[0:00:00]

Interviewer: Okay, good; alright. Okay, [Name of Respondent], so I want to start by asking you to tell me a bit about your connection to Huntington’s Disease.

Respondent: I met my wife [90’] on a blind date and she said, “To be honest I’m married but my husband has got Huntington’s; he’s been violent and I’ve had to move out”. So, she was living in a bungalow and within two or three weeks she’d moved in with and we fell in love. And her husband had Huntington’s and he subsequently died in [date] and we got married in [2015-2020]. And she was diagnosed with Huntington’s in [2000-2010].

Interviewer: Okay. So, they both had Huntington’s then?

Respondent: So, both had Huntington’s. And they’ve got a daughter [Name 1] who is now [40-50] who I go to see regularly in a nursing home.

Interviewer: Okay. And what was your wife’s name?

Respondent: [Name 2]

Interviewer: [Name 2]. Okay, so she got diagnosed in [2000-2010]; and can you tell me a bit about that process, about when she was diagnosed?

Respondent: She was a District Nurse at Grade G and when I met her she became incapable of holding her grade, so when she retired in [2000-2005] she was an E, and they thought it was the stress of her husband that was causing it. But as time went on we thought, “Well, we’ll just check out with the neurology department in [Location 1] and they did a blood test; we went back, “We’re very sorry to tell you that you’ve got Huntington’s”. And that was in [2000-2010]. And from then I was her Carer for approximately six years until she was sectioned for suicidal tendencies and she was sent to a psychiatric hospital. She was there for three months and made well again; she came back to live with me for another three years when she was sectioned again because she was psychotic and talking to people who weren’t there. Again she was sent to a psychiatric hospital for six months I think this time. And then we had a meeting with everybody and I said, “Well, I’d like her home”, and they said, “Well, I don’t think you would be able to cope with her at home”, so I acquiesced and said, “Okay”. So, we looked around for a nursing home for her. So, her daughter [Name 1], who is in the nursing home, and me looked at maybe 12 nursing homes in our area in [Place 1] and eventually found one that we thought was acceptable and she was discharged from the psychiatric hospital into [Location 2] in [Place 2], [Place 1].

Interviewer: Okay.

Respondent: And then she was I there for another three, three and a half, years before she died in [2020-2023].

Interviewer: So, [Name of Respondent], back when she wasn’t behaving like herself and you decided to take her to the Neurologist, or when you both decided to go to the Neurologist, what sort of symptoms was she showing back then?

[0:05:17]

Respondent: She had these ticks where she would kick her legs in bed mainly. And we thought it was the trauma of dealing with her husband. So, that was the reason for going.

Interviewer: Did she know there was Huntington’s Disease in her family?

Respondent: No. She knew there was Huntington’s in her husband’s family.

Interviewer: In her husband’s; okay.

Respondent: But not in her family.

Interviewer: Okay. And did she have some counselling back before she decided to test, do you know?

Respondent: No.

Interviewer: So, they were like, “Let’s do some blood tests”?

Respondent: No, because it was completely out of the blue. We didn’t think that that was necessary.

Interviewer: Okay. But was it offered?

Respondent: No, as far as I know. As soon as she was diagnosed with it she was offered genetic counselling, which was a waste of time, and then we pursued counselling ourselves. She went into a place in [Place 3] called [Location 3] which is attached to the church, and she’d go there – and I’ve subsequently been there myself at counselling.

Interviewer: Okay. That was like a private support?

Respondent: Yeah.

Interviewer: Okay. And back when she received the diagnosis were you signposted to where you could have more information about Huntington’s or how to prepare for what was coming?

Respondent: No. Well, me being a sort of a problem-solver sort of chap I found the nearest Huntington’s branch and contacted them and we went along to the meetings. All the way there in the car every time I would stop she was opening the car door to get out and I said, “Come on, [Name 2], you’ve got to come”. So, I sort of chivvied her along to come to the Huntington’s meeting. When we got there there was this Huntington’s Nurse who had written a book, [Name 3] I think his name was, and he droned on for hours and I thought, “She’s going to walk”. We were in the room with a load of strangers who didn’t all introduce themselves. But it was quite a long lecture he was giving, and eventually he finished and I was just surprised that [Name 2] stayed. And then we got to know everybody else in the group and eventually I became [role in branch].

Interviewer: Okay. And how about the connection, like any connection to the hospital at any points that she would be reviewed by the Neurologists?

Respondent: Yeah. We used to go to [Location 4] every year I would think.

Interviewer: Every year; alright. Was there other support you were having before she went to the nursing home? I’m trying to understand the services you had access to.

Respondent: My job was a [role] Engineer so I’m sort of a problem-solver, so immediately when it all happened I was coping well on my own no problem at all until she was sectioned the first time. And that’s when I contacted the Social Worker and it went under the umbrella of the Social Worker, sort of clicked into place, and we had Carer’s access and all the rest of it. They reviewed the access in the house for handrails etc. and we got all of those.

[0:09:32]

Interviewer: That was through the Social Worker?

