[0:00:00]

[redacted]

Interviewer: Thank you so much, [name 1]. It’s just safer to do it this way, so that, you know, anything with your main details are separate. Alright, so I want to start asking you to tell me a bit about your experience with Huntington’s Disease. I know you’re test positive, is that right?

Respondent: That’s right, yeah. So I think it was actually more than 30 years ago, so my brother became very poorly, [name 2], and we didn’t understand what was up with him, he couldn’t drive, he had shakes, and so my sister in law, [name 3], and I went and we investigated a lot of the doctors, a lot of minds, a lot of different places. We had no awareness of Huntington’s at that time, and I was present at his MRI scan when the doctor gave us the test results and told us both at that time that [name 2] had Huntington’s. Obviously we had no awareness about that in the family at all, and in that point in time, so it floored us completely, and obviously we were all in a state of shock at that initial time. So that’s more than…so [name 2] is [5-7] years older than me, so he would have been [60-70]. I’m [60-65] at the present moment in time. So that was my first awareness of Huntington’s in the family, given the CAG repeat score from the [location 1] clinic. But my brother’s foot was going like this, you know, he was lying on the MRI table, you know, he was having shakes and we just couldn’t understand why.

Interviewer: Okay, and that was 30 years ago?

Respondent: Yeah, [name 2] would have been [65-70] now, so he was [5-7] years older than me, as I say, I’m [60-65] currently.

[00:12:32]

Interviewer: Okay, you’re [60-65].

Respondent: Yeah.

Interviewer: Alright. And then when did you decide to test?

Respondent: Yeah, so this is the thing about youth, isn’t it, and this is always the thing that I’ve, in talking to [name 4], when [name 4] joined, because it was 17 years ago when we first started, we were chatting to her about whether to do the genetic test, and as always, because it’s a life changing event, you know, you can’t turn back from those crossroads once you’ve made your mind up. And you know, as you may know yourself, the thing is with families, Huntington’s isn’t like cancer, you know, cancer is…I say, bad, you know, and very bad if you’ve got it, and we’ve all come across, you know, family, my mum, you know, died from brain cancer from smoking, and different things like that. None of my parents are alive at the present moment in time. But when you dive into the…at that point in time, you know, as a new subject over understanding/absorbing Huntington’s, it blows your mind, you know, you can’t contain the possibilities that your life will be ending. And I think I was in my 20s. I think myself and my wife…have you got the date that I did the genetic tests?

Interviewer: No, no, I don’t have access to that data.

Respondent: I mean, thankfully…I say thankfully for me, but this is something else that we cover, obviously because in this hour, we come up to date, obviously, me being [60-65] . But we had no awareness in the family about Huntington’s, nothing at all, so I think we contacted [name 4], or somehow we got involved through the doctor and she’d just taken over from…I think it was [name 5] is the nurse for the local area, and I think [name 4] has been our major support for the whole [name] family, for all of us.

Interviewer: [name 4]?

Respondent: Yes, correct, yeah. She’s been 17 years, so even to today, up to today, you know, she’s still a major support for me, for [name 3], you know, she did the [redacted run] with us and we raised a lot of money for Huntington’s as well, so we tried to get the team in Huntington’s. But [name 4] and I sat down, and as a very young person at that point in time, I think I was in my 20s, and I think you’re a bit more resilient, and I think we just decided, you’re sort of a bit more confident when you’re that age, when you say, you know, “Let’s do it, let’s accept the test result.” And you know, obviously when you get the test result, you know, it’s devastating and for those first five years, you know, trying to survive and trying to think about life, you know, together. You know, luckily we had a very young family at that time, you know, very young, so only just been born, so you kind of had to get on with circumstances, and survive as best you could. Obviously I thought about work as well at that point in time, you know, I was majorly concerned about financial futures as well. The folly of youth, should we say, you know, [name 4] has sort of said to me, I’ve spoken to lots of different people over the period of time, you know, who are thinking about it, and I think there’s different people that I might talk to, but I think it depends on what people’s circumstances are, you know, and certainly understanding panic attacks, and sort of waking up at three o’clock in the morning in debilitation, I total physical inability to function in myself, you know, and my wife. We shared it at that point in time, we shared it with six very close couples in a circle, we’re still friends with them now at [60-65]. We never told anybody else, and kept it secret, and you know, at that point in time, I think we had to do it and we had to get on and survive the circumstances as best we could.

