[0:00:00]

[redacted]

Interviewer: So the idea is that we will have a nice conversation, it should take a bit less than an hour, now, accounting for this bit that we’ve spoken. And I do want you to be completely honest, you’re actually the first person from [location 1] that I’m interviewing, so I have no clue of care there, so it will be good for me to get this understanding. So can I start by asking you what’s your experience of Huntington’s Disease? How have you come in contact with it?

Respondent: In my husband’s family, his mother had Huntington’s, and [name 3] is one of three sons, and [name 3] was the only one, my husband is [name 3], he was the only one to have Huntington’s out of the three sons. But his mother, she was one of three, she had two brothers, and they all inherited the faulty gene.

Interviewer: Okay. So [name 3] had another two uncles with Huntington’s, aside from his mother?

Respondent: Yeah, and a lot of cousins. I think his uncle [name 4] had [8-11] children and all of them had Huntington’s.

Interviewer: Oh my goodness, really?

Respondent: Yeah, yeah.

Interviewer: Jesus, okay.

Respondent: I know, it’s horrible.

Interviewer: Yeah, some people think because it’s 50%, that you know, if you have two children, one is going to get it and one…

Respondent: Yeah.

Interviewer: Yes, it doesn’t…it doesn’t go like that.

Respondent: Yeah.

Interviewer: Sadly, yeah. Okay, so when was [name 3] tested then, he did…?

Respondent: [2010-2015].

Interviewer: Okay. And then he was tested because he as getting symptoms, or why…do you know why did he decide…?

[00:09:36]

Respondent: Because he was getting the symptoms.

Interviewer: Yeah .

Respondent: We decided, because we decided not to have children because PGD and CVS and what have you wasn’t available then, and we just decided, we said, “What’s the point in testing if we’ve decided not to have children anyway?” You just, you know, we buried our heads in the sand, if I’m honest, but it wasn’t until he started showing symptoms, not sleeping, that was one of the main symptoms really, he was really struggling to sleep, struggling to concentrate, and I just said, “Look, [name 3], I think it’s time to be tested, because you can get help with that, you know, there’ll be drugs available to help you with the sleeping, to help you with things.” So he got tested on the [Winter date], oh no, that was the day we got the result. He didn’t have any counselling beforehand, which in hindsight, I think would have been a good idea. Because he was showing symptoms, they decided not to give [name 3] the counselling, and just go straight in for the test. But his depression was horrendous afterwards.

Interviewer: After he got the result?

Respondent: Yeah. Afterwards. We sort of knew, but I think once you’re told for definite.

Interviewer: Yeah, of course.

Respondent: Maybe if he’d have had some counselling beforehand, I would definitely say that that is something that should be done with everyone. I know now it’s still not happening, because I was at a Huntington’s meeting on Sunday just gone, and there was people there who’d been tested and not had any counselling or anything.

Interviewer: Is this because they’re not offered, or, I mean, I don’t know if you know…

Respondent: Well, it wasn’t offered to [name 3] but this was 10 years ago, isn’t it, and I think things have changed. I know some people have the test results given to them by letter, definitely a no-no on that.

Interviewer: By letter, getting the results on….?

Respondent: Getting the results in a letter, yeah.

Interviewer: And where is this testing happening?

Respondent: [Name 3] testing actually happened in [location 2] because we were living in [location 2] at the time, but that said, [location 2] had a very good Huntington’s medical group, medical care, they had a specific occupational therapist, a specific speech and language therapist, the dietician, and the physiotherapist, they had a Huntington’s nurse, and I think her name was [name 5] who was the consultant there. So she had this group of people who were dedicated specifically to Huntington’s, and because we’re from up in the [location 3], once [name 3] was tested and positive, I decided we needed to move back home to be beside the family. And the [location 4], I don’t know if you’ve heard of that up here, where a lot of research goes on, I thought we’d be in good hands up here.

Interviewer: What’s the name, sorry, can you repeat that?

Respondent: It’s called the [location 3].

Interviewer: Okay.

Respondent: And it’s a massive medical research place in [location 4].

[00:13:19]

Interviewer: Okay.

Respondent: But when we first moved back, we didn’t have the group, the sort of Huntington’s dedicated medical people, you know, the physiotherapist and all of that. So I found it hard to get my head around that because we were seeing [name 5] who was the neuro consultant for Huntington’s at [location 3], but a lot of the other services came from what they call local services, so from your GP, and it was in my mind, the [location 2] set up was far better because there was people you could ring, you know, when [name 3] was having anxiety, and doing strange things, there was people I could ring to actually speak to to just confirm, “[Name 1], that is normal with Huntington’s, this is what people do with Huntington’s,” you know? But I didn’t have that in [location 4]. But as time’s gone on, [name 5] now does have a dedicated Huntington’s nurse and as far as I’m aware still, a physiotherapist and an occupational therapist, which are dedicated to the Huntington’s team.

Interviewer: But this wasn’t available?

Respondent: Yeah, it’s something I think they’re trying to set up regionally, but obviously it’s down to funding, and everything else.

Interviewer: So in that time, when you moved back home and I mean, it sounds like a lot of this team wasn’t yet built.

Respondent: No, it wasn’t.