Respondent: Yeah, it was all organised through the Social Worker.

Interviewer: And how did you reach the Social Worker?

Respondent: I Googled it online I think.

Interviewer: Online.

Respondent: Yeah. I just put in for [Place 1] County Council, that’s who we come under; found a Social Worker and… But lots of my friends have got partners with all sorts of dementia and they are not as proactive as me, and I can see they are under the weather and not coping with caring for their spouse but they don’t seem to be proactive at all; but there you go.

Interviewer: But, you being you, you went online; you looked through the Council how to access the Social Worker, which was really good of you. And then you were always seeing that same Social Worker?

Respondent: No. I think they changed over the years. I mean they call and sit down and have a chat with us from time to time and made sure everything was going alright.

Interviewer: Okay. And they helped you see what you could adapt around the house then?

Respondent: Well, she was fine most of the time and I was always with her anyway. And in the meantime she had to have a hip replacement so because of the hip replacement they put handrails on the stairs.

Interviewer: Okay. And with some funding as well or did you have to pay for all of that?

Respondent: No, that was all done free.

Interviewer: All done free through…

Respondent: Yeah. Throughout the whole experience I didn’t pay a penny.

Interviewer: Okay. And how did you find that? I’m asking because a lot of people, as you are saying, end up paying themselves or being out of pocket so I’m trying to understand if it was you again knowing how to navigate the system or was this a Social Worker that facilitated that with you?

Respondent: Well, as soon as you contact the local council… I don’t know whether they put me in touch with a Social Worker on the telephone whoever answered the phone; I don’t know, but I mean to me the local Social Worker is the key to getting everything organised because the thing is when she was sectioned because I’d already been in touch with – I must have been in touch with Social Work before. Yeah, that’s right; I think as she became worse before she was sectioned the first time. So, my theory was that once you are registered with a Social Worker they know who it is when an emergency comes up. Like when she was sectioned the path was quite smooth.

Interviewer: Okay. And were there conversations about her being sectioned or how did that happen?

Respondent: It needs two professionals to section her. The first time she was suicidal so they must have satisfied themselves that she was suicidal, so they took her away. I can’t remember if I went with her that time.

[0:13:20]

Interviewer: Had she tried to commit suicide and was stopped or caught before?

Respondent: Yeah. I had to make sure the knives were all out of the way in the kitchen. It was sort of a half-hearted attempt I feel because she was always a very caring lady, a very loving person, and I think she didn’t want to upset me too much but she knew how she felt.

Interviewer: And when she tried to commit suicide and it was becoming obvious that she had these suicidal thoughts and actions what was the response in terms of support? Was it immediately decided that she needed to be sectioned?

Respondent: Yeah. I mean I dialled 111 – or was it 999? I can’t remember; 111 I think – and then the people turned up and sat down and talked to [Name 2]. And because she’d been diagnosed with Huntington’s they obviously knew that she was a big suicide risk so it followed.

Interviewer: Okay. And she went to the psychiatric unit you said?

Respondent: Yeah. The one in [Place 4]; it’s called [Location 5].

Interviewer: Okay. And you said she stayed there for three months?

Respondent: Yeah.

Interviewer: Okay, alright. And you were allowed to visit her?

Respondent: Oh, yes; I was going in as often as I could. I took flowers and all of that and all the rest of it.

Interviewer: And when she went back home with you do you remember what was offered then for her check-ups or what happened?

Respondent: Well, the Regional Care Advisor, [Name 4] of the Huntington’s Disease Association, would call around and see us. And then there was another from some charitable organisation, I think it’s St. Anne’s – I can’t remember what it was. Anyway they came around and I had a chat with them. Plus the Social Worker would call occasionally. And as [Name 2] got worse she got the ear, nose, and throat would come and visit. But she was with me at home for three years after the first time she was sectioned and we went on normally. We went on cruises; fine.

Interviewer: Okay. So, yeah, you were trying to live the best way possible because there’s a lot more to living than the disease. Okay, and then you said she became psychotic again?

Respondent: Yeah.

Interviewer: Yeah, okay. And then she went back to that same psychiatric -?

Respondent: No. She went to [Location 6] and she was in there for six months. She was so depressed she couldn’t talk, and then they slowly got the meds right and she came back to us, and she was almost back to her old self but it took a long while.

Interviewer: And the team there: was there any connection with the Neurologist you used to see or she was only being cared for by the team at [Location 6]?

Respondent: As far as I know it was only the team at [Location 6]. There was a very excellent Psychiatric Doctor, a lady Doctor, who was Scottish – I can’t remember her name. Do you need any of the discharge stuff at all?

[0:17:30]

Interviewer: No, thank you. I don’t have permission.

Respondent: I have a huge file here. Anyway, yeah, go on.

Interviewer: No, I don’t have ethical permission to look at anyone’s medical records but thank you. Okay, [Name of Respondent], you were saying earlier how proactive you were being a problem-solver sort of person and that a lot of your friends are struggling, they don’t seem to be as active as you.

Respondent: Yeah.

