer: That you might, well, be trapped a little bit.

Respondent: Yeah. I have said though that I want to keep him at home for as long as is humanly possible.

Interviewer: Okay. And how do you… what do you think is going to happen then? As the disease progresses and you want to keep him at home?

Respondent: He will have to accept carers coming in to help him in and out of bed because there’s no way I can do it on my own, and I will make him understand that, you know, you’ve got choices, you either… if you want to stay at home, you have to accept that X, Y and Z are going to happen or if you’re not willing to accept that, you will have to go into a home.

Interviewer: Yeah, yeah.

Respondent: And I am rather abrupt with it when I say it.

Interviewer: Yeah. I think you’re being quite realistic. It’s still hard, of course.

Respondent: Yeah, yeah. I think if I’d not seen his mum go through it, I think I would be coping with it differently.

Interviewer: Well, I’m sure you did cope with it differently the first time.

Respondent: Yeah, yeah. And it does help, there’s like an online chat forum for the Huntington’s Disease Association, I’m on that, and I do get… even just reading through different posts, it gives me ideas, thinking, “Oh, I could do that. Oh, that’s good advice,” you know. It does help with things like that, plus you’re like anonymous on there.

[0:33:30]

Interviewer: Yeah, that’s really good because, again, basically you’re learning from each other’s experiences and not every single one of you needs to go through the same pain. You know, you learn as you go, but you can learn from people that have gone through it already.

Respondent: Yeah, yeah.

Interviewer: Yeah, that’s really good. So, it can be anonymous then, you’re saying?

Respondent: Yeah.

Interviewer: The post and everything. Okay, that’s good. Do you attend any support group or…?

Respondent: There’s none actually in the [location 2] area. I think the nearest one is [location 4], which is a bit of a drive. There’s none close. I do keep going on and checking, but there isn’t any close.

Interviewer: Okay, that’s a bit of a shame. Sometimes, I mean during Covid maybe there were online support groups, yeah. I don’t know your particular branch in there, I don’t know if they do anything, but you’re saying in person they don’t exist.

Respondent: Yeah. I mean I’m a member of the support group with the cancer that I had, that’s a rare cancer and we have a support group and there’s a charity thing, association. And we’ve all been through the same thing, you know, because it’s such a rare cancer, there’s not a lot of general knowledge. So, I am a member of that, and I’ve known them… some of those people for ten years, and we still keep in touch.

Interviewer: That’s wonderful because, again, especially as it’s rare, yeah, you can find that peer support in there.

Respondent: Yeah, yeah. And that’s why I was determined to join the Huntington’s Disease Association.

Interviewer: So, I mean it sounds like you may have as well some complicated health periods at times.

Respondent: Yeah.

Interviewer: Yeah, okay. How do you find managing your own health and your husband’s alongside it?

Respondent: Well, touch wood, I should be having my last scan for the [redacted] cancer this year, and if that’s clear, I will be finally discharged after 15 years.

Interviewer: Oh, wow.

Respondent: Because I had [redacted number] recurrences.

Interviewer: When was the last one, [name 2]? When was your last?

Respondent: Sorry?

Interviewer: When was your last recurrence?

Respondent: It will have been ten years ago. And then I’ve also had [redacted] cancer [redacted] times. I’m discharged from there now. And I have annual mammograms until I’m 60 because I’ve had breast cancer. So, between myself and [name 5], we’ve really had our money’s worth out of the NHS.

[0:37:15]

Interviewer: Yeah. Well, you’re also sparing a lot of money to the NHS by taking care of [name 5], so…

Respondent: Yeah, yeah.

Interviewer: So, you’re doing us a favour as well.

Respondent: Yeah.

Interviewer: Okay. Do you work?

Respondent: No, I left work to look after [name 5].

Interviewer: How do you manage finances?

Respondent: My dad was very savvy and as soon as me and my three sisters started working, he made us pay into a private pension pot. So, I took some money out of that to get stuff. We paid the car off, you know, paid bills off that we wouldn’t need to pay any more, things like that. And then I get my carer’s allowance each week. And then [name 5] gets… we put in for personal independence for [name 5], and he got it awarded straight away for ten years.

Interviewer: For ten years, okay. And who helped you? I mean was there anyone helping you apply for PIP?

Respondent: There was. There was a lady. She’s in neuro, well, she used to be a neurological nurse years ago. She retired and she works for a neurological charity, and they do, you know, support services. We’ve known her for quite some years, even before HD. And it was [name 11] that came and helped us fill the form in because I just looked at it and thought, “Ooh”. She filled the form in, helped us fill the form in.

Interviewer: That’s wonderful. And that was through the charity then?

Respondent: Yeah, yeah.

Interviewer: Okay. Have you ever had a social worker involved, [name 2]?

Respondent: Not with [name 5], no.

Interviewer: Not with [name 5], yeah. Yeah, with your mother-in-law you’ve mentioned.

Respondent: With my mum-in-law, we did, yeah.

Interviewer: Okay. Alright. And I mean these funding applications can be quite daunting, so do you feel yourself going more, like with these things, asking the charities more than health professionals?

Respondent: We don’t really need funding for anything. I think I would, rather than bother [name 11] again, although she’s does help, you know, she’s retired and I feel like she’s doing it out of a favour of being a friend, I think I would try to go more towards the professionals rather than bothering [name 11]. I don’t want to, you know, think I only get in touch when I need something.

Interviewer: Okay. And with [name 5]’s, well, humour that can be explosive, it’s been the psychologist helping you. Has there been any mental health team, or is the psychological connected to the mental health team?

Respondent: Psychology, I don’t know, I’m not sure. We’ve not had any mental health input, just the psychologist taught him coping strategies.