Interviewer: If you needed help, you know, if you needed advice regarding [name 3] Huntington’s, who would you speak to/

Respondent: I’d be trying to get through to the GP, or sometimes I did contact [name 5]. We have a place here called [location 5], a neurological hospital, which is specifically for neurological conditions, which is actually a really good hospital, and [name 3] was admitted to there for a period of time so they could monitor him, and in fact, I think he there for about eight weeks. So a lot of Huntington’s patients do go into [location 5] because it’s specifically for neurological conditions and brain injuries and stuff like that, which is really what Huntington’s is, isn’t it, a brain injury. And so that is a good part of being in the [location 3]. But I just found the connection, having to go through doctors for some things, having to go to the [location 4] for some things. If it’s centralised, wherever, like it was in [location 2] and the team all worked together in [location 2], it was a really good setup. Whether they still have that, I have no idea. But as I say, over the years, they’ve managed to get, you know, specific people moved onto the team and specifically deal with Huntington’s patients.

Interviewer: So [name 1], you had a situation, and as [name 3] disease progressed, what happened, who else was helping?

Respondent: Well, to be honest, I’m not someone that seeks a lot of help. We had the occupational therapist come every few months, the speech and language therapist, but she wasn’t part of the Huntington’s team, she was with the GP, the local services, [name 6] she was nice, she became…you know, would come out and see us. But in respect, we did have quite good care if I’m honest, but I just think the [location 2] setup was the best because, you know, you’ve got a dedicated team, you could have their phone numbers, you could ring them directly, or email someone direct, it was just that help there, where in [location 3] it was more fragmented.

Interviewer: Okay, so you had, like, the line was open, back when you were in [location 2], it was just a straight channel to get help?

Respondent: Yeah.

[00:18:04]

Interviewer: While in [location 3]…?

Respondent: Having that contact, is, for me, is key, being able to email someone or speak to someone directly is a massive thing, because… Because I’d seen [name 3] go through Huntington’s, but when you don’t live with someone with Huntington’s, and you’re sort of left floundering a bit wondering why they’re having these strange issues going on, and each day there’s something new with Huntington’s, isn’t it? You know, they do, obviously in the early stages, they’ve got this anxiety and then later stages, it was physical, it was mental, it was everything, but it was just fantastic in [location 2], just to be able to contact people directly either by telephone or email and just speak to someone. Yeah.

Interviewer: In [location 2], I mean, you weren’t there a long time, I mean, you didn’t stay long after [name 3] was diagnosed, right?

Respondent: No.

Interviewer: I was going to ask…

Respondent: We stayed about 18 months or something like that.

Interviewer: Yeah, okay. I was going to ask if people used to check on you without you having to ring them, or did you still have to do the chasing?

Respondent: They used to…I think in [location 2] they would ring, yeah, they would ring and check every couple of months. We did get letters to see – in [location 3] I’m talking now, [name 5] up in [location 3] but it would be every six months, something like that. But what I didn’t understand, [name 2], is [name 3] would go in to see the consultant, [name 5] and he would say…what I didnt’ get is they weren’t monitoring him, you know, say, doing tests, memory tests, things like that, his walking, but you know, looking at how his mobility was, they didn’t do anything like that, and I felt, “Well, how can they tell how he’s progressing from one six months to the next?” They didn’t weigh him. In my view, those sort of things are key for the consultant to see, then, “Oh, he’s lost a bit of weight,” or…it was up to me to keep saying, you know, “He’s lost weight.” He’d walk in and he’d say to [name 3], “Oh, how are you?” and [name 3] would say, “I’m fine.” And I would say, “He’s not fine,” you know how it is.

Interviewer: Yeah, yeah.

Respondent: With Huntington’s, people don’t like to admit that there’s anything wrong with them. But I thought that was something lacking, that they didn’t do a little memory test with him, or a little, you know, “Touch your nose,” you know, the cognitive tests.

Interviewer: Yeah, I know, I’ve done all the…

Respondent: Yeah, and that, to me, because I thought, “How can you gauge whether [name 3] has declined, or anything?” All he does is talk to him, and I literally was answering the questions for him because [name 3] didn’t know how to answer the questions. So I thought some physical tests would have been good.

Interviewer: So what were they doing then? What sort of questions were they doing?

Respondent: Just asking, “How are you?” Not much really, you know, we were in and out in 10 minutes, they didn’t really do anything.

Interviewer: And then they would check with you on how things were, like, separately? Or just in front of [name 3]?

[00:21:49]

Respondent: No, just when [name 3] was there, but [name 3] couldn’t really…eh would say, “Oh, I don’t know,” the doctor would ask him questions, and he would just say, “I don’t know, I don’t know.” But I just thought some physical tests might have been a good idea, just to see how his mind was, you know, what memory he had left, and things like that. But the other thing, for me, is people with Huntington’s suffer from horrendous anxiety, and that was the biggest thing for [name 3], his anxiety, going out the house, and getting him to these consultants visits, he was just a mess by the time I got him in the waiting room. And I thought it would be nice if they came to the house sometimes, you know, like, visited at home, because for people with Huntington’s and the anxiety that the suffer, I mean, I’ve got some videos of [name 3] and he’s in the waiting room with the doctor, at the consultant, and they’re just horrendous. And I had to end up videoing things that [name 3] did to show the consultant, because I don’t…sometimes I felt like, as though he thought I was making things up, you know? So if there was home visits, it would be…

Interviewer: So the home visits, were they ever offered, or was that something they offered at all?