Interviewer: Okay. I mean you were [role redacted] for the [Place 1] branch, was that it?

Respondent: For the [Place 1] branch of the Huntington’s Disease Association; and it’s now called the [Place 1] and [Place 5] branch.

Interviewer: Yeah. And your connection to the other families that I’m assuming you had a lot of contact with –

Respondent: Yeah. I used to arrange a Carers’ meeting every Tuesday night in a local pub and we used to get quite a good gang there, it was very good. So, I got to know lots of people being quite a social person and we used to arrange outings and stuff and, yeah, it was good.

Interviewer: And then you stopped going?

Respondent: No. I’m still on the committee but after [Name 2] died I thought it was too much. I don’t know why; I just felt that I didn’t want to continue as [role redacted] , so I made that known and within a year somebody else has stepped up. I think it’s when your partner dies you’ve no longer got the enthusiasm; all of the meetings would remind you too much.

Interviewer: Okay. And when was it that [Name 2] died?

Respondent: [date 2020-2023].

Interviewer: [2020-2023]; so, it’s fairly recent. And she passed at home or was it at the hospital?

Respondent: No, she was in [Location 7] which is a [name] nursing home for severe people in [Place 2].

Interviewer: Okay; for people with complex needs.

Respondent: But one of my regrets is that I didn’t get her into a hospice.

Interviewer: Okay.

Respondent: But you don’t know these things at the time. And since then at every meeting we have I try and push hospices to try and get people to get their loved ones into a hospice.

Interviewer: So, she was admitted to [Place 2]; she was already very advanced, like terminal, or she had -?

Respondent: No. When she joined [Location 7] I mean you could see a lot of change in her but of course when I see her everyday almost I couldn’t see the change in her, but there we go. I don’t know whether you can see that?

Interviewer: Yeah, I can; yeah.

Respondent: That’s me and her in the nursing home. But that was about a year before she died.

[0:21:30]

Interviewer: So, that was in the nursing home in [Place 2]?

Respondent: Yeah.

Interviewer: Okay, alright. And how long was she in the nursing home? Oh, look at her; wow.

Respondent: That’s her when I met her in [1990-2000].

Interviewer: Well, no wonder you feel in love. How long was she in the nursing home, [Name of Respondent]?

Respondent: Three and a bit years.

Interviewer: You’re saying you regret not…

Respondent: Well, it’s one of those things you only do once in your life – well, hopefully – and if I’d have had my time over again I would’ve got her into a hospice as soon as she became terminal.

Interviewer: Why?

Respondent: Because the care that she was getting… I mean I’ve got nothing against foreign people but the staff at nursing homes are all foreign basically whereas her as a District Nurse she was… I don’t know; I’m not explaining this very well but I just felt that she died amongst strangers.

Interviewer: Yeah, I can see that. If I would die in the middle of a nursing home where everyone was English I would find it strange as well. What I mean is you’re saying that and of course I’m Portuguese but I understand what you’re saying. And I think that’s an honest thought.

Respondent: Well, as a District Nurse when she was late home at night she’d probably been holding the hand of somebody who was dying because she always used to have a syringe driver under her arm, so she was an expert at giving people a gorgeous death. And that denied her I felt because there was no District Nurse to help her die. I mean when they put the syringe driver on her there were two girls, one from Zimbabwe and another one from I don’t know where – oh, I think it was Eastern European – and they were trying to decipher the words and get the… and I thought, “This is ridiculous”. If they’d have asked [Name 2] she’d have known exactly how to do it, but of course she was too far gone then. Because her feet were turning black and that was the way they knew that she was going to die.

Interviewer: Yeah; there wasn’t enough oxygen around.

Respondent: Well, that was about a week before she died. And I went in one day and they said, “Oh, her feet are turning black”.

Interviewer: Okay. And was there any palliative care?

Respondent: It was under the local GP. And she was under a local GP in [Place 2] who was over-worked, and I had to go down to the surgery and make a fuss and get her meds increased. Because the Nurse at the nursing home said that, “She’s not getting enough morphine”, so I had to go down and make a fuss to get the morphine increased.

Interviewer: So, the nursing home did not have a Doctor in-house?

Respondent: No. They rely on the local GPs. It’s the same with [Name 1]; [Name 1] is exactly the same.

Interviewer: The same; okay.

[0:25:42]

Respondent: Yeah. They don’t have a Doctor.

Interviewer: Okay. That’s interesting for me to know because the nursing homes I’ve worked in they didn’t have a 24/7 Doctor but they had a consulting Doctor that would review patients as needed. So, in this case you had to go and make a fuss at the GP so that she would get an appropriate dosage of morphine.

Respondent: Yeah.

Interviewer: Okay, alright. Yeah, so there was no referral to palliative care then. You are saying her Doctor was over-worked?

Respondent: Oh yeah.

Interviewer: Okay. And then after she died what happened to you, [Name of Respondent], in terms of did anyone check on you, in terms of bereavement support?

Respondent: No.

Interviewer: No, okay.