Interviewer: Did you, when you decided to take on the test, did you have genetic counselling first or was it different back then?

Respondent: No, I did it, so it was a year, yeah, and we thought about that, and yeah, I mean, my sister in law didn’t know at that point in time, we kept it secret from her for a long time, you know, even though I saw [name 2] die, my brother, and go ultimately at [location 2] where he was cared for properly, where the other nursing home was absolutely awful. I know this is us, you know, you and I, but I mean, hopefully you will talk to my sister in law, but like I said, all the other homes throughout the time, good and bad, and trying to do as much as we could do, as possible. But [name 2] was really poorly, you know, and his decline was very, very rapid.

[00:18:47]

Interviewer: Was [name 2] at different nursing homes then? He was…

Respondent: So what you’re doing with me, obviously…but I’m happy to…[name 3] story of desperateness, she is a total…[name 4] should have said to you, can you speak to my sister in law, [name 2], so you haven’t got her on the list, categorically she is running a crusade now and currently doing that, that’s why we’re supporting her. So I call her the [redacted] of Huntington’s, because she is championing with my [relative], [name 6], just blasting awareness….

Interviewer: Yeah, yeah. I’ve seen the posts.

Respondent: Great, yeah, no, so she’s fantastic. You need to talk to her, she has the whole history of going to all the horrible homes, you know, she did presentations…

Interviewer: I can’t approach her directly, you can let her know about the study, if she’s happy to take part…

Respondent: She will be.

Interviewer: …you have my details, but I can’t chase her personally.

Respondent: Did [name 4] give you any recommendations for who you should contact?

Interviewer: She can’t. For people leaving…so she can’t send me people’s details quite, you know, quite correctly, so she can pass on my details to people, but there’s something, so if you know of anyone, both living with Huntington’s or professionals caring for Huntington’s, that would be potentially interested, pass them on my details and then they can decide if they want to reach out or not. So maybe let’s focus on your experience then. I was asking if you had done genetic counselling, and you said you did, in your 20s. I was interested to understand what happened after you got the positive result, if any other support was offered to you after you got the test result back.

Respondent: Nothing. Well, I say nothing, Dr [name 7] at the time was fantastic. He was always really supportive, because obviously on my medical report throughout all my life, anybody looking at that, especially if they were a temporary doctor at the health centre here, Dr [name 7] was absolutely fantastic. He had a couple of other people in the area that he knew of, but effectively, he always said to us that we should talk to the children early and inform them more about my situation. [Name 4] being the primary support all the way through, you know, totally, in its totality, not just from a Huntington’s point of view, but you know, when you’re out of work, I’ve had sort of two loads, three loads of redundancies, [name 4] is 100% integrated into the [name] with [name 3] as well. She’s a key part of my family, this journey with Huntington’s. I’ll give you information and you can come back. So I’ve got two children, [name 7] is [30-35], and [name 8] is [25-30], and I’ve… So [name 8] has done the test and he’s okay, because he got married this year and they told him, obviously he couldn’t…because knowing about Huntington’s. But one of the things that I have difficulty with was that I came…what I couldn’t do, because we kept it secret, because my wife always was trying to duck and protect the kids from it, and she wanted them to get through school. So all the way through this is that theme of that conflict, all the way through between myself, my wife, the kids, where they are, and the doctor. And the doctor, who would say, you know, “You need to say to them, you know, when they’re younger, you know, they’re more resilient.” That’s all very well and good saying that, but [name 4] has been absolutely amazing in every part of the support that she’s given me, or that I’ve wanted. So in every capacity, so when you say, you know, “How did you get at that point in time?” well, alright, I think Dr [name 6] said, you know, put me on sleeping tablets or something like that, you know, I remember having panic attacks at three o’clock in the morning, down in the toilet, you know, downstairs, because you just couldn’t contain that, and it was the first time that I’d had that kind of….