Respondent: No, they didn’t offer that at all. But Huntington’s patients are a lot happier in their own environment, I mean, [name 3] anxiety was one of the worst things for him, but you know, at home, the doctor might have got more out of him, if he’d have visited him at home, he might have been able to answer the questions, but because he was so anxious, he would just say, “I don’t know, I don’t know, I don’t know,” to every question the consultant asked him.

Interviewer: And [name 1], I mean, when you were there then at the appointments and [name 3] was so, like, blocked by his anxiety and just unable to think, I imagine you were answering, you know, the best that you could, did you ever feel that you couldn’t be honest because [name 3] was there?

Respondent: Yeah, you do feel a bit like that, yeah, because you don’t… The thing is, they still understand, they’re not stupid, people with Huntington’s aren’t stupid, they’re still in there, somewhere, and they still understand, but yes, you do feel like that, and I did feel like I couldn’t answer everything because [name 3] was there.

Interviewer: Yeah. That should be something quite, I mean, easy to fix, right, if the team is aware that people with Huntington’s lack insight either way, so a lot of…even if they do answer, as you’re saying, it’s, “I’m fine, everything’s fine,” so would you find it beneficial if you had had, like, 10 minutes separately?

Respondent: Separately, yeah. I would.

Interviewer: Okay. Was a social worker ever involved, [name 3]?

Respondent: Absolutely hopeless, social services, hopeless. To be honest, I did everything myself, because they never replied to emails, you couldn’t get in touch with them or…no, they were rubbish, social services, absolutely useless.

Interviewer: YOu just gave up on them?

Respondent: Do you know, [name 3] had two social workers, and not one of them ever came to see [name 3], not one of them have ever met [name 3].

Interviewer: Really? And these were before Covid, so there wasn’t even Covid to give an excuse.

Respondent: No, no, they never met him once. And we got a referral to [location 6] from the doctor, absolutely brilliant, they were superb. We had a social worker there, she was fantastic. Because we asked [name 5] about doing [name 3] wishes, you know, when he got really poorly, what he wanted, like, he didn’t want to be PEG fed, he didn’t want the feeding tube, he didn’t want to be resuscitated, and we said, “Can we…?” You know, “This is what [name 3] wishes are, what can we do?” and we asked the consultant and he said we had to go and see a solicitor and get the solicitor to write it all down. I said, “Oh, right.” But when we got referred to [location 6] the social worker there organised the doctor to see [name 3] and organise [name 3] wishes. Honestly, I cannot say enough good about [location 6], they were fantastic.

[00:27:13]

Interviewer: So the Hosprice had a social worker there?

Respondent: They have social workers, they have doctors, they have nurses, they have everything.

Interviewer: But the neurologist didn’t have a social worker?

Respondent: No. No. That’s what I’m saying, it’s fragmented, because you’ve got the [location 4] and then you’ve got your location authority with your social worker, then you’ve got your GP, the speech and language therapist, and the district nurses coming in to check his skin and, you now, they just turn up without an appointment, without ringing, to say, “We’re coming in.” You know, Huntington’s people don’t like things landing on them, it has to be, you know, “We’re going here, we’re going there.” So no, I couldn’t praise them enough at [location 6], they were absolutely brilliant.

Interviewer: And who came up with this need to discuss end of life decisions before, you know, in time?

Respondent: Well, [name 3] came with it to the doctor at [location 6], to discuss, you know, that he didn’t want to be fed by a tube, and what the implications of that were. He did understand that, but I have lasting power of attorney for him as well. You know, he did understand, but he’s always said all along, “I don’t want to be kept alive by a tube,” so…

Interviewer: How did you sort out power of attorney, [name 1]?

Respondent: We did that 10 years ago, [name 3], when he was first diagnosed, but he was alright then, you know, the solicitor came and interviewed him to make sure he had capacity, so we did that a long time ago.

Interviewer: Who advised you, was there anyone advising you to do this?

Respondent: No, I’m pretty…I do a lot of looking on the internet, and obviously checking out what, if [name 3] lost capacity, what would happen. So I just decided to get it done and we got a solicitor to come and do it, and they came to the house and they interviewed [name 3] and he was more than happy, because you know, these were the early stages of [name 3] Huntington’s, and he was alright then. But yeah, I’ve got some myself, even though I’m fine and I’m in good health, you just…the thing is, if you don’t have it, it’ sone of the things I tell people, not just someone who’s ill. Everyone, I’d say, really should have this power of attorney, because nobody…everyone I spoke to, whether it was the consultant, the social worker, “Have you got power of attorney?” or they wouldn’t speak to me, so I had to send them, you know, copes of the power of attorney. So it’s really important, so I think everyone should have it, not just someone who’s ill. But we obviously knew [name 3] would lose capacity and that’s why I got it done straight away.

Interviewer: And when he was at home still and with his anxiety, that seemed hard to manage, was he getting any support from mental health services, [name 1]?