Respondent: All the way through caring for [Name 2] every year I used to have a cancerous lump cut off me somewhere or other. I think you can see there; there was one there. And that was regularly every year. And then after she died I had these severe ulcers on my hips; both hips were oozing ulcers. And I went to the Doctor and I saw the practice Nurse and they changed the dressing every couple of days, and they called the Doctors and said, “Well, what’s causing this?” and they didn’t have a clue, and I said, “Well, it’s grief that’s causing it”. Seeing the one you love… seeing her… and then eventually die it was exceedingly traumatic. So, after they healed up I signed up for counselling and I had about six sessions of counselling, which helped.

Interviewer: So, how did you access the counselling?

Respondent: I just phoned them up and booked a slot.

Interviewer: And that was privately?

Respondent: Yeah; privately, yeah.

Interviewer: Did you ever ask the GP to arrange for a Psychologist referral or a counselling referral?

Respondent: No. They obviously didn’t think that was necessary. I don’t know.

Interviewer: But you told the Nurses you were having these wounds because you were grieving.

Respondent: Oh yes.

Interviewer: There was no response in action?

Respondent: No.

Interviewer: Okay. So, what do you think…? I mean of course no one could avoid that [Name 2] would die; of course there are different ways to die. I have a specialty in palliative care so dying is part but there are ways. And to me it sounds like when a person misses her loved one, when [Name 2] passed, that a person needs support appropriate to them but, I don’t know, to you, [Name of Respondent], was there anything you would’ve liked to have been offered when [Name 2] died or after a while? Was anything missing for you?

[0:30:04]

Respondent: I don’t know really. I suppose it would’ve been nice to have got counselling. But going back a while: I think it was [2005-2010] I was diagnosed with Essential Thrombocythaemia, which is over-production of platelets, so I was on a chemo drug for eight years. They’ve taken me off it now and I’m just on aspirin every other day. So, I had that to contend with. Oh, and in [2010-2015] I joined the [Place 3] Mental Health Befriending Service and I used to go out and befriend people with mental health problems, and I think that helped a lot. And I’ve still got one friend. And it’s since been disbanded because of lack of lottery funding, but I’ve still got a friend that I go and see every Saturday. I’ll be seeing him tomorrow.

Interviewer: Was that like you were paired with someone with mental health problems?

Respondent: Yeah.

Interviewer: And you started this when [Name 2] was still alive?

Respondent: Yeah. In fact [Name 2] used to come with me sometimes to have chats, yeah.

Interviewer: And it helped you?

Respondent: Well, yeah, meeting and talking to people always helps doesn’t it?

Interviewer: But it’s interesting that although you had a lot of your own issues and you knew about [Name 2]’s diagnosis as well – of course that was up and down I guess with [Name 2] a bit in terms of care – but you still made a way to be helpful as well to others, and again from that relationship as well which has continued for years after.

Respondent: Yeah.

Interviewer: As you say, you are very proactive.

Respondent: Yeah.

Interviewer: Do you have other friends that did this, this befriending?

Respondent: No.

Interviewer: No; okay.

Respondent: No, I just saw an advert in the newspaper I think. We used to get the [Place 1] Chronicle and it was in there, and I was, “Oh, that looks interesting; I’ll apply to that”. I think it was because [Name 2] was the first introduction to anybody with mental difficulties so I was interested to learn a bit more about mental health.

Interviewer: Interesting; good. Okay, so you are saying you would have liked to have asked maybe the GP for counselling or have been offered counselling?

Respondent: Well, I just felt that the way [Name 2] died was very like a conveyer belt in the nursing home and it was just, “Oh yeah, well she’s going to die soon so…” In fact I got a phone call in the night because the previous night in the nursing home I thought she was going to die and then I stayed there overnight and slept on a mattress on the floor, and then I went home the following morning and then came back in the afternoon. And I was going to do the same thing but I was so fatigued, so tired out, that I left the nursing home about half past nine at night and she died about two o’clock in the morning, or that was when the Nurse did her rounds and found her. And I always felt guilty that I wasn’t there when she died, but you can only do what you can do and I was so absolutely tired out when she died. In fact she died on a Saturday and I was immediately there on the Sunday the next day in the nursing home; I don’t know what I was doing really. And then I went around to the Undertaker and of course they were closed up and [Name 2] was in cold storage somewhere, and I remember ringing the bell and phoning and I said, “Oh, I’ve come to see [Name 2]”, because I couldn’t stop seeing her sort of thing.

[0:34:39]

Interviewer: Well, you went to see her I guess still.

Respondent: Yeah. And eventually I did get to see her and I ran a mile because her hair was done differently, she had lipstick on which was the wrong colour – she wouldn’t have had that – she just looked a completely different person. And I thought I’d be able to sit down and say my goodbyes to her but I just ran a mile. Anyway, there you go.