[00:24:30]

Interviewer: Reactions.

Respondent: Yeah, no, exactly, because of that stress. And obviously they really called…the three lots of couples that I confided in, one of them cleared off to Spain, which was really unfortunate, and they actually moved out there just as we got the result and could have done with their support. So you know, there’s a lot in this, apart from when you’re talking to [name 4], I didn’t go to yourself at the [location 1], I don’t think I went up there for a while because we were trying to avoid meeting anybody physically, should we say, that may have physical Huntington’s, because we were sort of trying to work through that ourselves. So there was another gentleman as well, who came to the home, and he was from the team, and his wife… [name 9], was it [name 9] something or other? Yes, I’ve forgotten what his surname is, but he was amazing as well in those early days. So again, you know, with the voluntary team, and the Huntington’s team that is there currently, with that support network, you know, there’s a lot more people, a lot of people that have had a lot longer journey, with people actually passing away, you know, and are older than I am. So there might be some other people that would be useful for you to talk to as well. So in that early time, you know, total…what’s the word, inability to function in its entirety, definitely.

Interviewer: Okay. So it sounds like you were a little bit left to process the positive result?

Respondent: Yeah, I was…

Interviewer: It sounds very hard, like, I mean…

Respondent: The words [name 10] said to me, my wife, we’re still married, for [30-40] years, she said, “I will lose my rock,” and I still remember those days, and you think how she was concerned about the family at that point in time, and you know, you don’t forget those times, you know, you don’t forget when, as I say, your parents die or somebody has cancer, when you’re sitting there, those unfortunately are days you never forget.

Interviewer: Okay. Yeah. Sure. And you have young children and you were trying to stay at work, you know, continue to work, you were mentioning there were some layoffs and….

Respondent: Yeah, so I mean, this is later. At this time period, right at the beginning, when I was younger, I think…I was working at that point in time. But yes, you know, they were a distraction and you know, there’s two years between them, so you know, the youngest one…no, the oldest one is the trailblazer, so you just put them in the pushchair, you know, put them down the seafront or whatever it is, and you’re just doing everything automatically, you know, with the baby. But yes, you know, as I say, Dr [name 7] and the Huntington’s…I’d say not the team where you were, but the [name 9], I’ve forgotten what his surname is, but you know, he came round to the house to talk to us, because his wife had died of Huntington’s as well, so I don’t think he’s…

Interviewer: But you found the Huntington’s Disease support group, is that it, like…

Respondent: No, not then, you know, it was basically, it was another lady called, I think it was [name 11] and [name 4] took over from [name 11]. So I think it was basically the doctor, [name 11], [name 4] and [name 9], that really were the only people at that point in time that we were talking to.

Interviewer: But [name 9] was, like, a physician, or was he from the Huntington’s Disease charity?

Respondent: Yeah, from the charity. So, yeah, he was one of the founders, I think, if you like, and you know, sort of one of the trailblazers with trying to get information out there for everybody whose partner was poorly.

[00:29:23]

Interviewer: Yeah, okay. Was it the one that wrote the book? No, *The Pig’s Guide to….*I think something Marriot? Or something, there’s a book that one of the partners from…his wife had Huntington’s and they wrote a book. So the name is ringing a bell associated to the book, but never mind.

Respondent: I don’t think he was a doctor, he was…just, like, let’s say the Chairman of the Social Society.

Interviewer: Yeah, yeah.

Respondent: Oh right.

Interviewer: Yeah, yeah, so just a partner, not a doctor, so there was…there’s quite a famous book in the Huntington’s community that sort of helps how to care for the loved one with Huntington’s, and it was written by I think someone that was leading on the charity, so just a normal person, let’s say so, and I think it was the *Pig’s Guide to Caring* or something. I’ll send you the link in case you’re…I read the book before, but just to see if it’s the same individual that you’re talking about, it could be the same person.

Respondent: Okay.

Interviewer: So [name 1], thinking about what care or support you’re using now, who are you in contact with for…is there anything you need at the moment?

Respondent: So the journey now to this point in time, I’m very lucky, because at [60-65] , I’m fit and healthy, and obviously the contexts of Huntington’s is specifically what we’re talking about, so I bless…I’m very…you know, we’ve seen so many people….