Respondent: He did, he got support from something called [location 7] up here, again, it’s something separate from everything else, but they had a psychologist, she was absolutely…she was a young girl, just out of uni, and she came to the house to see [name 3] to try and, you know, work out what was causing him this anxiety. And one day I stayed in the house and I was just doing the ironing and he was alright, and she was there for an hour. The next she came, I said, “I’m going to nip to the shops while you’re here with [name 3],” and she said, “[name 1]…” when I got back, he was sweating, like, that’s what [name 3] did, he shook and he sweated. And she said, “[Name 1], I’m going to write to the GP about getting him on some new medication,” and she did, and he did put [name 3] on some new medication. So she was really good and then [name 3] used to go to the counsellor at [location 7] once a week, and sit and talk and I’d just wait there with him, not in the room, but then he would go in with the lad called [name 7]. He was a volunteer. But it was closed down. And that was really good, yeah, but this was called [location 7].

[00:32:12]

Interviewer: [Location 7], did you say?

Respondent: Pardon?

Interviewer: Did you say [location 7]?

Respondent: [Location 7], yes.

Interviewer: Okay.

Respondent: It’s right opposite the [location 8] up here, I think it’s privately run, or it’s like a charity-run thing.

Interviewer: Yeah, it sounds like it.

Respondent: Yeah, but that was really good, and the counselling, going to see this lad, [name 3] would go and talk to him, because he wouldn’t talk to me about anything, I used to try and, you know, say, “If you tell us what’s causing it, I can help you,” but he couldn’t tell us what caused his anxiety, he didn’t know, he would just say, “it’s one of those things,” that’s exactly what he said, “It’s one of those things.” And I said, “[Name 3], are you scared that people will look at you because you’re unsteady on your feet, or that they’ll think you’re drunk or…?” But he wouldn’t tell me, and of course, when he went to see the counsellor, the counsellor couldn’t give me, it was confidential, he couldn’t tell me what [name 3] had said. So I couldn’t really…

Interviewer: Yeah, you wanted to help, but you were caught a bit between….

Respondent: Yeah.

Interviewer: A rock and a hard place, isn’t that the expression?

Respondent: It is, yeah.

Interviewer: Okay, alright, and so he was getting this counselling and, like, the psychologist came through [location 7] which sounds like it was a charitable service.

Respondent: I think, yeah, because he was a volunteer, the counsellor who did it. I mean, the building is still there and they have disability scooters and all disability aids, you know, and they’ve got, like, a showroom, and this was something…I think it was like a charitable thing, some sort of charitable thing.

Interviewer: And so the psychologist was then able to write to [name 3] GP and ask for medication?

Respondent: [Name 3] consultant, yeah, [name 5].

Interviewer: Oh, to the consultant, okay. And…okay, alright. I’m surprised he didn’t get support, like, through the GP, like, referred to a psychologist or, you know, to a mental health team, there was nothing like that?

Respondent: No, no.

Interviewer: And [location 7]…

Respondent: Sorry, [name 2], I asked the GP how many patients he was treating for Huntington’s, at the practice, at the [location 8], and [name 3] was the only one.

[00:34:59]

Interviewer: Okay, yeah, so not much experience.

Respondent: Well, no, and I’m not blowing my own trumpet here, but I think I have more experience than the GP because I live with [name 3].

Interviewer: Yeah, no, you’re the person who knows best, yeah.

Respondent: And that’s something I think would be a great thing for somebody to do, the consultant maybe, go and…you know, these back to the floor things, there was a programme once where the GP went and lived with the patient for seven days, and I think… I know he’s an expert in his field, in neurology and when it goes wrong, but he’s not an expert of living with someone with Huntington’s and how it affects their daily life.

Interviewer: Did you invite him?

Respondent: Pardon?

Interviewer: Did you invite him?

Respondent: No, no, I don’t think he would have come anyway.

Interviewer: I’m asking because I have heard of carers inviting their neurologists to come, you know, not to stay for a week, but to spend the weekend. I’ve heard this. They said no, but they were invited.

Respondent: I think it would be a great idea. There was a television programme on where a GP did, he had a woman who was having seizures, like, loads of seizures every day, and he didn’t understand how it affected her life and he went and stayed with the family for a week, and I just thought that was fantastic, because you actually see, you know, real time issues that affect the family though her seizures.

Interviewer: Yeah, as you were saying, it’s like you felt that they almost weren’t believing in you and you had to do, like, some recordings.

Respondent: Yeah, videos, yeah.

Interviewer: I mean, if you had stayed with the psychologist, for example, at the appointment, she probably…it would have been like the other time when everything was just fine, and because you left, she could see the difference and truly believe.

Respondent: Yeah, that’s right, yeah.

Interviewer: And [name 1], did [name 3] have any carers coming into the house at some point or…?