Interviewer: No, this is important [Name of Respondent]. It’s important because, first, I mean you had counselling in a way but just to tell you it is quite often people don’t die while their loved ones are close to them. They feel they don’t have the permission sort of thing. As a Nurse, like [Name 2], that has seen many people die - I get the feeling that I look younger today for some reason but I’ve seen a lot of people die, I’ve had my share, I’ve held a lot of hands – and it is my experience that often people don’t want to leave their bedside and they want to hold their hands until their last breath, but their last breath isn’t given until people leave their side. So, we have this a lot and we see this a lot when we have people dying. I mean I can’t explain to you why it is, I’m just stating the fact that this happens a lot. So, I wouldn’t feel bad because you might have given her the permission that she needed to rest okay? And then the other point that I wanted to make – and that’s why I’m saying it’s important what you are saying – is that when she died and you went to see her she wasn’t treated like… she wasn’t herself; she didn’t have the hair she used to use, and you had to see her first, she was dead so of course she looked different but they made her different. So, they’ve put things on her that wasn’t [Name 2]’s like; and for me that’s not personalised. So, you had to see a different [Name 2]; even more different than what you should have seen, which I think is a very good point. And as a Nurse I feel that you need to respect people with their… It’s the same as in following… that’s why you ask people for their wishes, isn’t it, because you want to follow what their wishes after they pass are. And a simple thing like the lipstick colour that she used to wear or the hair she used to wear needs to be respected, and that’s something simple and it would have made a difference to you in your moment of grief to have seen your wife the way she was, not the way they made her. So, I think that’s important. So, it’s not like something that you’re, “Oh never mind, let’s carry on”; this is important, this is care, okay? And this is care to you because these are images that stuck with you.

Respondent: Yeah. But that’s what I found with [Location 7]. I mean I got to know the Manager really well and I used to go in and have a chat with him, but they didn’t have any protocol for when people were dying. I thought that they let everybody down; they just left it to the Nurses or the Carers who were on that night to do and that was it. I mean I got a phone call in the night at half past one in the morning saying, “Oh, she’s gone”, and that was it. It was an African Nurse who phoned; and they can be very blunt, and she was blunt. There we go.

Interviewer: Well, dying is cultural but you are from a different culture and we need to give the news the way people will receive it, not the way… well, again, we’re giving care; care needs to be adapted to the person that’s receiving it, not to the person that’s giving it. Okay, thank you for sharing that with me. I’m sorry I’m poking around the wounds today. Okay, so can you tell me the things that you think have gone well in terms of your life with Huntington’s? I know you are not the one personally diagnosed but you had a life with Huntington’s Disease as well. Are there things that went well that you think, “Everyone should have access to these things”?

[0:40:01]

Respondent: The first thing to say about Huntington’s Disease is that it’s a secret society. If you’ve got Huntington’s in the family you don’t exactly broadcast it because it’s genetically followed on, as you know, so if affects much your prospects, work prospects, the career line. I mean I think until recently you couldn’t join the services if you had Huntington’s in the family. So, it’s a completely unique… I think there’s one other dementia illness that is genetic; apart from that all the rest of them are purely random. Is that correct?

Interviewer: Yeah. I think there’s something called a Kawasaki, I’m not quite sure, which is also rare but it’s genetic. I think they have a centre in the Netherlands for it. But, yes, are you saying the majority of these conditions aren’t in the bloodline so they are random while this one is familiar.

Respondent: Yeah. It was just one instance that [Name 4] and I – she was the Regional Care Advisor at Huntington’s – we set up a stall in [Location 8] and there were about 200 non-symptomatic HD people there for a meeting, and there was only about one that signed up for the Huntington’s Disease Association. So, we were trying to promote the benefits of joining but it was only about one person was interested, all the rest just walked by.

Interviewer: Why do you think that was?

Respondent: Well, because it affects everybody doesn’t it? It affects their whole prospects in life. It was obvious to me that it was a secret society and you will never get over that. As you say, there is Huntington’s and this other thing that people just keep quiet about. They say that there are 10,000 cases in the country; well, I reckon there’s about five times that amount but they’re all keeping quiet about it.

Interviewer: Yeah.

Respondent: And you always find that people just ignore it and they carry on having babies and they are completely irresponsible. Like [Name 1]: she had five terminations and they kept testing the placenta – this is my stepdaughter – and she had five terminations and the last termination she almost haemorrhaged to death and so the next time she got pregnant they decided, “We’re just going to have a baby”. So, I’ve got a step-granddaughter, [Name 5], who is now 18 and studying forensic science in London who is at risk of Huntington’s.

Interviewer: Okay. So, [Name 1] you’re saying was doing this PGD; she was trying to select an embryo without the Huntington’s Disease gene, is that it?

Respondent: Yeah. It wasn’t five terminations; it was four terminations. And then on the last termination she haemorrhaged so badly she almost died and they said, “Oh well, we’ll just go ahead and the next time she’s pregnant we’re just going to go ahead”, but I think there’s a good chance that [Name 5] has got it. But then if it comes out like [Name 2] – it came out with [Name 2] when she was… she was [50’] when she started showing signs of it.

Interviewer: So, both [Name 1] and… is it [Name 5]?

Respondent: [Name 5], yeah.