[0:41:21]

Interviewer: Okay, that’s fine.

Respondent: But I just know the mental health team in [location 2] and in [location 2] in particular, where we are, I know they’re just inundated and there’s just such a long waiting list.

Interviewer: Okay. But for now it sounds like it’s working, whatever it’s…

Respondent: Yeah, yeah, what we’re doing seems to be working.

Interviewer: Okay. Do you want to talk anything about your children? You’ve mentioned that they’re both adults, but they don’t want to get tested.

Respondent: Yeah, they’d just rather wait and see. My younger son, he’s a [role redacted], and when [name 5] was first diagnosed, his boss did a discreet enquiry to insurance companies and even though if [name 12] had the genetic test and it showed he was positive, even though he had no symptoms, he would not get insurance. So, that would be his job over, plus he doesn’t want… neither of them want the cloud hanging over them. They’d prefer to wait and see. With [name 4], the older one, he does have a little girl, [name 13], our granddaughter, she’s [5-10]. He’s divorced from her mum. And it’s rather… there’s a lot of animosity. But HD has nothing to do with it.

Interviewer: Yeah, I mean there’s divorces and marriage problems much beyond HD, yeah.

Respondent: Yeah. But [name 4] doesn’t want to have the test either because I don’t think either of them would be able to cope mentally with it, with the result if it came back they’d got it.

Interviewer: Are they under the same GP as [name 5]? Would it be the same…?

Respondent: Yeah, yeah, we’re all… yeah, we’re all at the same surgery.

Interviewer: Okay.

Respondent: I mean they do laugh about it, their genetics are really good because they’ve got the possibility of the HD gene and also have a cancer gene, that’s why (overspeaking).

Interviewer: Oh, yes, that’s a lot to rewrite.

Respondent: Yeah. I’ve had a genetic test done and I have got a cancer gene, so they said basically, “Let’s just hope that we’ve got either none of them or one of them. We don’t want both of them”. So, I mean I know it scares them, but we do laugh about it as well, you know, the irony of it.

Interviewer: Yeah, yeah. I can imagine. At least they have, yeah, a good sense of humour.

Respondent: Yeah, yeah.

Interviewer: Yeah, that’s good.

Respondent: They’ve got to have a sense of humour. They’re [location 2] [redacted] fans.

Interviewer: Yeah. I mean it lives with you every day, isn’t it, with your family every day, so it’s good to lighten up a bit. Okay.

Respondent: Yeah.

[0:44:42]

Interviewer: [name 2], what do you think… I mean you’ve mentioned you want your husband to stay at home for as long as it’s humanly possible.

Respondent: Yeah.

Interviewer: What would quality mean? I mean aside of that, what would quality mean to you and you think your husband as well? If care is well… you did say you are happy with care, but how do you think I can measure this in terms of success? What should other people be aiming for in terms of making, you know, offering their families and… what would quality look like?

Respondent: I’m not sure. Different people look at… you know, have different opinions. It would help enormously for whoever is doing the caring that they have an understanding of Huntington’s. I mean if it came to it that I needed to get carers in to come and help me with [name 5], I would want them to understand Huntington’s disease and what symptoms are, what helps them, you know, what the problems could be, things like that. You know, specialist… not specialist carers, but they need to… because there is caring companies that specifically deal with dementia patients or Parkinson’s, things like that, but it would be nice just to have an understanding, you know, even a small understanding of the disease, it would help them to care for the patient or [name 5] better.

Interviewer: Yeah, no, I understand. I mean the same way you had your mother-in-law going into a home, there was that understanding and you felt she was well taken care of.

Respondent: Yeah, yeah.

Interviewer: Yeah, okay. That’s good. Do you know, is there… I don’t know if you’ve looked into places around closer to you, aside from that one that will take, you know, Huntington’s disease patients.

Respondent: If [name 5] had to go into a nursing home, I would fight tooth and nail to get him back into [name 1], where his mum was. I know that’s the only one close enough to us.

Interviewer: And the social care support was funding her stay there or do you know?

Respondent: I think social care would fund it, but, you know, I’d look at that when it was coming closer to needing that. I mean it came to it where I needed to get carers, if I kept him at home and I needed carers to come in, I would look at a caring company that has knowledge of HD.

Interviewer: Yeah. And as you were saying, you go into…

Respondent: Yeah, if there is any care companies that have knowledge of it, you know, the home care ones.

Interviewer: Yeah, and you go to the HDA, like the online forum, for example, that’s the sort of thing I guess people also discuss.

Respondent: Yeah, yeah.

Interviewer: Okay. [name 2], I’m going to ask you a couple of boring questions now that I ask everyone. How old are you?

[redacted]

Interviewer: Okay, okay. I mean we’re all about discussing what sort of resources you’re using and what’s working well and what’s potentially not working so well. It does sound to me that between you and [name 5], you’re the one least looked after, which is very similar to many of the conversations I’m having. That’s one of the takes I get from our conversation today. But it also sounds like you have very well in your head like which professionals are involved and who can help with what, so you’re being really good at identifying all of these, which, as you were saying, it’s coming from your experience as well and learning the hard way as well.

Respondent: Yeah.

Interviewer: Okay. Alright.

Respondent: I know it’s the same as when I was diagnosed with the rare cancer, I went online and I found all these different resources myself to help me, you know, to help.

Interviewer: Yeah, you’re very proactive, you know. You’re physically looking. You’re not just sitting in your own problems, you’re tackling them.

Respondent: Yeah, yeah.

Interviewer: Okay. [name 2], do you have any suggestions to improve future interviews? Anything I should do differently?

Respondent: No, you’ve been really good.

[redacted]

[End of Transcript]