Respondent: He did eventually, for the last year, it just got too much for me, I didn’t have any…you know, I gave up my job to look after him and everything, I just didn’t have any time for myself, so we got the care company and they sent the same two carers all the time. There was one lady who her daughter had Down’s Syndrome, so she understood the anxiety and the…I have to say, the carers were brilliant, really good. But one of them was actually an old family friend of [name 3] who worked for… So [name 3] had his own little company, and when he said…”When I saw the name [name 8], I thought, ‘Oh, I used to work with a [name 8],” and I said, “Well, that was [name 3] dad.” So that was nice, that he sort of knew the family. But yeah, the care company were fantastic, they tried as much as they could to send the same carers every week so [name 3] got used to them. It was hard at first, but he did get used to them and they didn’t…they just took him out for a walk in his wheelchair round the park, that was really their role, to take [name 3] out. And swimming, we used to…he couldn’t swim, he forgot how to swim, but he loved going to the pool, and me and one of the carers would take him to the pool and then he’d have the inflatable, you know, to keep him up, and just doing exercise in the pool, and he absolutely loved it, he really loved going to the pool. So you know, I ended up being the second carer, but I didn’t mind, as long as [name 3] was happy. But I applied for continuing healthcare, and I got it, we got it, we got awarded it, and so that was good, because they paid for it. And the care company was more expensive than others, but they were worth the money, and I thought maybe continuing healthcare wouldn’t pay for it, but they did.

[00:39:46 ]

Interviewer: Okay, and how did you apply for CHC then? Was it then you just going on the web, on the internet and…?

Respondent: Yeah, reading up the background, preparing. Although the social worker that we had, although she never met [name 3], I met her on a Teams call, and I said, “I’ve done the application for continuing healthcare,” and luckily she used to be an advisor for the Huntington’s Disease Association, so she knew a lot about Huntington’s. Although she never met [name 3], she knew a lot about Huntington’s, so we did get it awarded, which I was surprised at, because I’ve heard some horror stories of people applying for continuing healthcare. But I’d done my background.

Interviewer: Yeah, it sounds like you did your homework.

Respondent: You’ve got to. I think the problem with continuing healthcare is people say, “Oh, apply for it,” but they’ve got no idea what they’re applying for, and they go into this conversation and they haven’t got a clue what the assessors are asking them. But yeah, so I did get that.

Interviewer: Okay. I’ll follow up after our talk when I send you a copy of the consent, I will ask you if you can share some of your social workers’ details because I am trying to interview a social worker. I never tell them where I’m coming from, I just say I know they’ve supported in the past or are currently supporting someone with Huntington’s, and then I invite them. But yeah, so just to let you know, I will ask you by email and then you can have a think.

Respondent: Yeah, the one that worked for the Huntington’s Disease Association, she moved on, and then we got this other one who never got in contact at all. Whether she’s still a social worker or not, I have no idea, but I’ll give you her details, I don’t mind at all.

Interviewer: Thank you.

Respondent: If I can find them, I might have deleted them off, you know, I got through every now and again and delete my emails, I may have deleted… I think her name was [name 9]. But we never met any of them. The one who worked at [location 6], unfortunately she retired, yeah, but there is a social worker at [location 6] in [location 3], they do still have a social worker, you can probably find her through…

Interviewer: Okay, thank you, yeah, that’s a good idea.

Respondent: Yeah.

Interviewer: Okay, so when did [name 3] pass?

Respondent: When did [name 3]…?

Interviewer: Pass away?

Respondent: [winter 2020-2025]

Interviewer: Oh wow, that was fairly recent?

[00:42:39 ]

Respondent: Yeah, the past [Winter month].

Interviewer: Okay. And was he in the Hospice, [name 1]?

Respondent: No, he was in respite care.

Interviewer: Okay.

Respondent: Yeah, he choked on his sick, he’d started having seizures, and he had a seizure and aspirated.

Interviewer: Okay.

Respondent: And choked on his sick.

Interviewer: I’m very sorry, it’s…

Respondent: Thank you…you know, it’s hard, because you feel left, you know, like, that was my job…

Interviewer: Yeah, and you are doing a brilliant job, and it was your purpose for such a long time.

Respondent: Oh, 10 years, two house moves, a bungalow renovation… I don’t know how I did it, I’m laughing now, I used to be terrible when I was left alone.

Interviewer: You’re wonder woman.

Respondent: I’ve been to the doctors and I’m saying, “I can’t understand why I feel so tired.” I’ll say, “Well, I cared for my husband for 10 years, did absolutely everything for him, and now…” I never felt tired, you know, but never mind, I’ve got my little dog, my little dog…

Interviewer: Yeah, but you know, you don’t, you know, you can’t…it’s not possible to downgrade it, because you were, like, it was 24/7, you know, for such a long time, and then just, poof, and then what? It’s such a mindset shift.

Respondent: It is. You just feel like you’ve lost your purpose in life, you know, it’s that sort of thing. I’ve got my little dog who I take out for a walk every day, but I don’t know…it’s lonely, obviously, but…

Interviewer: Yeah, and you had decided as well not to have children, so of course, like…

Respondent: No, I don’t have children, I’ve got a big family, I’ve got four sisters, who are fantastic, and you know, some really good friends that I’ve made over the years. I’ve got one particular friend who I made when I was [teenager], when we worked together, before we moved to [location 2], and we’ve remained… She’s more like a sister to us than a friend, so I’m very lucky in that respect, you know, to have such…

Interviewer: It’s not just lucky, it’s because, you know, something is attracting them to you as well, it’s not just luck, it’s because they see something in you and you give them something back as well.

Respondent: Yeah.

Interviewer: So, [name 1], did you get any support after [name 3] passed away?