Interviewer: They are both your stepdaughters?

Respondent: No. [Name 1] is my stepdaughter; [Name 5] is my step-granddaughter.

Interviewer: Okay. So, [Name 1] is a daughter of [Name 2] and her ex-husband – well, husband he was –

Respondent: Who also had Huntington’s.

Interviewer: Both had Huntington’s.

[0:44:54]

Respondent: Which is why [Name 1] is in a nursing home at the age of 50.

Interviewer: She’s in the nursing home and she’s still attempting to have children?

Respondent: No. I mean [Name 1] at the moment can hardly talk. Well, she’s quite on with her Huntington’s; I would think she’s got another year or two I should say.

Interviewer: So, [Name 5] is her daughter.

Respondent: Yeah.

Interviewer: Okay, alright. Which she was never tested in the womb?

Respondent: Well, no, she was never tested in the womb.

Interviewer: Okay. So, you believe she’s at risk.

Respondent: So, with a history of four positive I think there’s a good chance that she has it but you just don’t know.

Interviewer: Well, the chance is always… if her father doesn’t have Huntington’s her chance is always 50 regardless while [Name 1]’s chance was 70% because both her parents had Huntington’s.

Respondent: Oh, right.

Interviewer: 70%. So, if one parent is affected the chance is 50% but if both parents are affected the chances are 70%; it’s high.

Respondent: I’ll tell you about [Name 6] and [Name 7]. They lived in [Place 6] and they used to come to the meetings and [Name 2] and I got friendly with them so we used to socialise with them a lot and go out to pub meals etc. and [Name 6] had Huntington’s, and I think he died a year ago. He died the year after [Name 2] so [2020-2025]. And he was an electronics expert who had a factory in [Place 7] making electronic components. I was an [redacted] Engineer so him and I used to get on well. So, that was all part of our social circle I suppose.

Interviewer: Yeah, okay. So, you had good friends?

Respondent: I had good friends, yeah.

Interviewer: Okay, that’s good. Okay, [Name of Respondent], so do you still want to point out to me something that has worked really well? I mean you were mentioning the Huntington’s Association; you were trying to get people to sign up.

Respondent: Well, the only things that worked well is what I’ve motivated myself I think really. In honesty if I wasn’t proactive about things nothing would happen I don’t think so, no, I can’t really think of anything positive.

Interviewer: Okay. So, it’s very much intrinsic to the individual then because the system won’t recue you, so you’d better rescue yourself is that it?

Respondent: Yeah.

Interviewer: It reminds me of… I don’t know if you’ve seen the Charles Sabin Ted Talk that’s going around social media? So, Charles Sabin is a BBC Reporter that has Huntington’s Disease and he’s done a Ted Talk and basically his message is, “Don’t leave it to the government; you do you, what’s best for you and your family, because it’s not going to be the other entities saving you”; so, you remind me of that. You could do a Ted Talk yourself basically.

[0:49:00]

Respondent: Oh, the other thing I was going to say to you: when she was diagnosed we went on a cruise a few weeks afterwards and the entire cruise she cried the entire time. In fact I thought that the people in the next door cabin were going to knock on the door and say, “Are you knocking her about in there?” But she was so upset that it was a nightmare really.

Interviewer: She was upset with what?

Respondent: Well, she was coming to terms with the fact that she had Huntington’s having watched her husband die of it and realising the implications with [Name 1] and [Name 5].

Interviewer: Okay.

Respondent: Yeah, let’s get this straight. When [Name 1] was having [Name 5] they didn’t know that their mum had it. So, in a way it was a good thing that [Name 2] died when she did because it would break her heart to see her daughter going through… you know.

Interviewer: Yeah. And she started with symptoms earlier, right?

Respondent: That’s [Name 1] and [Name 2].

Interviewer: Wow, they are both gorgeous and they really look alike.

Respondent: Yeah, they do. Yes, so in a way it’s a good job that [Name 2] died when she did because it would break her heart. I mean it affects me when I go in and see [Name 1]. They were both Nurses; there you go.

Interviewer: [Name 1] was a Nurse as well?

Respondent: Yeah, she was a Nurse.

Interviewer: Okay. And [Name 5] knows her mother has Huntington’s Disease?

Respondent: Yeah.

Interviewer: She does, okay; alright. Okay, so not everyone is as dynamic and knows how – you need a certain level of not just intelligence but, yeah, resourcefulness to be able to go on the internet or call people and things like that, so you’ve had contact with a lot more families and I wanted to pick your brain in terms of the system offering something or the way the care is managed. What could help people? What could work for people? If I wanted to develop something or create a role or offer a Specialist Nurse to everyone what do you think would work?

Respondent: Can I just go and get a glass of water?

Interviewer: Of course.