Interviewer: Take your time, [name 1], it’s fine. It’s beyond you, isn’t it, you’ve seen a lot of families as well.

Respondent: You’ve seen a lot down in [location 1].

Interviewer: Yeah.

Respondent: You’ve seen the kind of times that I’ve experienced. And it’s very…apparently my brother has been exceptional, what I mean is…

Interviewer: Yeah, yeah, take your time. If you have a drink with you….

Respondent: Apparently, when I’ve been talking to my sister in law, [name 3], who you will have to, 100% talk to, and I will ensure…I talk to her all the time. Now, in the early days, you know, one part of the family got upset for various different reasons, and [name 3] felt that she was left alone, you know. We talk all the time now, all the time, on the WhatsApp, it doesn’t matter, she still comes up to me, you know, we’re there. I think she said, when she was talking to my wife, [name 10], that she just felt that…I think [name 2] reactions to…she’s not seen anybody react so extreme as [name 2] has, because we’ve had the conversation. Because obviously, 20-30 years ago when I did the genetic tests and I was expecting…I’ve had three lots of redundancies, you know, and I thought to myself, “Here I am now at [60-65], from a Huntington’s point of view, I’m fit and healthy.” So [name 4] has been an amazing support all the way through, totally. Finding her, you know, I’ve had problems in the family, you know, she’s guided me with basically other issues with my daughter, blowing us apart from a social point of view, stress inside the family where I was blamed for everything, every failed relationship, my daughter and other people are looking at this letter thinking, “Oh my god, you know, what the hell’s going on?” But [name 4] has been a pivotal part in the family, and we can talk all the time, you know, I know about my dad, you know, we’re close enough to talk about that, and you know, I offer support back to her with that because I had that myself. But we, because the wife wanted to do the, like, the albatross, you know, like the parrot sitting on the shoulder when you’re walking in the room, because we knew a long time ago that I had the Huntington’s and we hadn’t told anybody, and Dr [name 7] said, “You must, you must, you must.”

[00:34:52]

What happened was when the kids were younger and they were teenagers, I overhead one of my aunties, who’s very…talking about [name 12]. So [name 12] is [name 3] first child, so she’s had two kids, so this is [name 12]. So obviously she got out of home and was living at home when [name 2] was poorly, and he was, you know, I would take [name 2] to karate, I’d pick [name 2] up, you know, for [name 3], try and give her a rest, because he still lived at home and wasn’t able to do work. So the Huntington’s charity was trying to find him work round the corner, but he was…at the point of not being able to continue, although he was looking at karate and there was different people round the corner here, were trying to sort of keep him going from a charity point of view. So [name 12], which is [name 2] first daughter, has had two kids and she hasn’t done the genetic testing, you know, they blanked that off. I think she’s 40…I don’t think she’s 50, so she doesn’t want anything to do with that, because obviously she’s seen [name 2] at home when he lived through that, you know, it’s horrific. She wouldn’t even visit [name 2] at [location 2] or anything else like that, which I completely and utterly understand.

So redundancies as well, when you’re under pressure, you think to yourself, you know, when you do your full, you know, 360, if you like, on your own wellbeing, the Huntington’s sheet – I’m not just saying that, I keep that in the file, but I do try to… I’m not an unhealthy person, should we say, from a fitness point of view. We take the dog out and we’ve got…we eat properly, you know, good food and fish and everything else like that. But yes, so…

Interviewer: So you’re fit and healthy at the moment, Huntington’s is a chronic condition, so it’s, you know, you don’t need to feel sick, so I’m quite pleased to hear you’re feeling well, relatively well. But so, do you mean that you’re actually not accessing care right now?

Respondent: No, so we’re going to see [name 13]. The only reason why we did that was when we chatted to [name 4], I’m – and this is current information – what we’re doing is one of the things that I was concerned about when [name 4] first started, was my swallowing, and I’ve always had a very small swallow and a [redacted] hernia, so I’ve always had that as a condition, if you like, and when [name 4] was on the scene, I was majorly concerned, saying to her, “Is this Huntington’s, is this Huntington’s?” because obviously, you know, it can essentially start in the throat. It’s not…it’s definitely not, you know, we’ve covered that off, you know. I’ve got a very, very small swallow, we did the barium meal, and when I say this to everybody, they all know when I’m eating, I can’t talk and eat at the same time.