Respondent: No, the doctor…I went to the doctor, because I’ve been having these palpitations, strange things going on, and he said, did I want to go to Cruse, because he said it’s… “I think it’s probably anxiety that you’re suffering with,” and I said, “But I don’t feel anxious, I don’t,” but I don’t know what it is, it’s like these palpitations that I keep getting. But he offered us Cruse counselling. But I did have counselling when [name 3] was bad, you know, with his moods and doing silly things, and to be honest, I didn’t get anything out of it, [name 1], because they didn’t understand Huntington’s. So I’m in a little group on Facebook, just a little private group that we talking and, you know, put things on there, and I feel more that people who’ve lived with it understand it a bit more.

[00:46:32]

Interviewer: Yeah.

Respondent: And [name 3] cousin, his wife, she was a hairdresser and she used to cut my hair years ago and they didn’t even know that [name 3] and [name 9] were cousins until I moved back here, so I talk to her sometimes because she…he’s just died, [name 9] just died a couple of weeks ago. But you know, we understand each other, we know what it was like. And it’s like anything, isn’t it, if you’ve gone through it, you understand it.

Interviewer: Yes, of course, you’ve been on the same boat, yeah.

Respondent: Yeah. [Name 1], can I ask you where you’re from?

Interviewer: I’m Portuguese.

Respondent: Oh, are you?

Interviewer: Yeah, yeah, my name is clearly not English.

Respondent: Whereabouts in [Location 8] are you from?

Interviewer: The centre of [Location 8], interior, towards [location 13]…sorry, towards [location 10], that’s what I meant, aligned with [location 13] but more to the interior of [Location 8], so centre. Have you been to [Location 8], [name 1]?

Respondent: I’ve been a lot…we had a holiday…that’s why [name 3] was in respite, we were selling the holiday home in [location 9].

Interviewer: Oh, [location 9], in [location 10].

Respondent: Yeah, we’ve had it 20 years, so we couldn’t go, so you know, it was one of those things that I just put on the backburner, but I said to [name 3], “Look,” I says, “I’m going to get it on the market, let’[s just sell it now, and I’m going to go out and get our personal things, the photographs, you know, photographs,” you know, we had a lot of personal things over there, “So I’m going to empty it, [name 3] and bring all the photographs back, and the DVDs and all of that.” And I went over, [name 3] was in respite, but all my sisters were looking after him, she’d had him out on the Monday, one sister, we had a rota going, so that somebody was there every day, all day with him, at the respite, taking him out for his walks as usual, and he died when I was in [location 10.]

Interviewer: Oh…

Respondent: I couldn’t believe it.

Interviewer: Yeah, I know, I mean, it’s…

Respondent: I was like, “How has that happened when I wasn’t there?”

Interviewer: I know, but you know, you were always there, so I mean, at some point something was going to happen.

Respondent: I’d only been there one day, I’d only been there one night and he passed away the next night, in the night, he passed away, at night there. But saying that, if it had have happened here, I probably wouldn’t have heard him choking on his sick, because he slept in a separate bedroom.

[00:49:10]

Interviewer: Yeah, that’s the thing, you know, you just…you never know, you know, it’s…something worse could have happened as well, you know, like a more… Yeah, it’s very hard not to have control over these things.

Respondent: Oh gosh, the guilt you feel is horrendous, absolutely, but then, if he was in respite, I wouldn’t have been there anyway, but I think if I hadn’t have gone to get the stuff back, you know…

Interviewer: But you were still taking care of your lives, you know, your life together, you were managing for him as well.

Respondent: We were married, well, 40 years, we had celebrated our 40th wedding anniversary in [Summer], and then he passed away in [Winter], just after his birthday. But yeah, so I do know [location 10] very well, we’ve been to [location 11]…

Interviewer: Oh, so I live close to [location 11], well, about an hour and a half from [location 11].

Respondent: Oh really? I love [location 11], the university?

Interviewer: Yeah, I know, it’s beautiful.

Respondent: Yeah, I love [location 10].

Interviewer: Yeah, me too.

Respondent: It was nice to be in [location 9] because you got the best of both worlds, because you’ve got the [location 10], and 10 minutes over on the ferry, I drive over the bridge, and you’re in [location 8] and I like the eastern side of [location 8], because to me, it’s not as commercial.

Interviewer: Yeah, yeah, less touristic, yeah.

Respondent: Yeah, so yeah, we spent loads of time in [location 8], absolutely loads.

Interviewer: I’ve lived nine years in England, so I’m a third English. Yeah, I’ve lived nine years in [location 12].

Respondent: Yeah, oh right. Because we’d got the apartment, you know, with [name 3] dying and evening, I just didn’t want to go and throw anything out, but I just went in February this year with a friend, and the carnival was on in [location 9] and that was nice. But I had…because [name 3] died, I had to get…it’s cost a fortune, to have to give the solicitor power of attorney, and everything’s had to be (inaudible 00:49:10) and translated from English, to get…because I have to inherit [name 3] half of the property now, because in [location 10], when you buy, you only own half of it. So it’s cost us a fortune to do that because I can’t sell it until I inherit [name 3] half. So I still haven’t got…it’s still not sorted out, but never mind, it’s just something that has to be sorted.

Interviewer: Just endless bureaucracy, you can’t even grieve properly, honestly.