Respondent: Well, to answer your question it comes down to politics because at the moment we’ve got the bloke who runs [Place 1] County Council is closing five residential nursing homes in [Place 1] to open three severe nursing homes. And I’ve got a friend called [Name 8] and he’s just joined a residential nursing home in [Place 8] and they are closing this month and being turfed out to make room for these other three sever nursing homes. So, you’ve got these residential nursing homes with all the domestic staff sourced locally so, not being funny but, they are all British mainly. And when I went to see him at the nursing home it was like going back in time where all the staff were British, and there’s so much conviviality that comes from that and it’s a joy to be there. I’m not saying there’s anything wrong with foreign people but they will be replaced by three severely and they will try and manage all these people at home, so you go back to Care in the Community. So, all these people in the nursing homes – wherever they are going to end up, I really don’t know. And then what they’ll be replaced with because it’s cheaper for the government to employ these foreigners who will come in at half the wages and are a much more malleable workforce who won’t be going on strike over this, that, and the other, and they are cheaper to employ so that saves money. So, what it all comes down to is money in the end. Do you understand what I’m saying?

[0:54:44]

Interviewer: I do. I mean your friend just joined the nursing home so is there a plan to reallocate people?

Respondent: I don’t know. I haven’t been to see him lately. I’ll have to go and see him again and see what his situation is. But he’s only been in there about six months and he knows he’s got to leave. But it’s so sad. I mean there’s a lovely little nursing home in [Place 8] with all the people who have just got dementia or whatever; they’re not severe, they are not like Huntington’s or anything, and it’s a gorgeous little place and when I went to see him I thought this was really nice. Part of my job I used to work for [Place 9] City Council on contract as an [redacted] Engineer and I was responsible for [redacted] I was going backwards and forwards and then I’d go for another contract back at [Place 9] and I’d find that all the nursing homes that they had there have all gone. And every local authority and city are getting rid of their nursing homes because they are too expensive; they are trying to privatise them and they all realise that you can get in this foreign labour and half the cost. But what results: it’s not the same quality of care.

Interviewer: Okay. So, [Name of Respondent], to think of [Name 2]’s life and then death what would quality of care mean? How do I quantify this? Is it quality of life? Is it the time that she spent at home to gain those other three years, for example, that she stayed with you? What is the quality here?

Respondent: Well, the first thing is, “Can the space cope with caring for somebody with Huntington’s?” And the space had to decide whether they can. And it’s quite common for the space to just walk because they realise what’s in front of them when they realise that they could not cope with it; which is fine, you can either cope or you can’t. So, that leaves the person with Huntington’s either on their own or with a Carer. And then that goes forward and it does deplete the Carer watching your loved one go downhill and eventually die. Well, that’s all I can say really; I don’t know what else you want me to say.

Interviewer: That’s alright. So, you are saying of course not everyone comes with the same baggage to be able to manage Huntington’s Disease; that some Carers –

Respondent: Well, I think that’s what I’ve found with my friends; that I’m gobsmacked by the way that… I say, “Well, haven’t you contacted a Social Worker?” “Oh no, we’re not.” And I can see them all going downhill and everything falling apart. Anyway, there you go.

Interviewer: No. It’s not, “Anyway”; that’s important again to what is the level of support each person needs.

Respondent: So, what you could be saying is really that the GP should contact the Social Worker on their behalf but we all know that all these Social Workers are very thin on the ground and they’ve got big workloads, and the last thing that they want is a phone call from a GP giving them extra work. So, to me it comes down to politics.

Interviewer: [Name of Respondent], did [Name 2] ever have a Specialist Nurse or was that not something?

Respondent: Yeah, we had [Name 9] who you probably know, do you?

Interviewer: I do, yeah; but that doesn’t matter.

[0:59:20]

Respondent: Pardon?

Interviewer: I do know her but that doesn’t matter. This is a study; I’m doing research, so… I know her because I’ve worked at [Place 10].

Respondent: Yeah.

Interviewer: I’ve asked you to be honest from the beginning so…

Respondent: I mean there’s the Huntington’s newsletter and on the back is the contact. Can you see that?

Interviewer: I read, “Keep calm and carry on; [Name 10], Name 2]; Specialist HD Advisor [Name 9]”, yeah?

Respondent: Yeah. So, that goes around to all our members. There are 150 postal members we used to send this out to. I can’t remember how many email people, but there we go, in [Place 1].

Interviewer: So, aside from the emails you would send that by post to 150 people?

Respondent: Yeah.

Interviewer: Okay. So, did you find that the Specialist Nurse was useful or not?

Respondent: Yeah, I suppose so. I was Carer for [Name 2] really finally and I didn’t have a problem caring for [Name 2] at all.

Interviewer: Okay; apart from the ulcers that then came out with the… well, I guess it was processing grief.

Respondent: Well, the funny thing is as soon as she died and I finished my counselling all these cancerous growths have all gone away; so, there you go. So, perhaps I was coping with it in my unique way.

Interviewer: Yeah, that’s what I was getting to. I mean you were amazing; by the sounds of it you moved every rock you could turn, you were turning the rocks, and opening the way basically to you and [Name 2] but it comes with a cost I guess.

Respondent: Yeah.

Interviewer: Okay. Okay, [Name of Respondent], is there anything we haven’t covered that you would like to add to our conversation?