Respondent: No, I know. I mean…but yeah. The solicitor’s sorting it out. But then I had…there was a problem with my NIA number, so that’s been another back in the backside. You know when you’re not there, I can’t just get up and fly to [location 10], I’ve got a little dog to look after.

Interviewer: Yeah, I know, I know. [Name 1], looking at everything you’ve gone through, you know, with [name 3] and [name 3] care, what do you think would have made a real difference to you?

[00:52:58]

Respondent: Well, I think just having someone to talk to sometimes, someone who understands Huntington’s, like I say, the [location 2] set up was good because inevitably, you know, as the disease progresses, they start doing odder and odder things, and you’re, like, “Is this what happens?” you know? Just having that support there, like, someone that you could email or pick the phone up and speak to, you know, that’s gone, but then it’s gone for everybody now since Covid. You know, you can’t get an appointment at the dentist, you can’t get an appointment at the doctors, but that, for me… And just when you saw the consultant, to do some physical tests, so we could gauge the progression of the disease. Because I used to say to [name 5], “What stage…?” because they always said there was five stages of Huntington’s, don’t they? “What stage do you think [name 3] is at?” And he couldn’t really tell us, you know, he could never tell us. And I thought, “Well, if you do some physical tests on him, his memory, then maybe that would give us some indication as to where [name 3] is at.”

Interviewer: Do you think that would have helped you manage, you know, sort of, like, “Where are we at in this journey?”

Respondent: Yeah, I think it helps you to plan a bit more for the future, you know, you’re thinking more…I don’t know, I just felt like if they knew what stage he was at, it might help just plan a bit for the future.

Interviewer: And if these things would have happened, what difference do you think it would have made in terms of, like, you know, would you feel less anxious, would you have got better access, or, you know, what do you think would improve?

Respondent: Well, I think it would have helped to understand more…don’t get me wrong, I mean, everyone…I know people have totally different journeys with Huntington’s Disease, but I just think having someone like a Huntington’s nurse, someone…although they don’t live with it, they see it on a daily basis, and they totally understand, and just have that reassurance that the things [name 3] was doing is Huntington’s related and not, you know, “These are common…” you know, the anxiety. He wouldn’t leave the house, he would run to the toilet when people turned up unexpected. For that person, if you’d have met the person [name 3] was before, he was the life and soul of the party, he was witty, he was funny, he was…you know, just great company, and for someone like that to running out the door, because someone was knocking at the door, running to the toilet or hiding in the bathroom, you know, all these strange things. But I was, like, “What the…?” you know, it takes a lot for you to get your head round.

Interviewer: Yeah, so you think it would have given him…

Respondent: For someone there to say, you know, “Is this normal for someone with Huntington’s to be doing this?”

Interviewer: So it would have given you more…even if they couldn’t change the behaviour, it would give you more confidence, more…that it was expected.

Respondent: Yeah, yeah.

Interviewer: Alright, [name 1], okay, thank you. I’m going to do a couple of boring questions, and then we’ll move on. How old are you?

[redacted]

Interviewer: Okay, alright. Okay, [name 1], is there anything that you’d like to add, something that you were, like, expecting that I would ask you that we didn’t cover?

Respondent: Not that I can think of at the moment. Is there anything, I’ll email you, I can’t think of anything at the moment.

Interviewer: Okay, okay, that’s fine. And do you have any suggestions of how to improve other interviews, you know, like the correspondence with you or anything that I should be doing differently?

Respondent: I can’t think of anything.

Interviewer: Okay, if you find it hard on the spot to criticise someone, so if anything comes up in your mind, let me know.

Respondent: You know, everybody’s suggestions are always good, aren’t they, as long as they’re constructive.

Interviewer: Yes, yes, but you know, if you have anything, if anything comes to your mind, do let me know.

Respondent: Yeah.

Interviewer: And for me, it was a pleasure to speak to you.

Respondent: And you.

Interviewer: And for me, I’m always, like, you know, I mean, I care for a six year old daughter, a relatively happy, healthy child, and it’s a headache sometimes, so I can’t imagine. And it’s something positive and happy, so I can’t imagine to, like, to dedicate your life to your husband and then having him gone. I think, you know, the palpitations and everything, it’s almost like, for me, it’s almost like grief is trying to, you know, it’s giving you signals through the body, but how to… I don’t know if people should have a bit more support when their loved ones pass away. I think you shouldn’t be left.

[00:59:39]

Respondent: Yeah, you do feel empty.

Interviewer: Yeah, I think you shouldn’t be left to it.

Respondent: No, I struggle in…so you know, we were a popular couple, if you like, and I’ve got lots of friends, but I do struggle in situations, like, they’ll say, “Do you want to come here?” but you know when you have a load of couples and I’m on my own, I’m starting to turn them down because I don’t feel comfortable being with a load of… And they’d go mad if they knew I felt like that, because they don’t make you feel uncomfortable or anything at all, it’s just me, you know, it’s just strange being on your own.

Interviewer: Of course, yeah.

Respondent: And I’m not backwards in coming forwards, like, I went to he [location 12] last year on my own with my little dog, I’ve just come back from [location 13], I went up to see the [location 14], just me and [name 9], you know, I’m a confident person, but it’s, like, just being around couples I struggle with now.

Interviewer: Yeah, of course.

Respondent: You know, but, yeah.

Interviewer: What’s your dog’s name?

Respondent: [Name 9]. She’s gorgeous, yeah. We got her for [name 3] really, she was the best thing, yeah, animals for people with Huntington’s. [Name 3], he would be careful stroking her because of his movements, in case he hit her, and I would say, “Stroke [name 9],” but he was a bit hesitant at times. But that’s one thing I would say to people, I’d recommend that you get a dog for people with Huntington’s, because they’re just… [Name 3], [name 9] was his world, you know.

Interviewer: So it’s like therapy.

Respondent: Yeah, it’s a therapy, definitely. She was a little rescue, I mean, she’s gorgeous, but honestly, it was, “[Name 9], [name 9], where’s [name 9]?” And she would go out with the carers and [name 3] in the wheelchair, and she just sat on his knee until they got to the park and then she’d have a little run around and then back on [name 3] knee. And honestly, he absolutely loved her. And so I do think the dogs, for people with Huntington’s. Not for them to care for, because they wouldn’t have the capacity to care for a dog.

Interviewer: Yeah, of course.

Respondent: You’d have to have…he wouldn’t have thought to let [name 9] out in the garden, I didn’t leave him at home in the end, on his own, ever. But he wouldn’t have thought, “Oh, she’s got no water,” or…he couldn’t care for [name 9], but he loved [name 9], absolutely, unconditionally, it was always, “Oh, where’s [name 9]?” And in the morning, when I’d had her for a walk, I would come home and she’d be on the bed with [name 9] and the pair of them would lie there, and he loved here, she was a really good little therapy dog for him.

Interviewer: That’s lovely, that’s it, I think animals, they can’t speak, but they still feel that caring presence, isn’t it?

Respondent: Yeah, oh, he loved her, absolutely loved [name 9]. She loved him as well, she knew. Do you know h what, dogs have a sense, as well, no doubt about it, she absolutely loved [name 9]. And when [name 9] died, his brother came over from [country abroad], and he stayed here for the funeral and I think [name 9]… he looks like [name 3] and he sounds like [name 3] and I think [name 9] thought it was [name 3] and she would jump up on the settee and lie on him, because he used to lie on the sofa when he came over from [country abroad]. He was tired and what have you, and she would jump up on him, and I said to [name 10], [name 3] brother, I said, “I think [name 9] thinks you’re [name 3].” But it was definitely good therapy. You need a calm one though for someone with Huntington’s, a jumping around dog probably wouldn’t be all that good for them, but…

[01:03:42]

Interviewer: It sounds like you were a wonderful trio.

Respondent: We were, we were, yeah.

[redacted]

[01:05:18]

Interviewer: I’ll follow up by email and I’ll send you a copy of the consent and I’ll ask you, you know about any social worker that may come to mind, and I’ll follow your suggestion as well to get in contact with the Hospice, because they may have someone in place.

Respondent: Oh yeah, the hospice, [location 6] was, oh… Like when [name 3] died, I got all the money from the funeral, I donated to [location 6]. The other thing they did, as well, [name 2], was [name 3] movements were bad, and they used to send ladies from the Living Well team and they’d come and do [name 3] a…at home, so he didn’t have to travel. They’d come to the house, I used to set his bedroom up as a spa, put this little waterfall and the candles and the pipe music, and you name it, he had it. And the ladies used to come here. One would go in with [name 3] and do him a facial, massage his hands and his arms and his legs and his feet, and he never moved, he was as still as anything, unbelievable. And the other lady would come into my bed, into the bedroom with me and do reflexology on me, and I would literally fall asleep. They’d come for half an hour, they were absolutely brilliant. I used to say, “I’ll pay for it,” but they said, “YOu can’t pay for it because we’re a charity.” But when [name 3] died, I sent over £2000 to them to say, “Look, you were so good to us.” It was the Focus on Living team, that was the team at [location 6] and they said, “Well, we’re having a training day for the staff,” so I got a lovely card of them last July, and some photos, saying, “This is what we did with your money, and there’s still some left for next year.” So that’s really nice. And then it's Christmas, I stopped sending Christmas cards, so I’ve got £70 to send up to them to help with this year’s training day for the ladies.

Interviewer: That’s very nice of you, [name 1].

Respondent: [Name 3] loved it, he loved…

Interviewer: It’s like you’re returning, you don’t have to, but you’re returning the…well, you’re making them feel appreciated, because they also appreciate you and [name 3] and gave you the care when you needed it.

Respondent: Definitely. And [name 3], he loved them coming here, he was happy in the house, in his own space, where he was familiar with everything. Honestly, I said, “What was his movement’s like?” and she said, “[Name 1], he never moved.” In fact, he would fall asleep sometimes.

Interviewer: How interesting, yeah.

Respondent: So complementary therapies, [name 2], talking about things, is another thing. YOu know…

Interviewer: We’re already, like, on animals and, like, spa sort of…relaxing treatments.

Respondent: Yeah, absolutely.

Interviewer: And you know, it’s interesting that for this, they would care for [name 3] and they would care for you individually.

Respondent: Mm hmm.

Interviewer: And in the neurologist appointment, you couldn’t get this. But there you go.

[End of Transcript]