Respondent: No. It’s only the political aspect of it all that galls me really. All they are interested in is saving money; there’s no heart in any of it really, it’s all down to the bottom line.

Interviewer: I guess we will have to find something that works and, I’m not going to say, saves money because that’s quite naïve but that at least is neutral, that doesn’t cost more. I think politically you tend to look at goals in a short, medium, term when things like this you can only measure the true impact with years in-between; it’s not with six months or anything like that.

Respondent: I just feel that the NHS system since the Tories have had it has just gone downhill so terribly. I think [Name 2] would be so upset if she could see the way… Doctors going on strike: it’s unheard of, isn’t it?

Interviewer: Yeah. And I think since I’ve left… Of course I’m still working in England although now I’m not living in England so I sort of feel between the countries, but the perception that I have is that there have been a lot more strikes. And I think it’s good that people are showing their discontent, but then again it always comes at a cost. It’s been the same in Portugal, there have been a lot more strikes – in Education as well, not just Health.

[1:04:02]

Respondent: The only thing I could mention: in [date 2020-2023] – that was before [Name 2] died – I was rushed to hospital with a burst bowel. So, I was diagnosed with diverticulitis and I had a diverticulitis burst so I was in the hospital for two weeks and almost died. So, I think that was all to do with the stress of caring.

Interviewer: And who stayed with [Name 2]?

Respondent: She was in a home then.

Interviewer: Ah, she was in a home; yeah.

Respondent: Was that pre-Covid? I think it was pre-Covid… or post-Covid? [date 2020-2023].

Interviewer: That was during Covid already.

Respondent: Was it?

Interviewer: Yeah. Well, it was Covid-19; it struck England in 2020.

Respondent: No, sorry; 2019 – get it right.

Interviewer: Oh, 2019.

Respondent: 2019 I had this burst bowel.

Interviewer: So, that was pre-Covid yeah.

Respondent: Yeah. And I was in intensive care and all that.

Interviewer: Because, yeah, that’s life-threatening.

Respondent: Oh yeah; yeah, potential peritonitis. So, that’s the stress of caring really.

Interviewer: Of caring; yeah, okay. Thank you, [Name of Respondent]. Okay, now I have only light questions like, “How old are you, [Name of Respondent]?”

[redacted]

Interviewer: Okay, alright. [Name of Respondent], now I want to know about how the interview went in terms of what can I do in the next interviews that I have so that people have a better experience.

Respondent: Well, it’s going to be traumatic for the person; there is no getting away from that. And there’s not much else you can do really, is there? Yeah, I don’t see as you can conduct it any other way.

Interviewer: Yeah. I mean I was thinking could I email people the next day for example and say, “How are you after our interview? Is there anything you need?”

Respondent: No; I shouldn’t bother really.

Interviewer: I’m not sure if that’s more invasive.

Respondent: But you will find out in the interview whether you think the person needs any extra chat or anything wouldn’t you?

Interviewer: Yeah, I will. I did a list of resources I think which I can start sending people if I see that they need a follow-up with… but it was mainly to charities as well that don’t have a cost associated like the Huntington’s Disease Association or Mind, things like that. I mean is that something you would like to receive?

Respondent: I was just thinking that the people you are going to be talking to are people like me who are open to discussing the Huntington’s, but if I had Huntington’s in my family I wouldn’t be conducive to talking about it. So, you are looking for neutral people who care and aren’t involved in the family with Huntington’s aren’t you?

Interviewer: Well, no. I’ve been speaking to people that are diagnosed with Huntington’s and people that are at risk of Huntington’s and people that are actively caring for Huntington’s being relatives or professionals. So, I’m speaking to pretty much everyone but I am biased because only people that are open to speak about it will come and contact me.

Respondent: But all the Carers wouldn’t have Huntington’s in their personal families would they?

[1:10:37]

Interviewer: The professionals?

Respondent: No. All the Carers you are talking to wouldn’t have Huntington’s in their own family. But I’ve married into it.

Interviewer: Yes, I see your point. I mean usually – it could happen but it’s rare – the Carer unless they are a Carer at risk of Huntington’s or diagnosed with Huntington’s, which I have spoken to, then they have Huntington’s in the family directly and on their bloodline as well.

Respondent: But I think it’s so important that when they get to a certain point with Huntington’s that they should be transferred into a hospice to have a really good death because I just feel that the nursing homes that I’ve visited – the one that [Name 1] is in and the one that [Name 2] was in – it’s full of foreign workers. Now that makes me sound racist but I’m not; I’m just knowing that…

Interviewer: Yeah. I think what you’re trying to say is their training and the standard of care is not as good as it should be.

Respondent: Yeah.

Interviewer: It’s not specifically because they are foreign, it’s more that the training and the care they are delivering is not up to scratch to what people should have when they are dying. This is something I’ve been hearing a lot, [Name of Respondent], about the nursing homes not being monitored enough and the quality not being good enough. So, I think this is important. Is there anything you would like to add, [Name of Respondent]?

Respondent: No, not really.

[redacted]

[End of Transcript]