Interviewer: Yeah, you might choke.

Respondent: Yeah, so [name 14], currently, in the Huntington’s team with [name 13], I’m hoping for an appointment to go and see him, and it was only because when we were chatting to [name 4], there were, like, four areas, and when we got to the food area. So mentally I felt fine, physically I felt fine, I say…not spiritually….no, so the other areas I felt absolutely fine, but when we chatted about the food, I am a [30-35] waist, and a medium t-shirt. Now people have been concerned about that, because I used to be a [3540] inch waist. I haven’t plummeted overnight, don’t get me wrong. So I’ve done running, I’ve got a dog, I do badminton. I’m active, I’m an active person. So just to cover it off currently, [name 15] is my current doctor at the health centre, and I asked him for a referral to the team in [location 1], which [name 14] came and visited me. So at some point in time, we are going to explore that and talk more about that area. I’m actually not overly concerned with it, what I mean is when I was at work and there was, let’s say the wife was working on a Saturday, I used to go and get a curry, so I used to get a Chinese, and I jokingly used to say, round the corner at the [location 4] and have it all cooked, so I had prawn curry and chips, and a pancake roll. I’m lactose intolerant, so currently in the last, let’s say, two or three years, when I got food stuck in my throat – so I got steak stuck in my throat when my son was here, because it was a sirloin steak when we were cooking it. So I’ve had the ambulance here. So I’ve always had that history with eating. I was talking to the wife the other day, and I said, “I haven’t collected a Chinese, I don’t have Chinese because of the lactose in it or the MSG.” It’s the lactose in it that I have a problem with it, so I haven’t had a takeaway from this place for years, and I said to the wife, “I feel exceptionally healthy,” you know, I said, “I have a jacket potato,” she feeds me well, we eat well, you know, so I’m eating healthy and being active. But let’s say, the concern…or it’s just a noted concern, it was to do with losing weight because of Huntington’s, because you can eat a lot of food and not put on weight.

[00:42:22]

Interviewer: Yeah, yeah.

Respondent: So we were exploring that, but I think to some degree, when we go and see [name 13], obviously once we got the referral, was we’ve looked at it more and I’m not having…MSG, whatever it is in the Chinese, so I mean, I haven’t had that for years, and I had a bacon sandwich the other day, and I choked on it, and I said to the wife, “This hasn’t happened for a long time.” So I sat back, and I thought, “I used to be doing this all the time.” So we have now sort of eliminated the foods, we have salmon meals, you know, I’m eating healthily, I’m eating proper meals, you know, I’m trying to eat properly as well.

Interviewer: Okay. So you will be seeing [name 13] and that’s gone through, so [name 14] saw you at home? And you asked for a referral. [Name 4], you’ve seen forever, and…

Respondent: Yes, it’s been for years, yeah.

Interviewer: And then you’ve mentioned [name 15] from the surgery, your GP?

Respondent: So I mean, because what I’ve done is when I’m on the group meetings, because I’m fit and healthy, we’ve done all the paperwork, so categorically, I went to this doctor and I said, “Right,” because [name 7] had retired, I said, “Look, you know about Huntington’s,” I sat in front of him and said, “What do you know about it?” I think he sort of had somebody in the family, although he didn’t allude obviously specifically, he knows of it. And he said, “No, no, you’re fit and healthy,” I said, “I want you as my nominated doctor from this point on in time and I want you to write me a letter for a referral,” which he did do, and he’s kept his promises. So I’ve got my will done, I’ve done the power of attorney, I’ve done all the correct paperwork. We haven’t got a mortgage, we’ve paid the mortgage off, so with everybody’s advice that has had problems in the past, at this point in time, all the paperwork, you know, has been done and has been signed off.

Interviewer: You’ve done your homework, [name 1].

Respondent: Yes.

Interviewer: So can I just go back a bit, because I’m not sure I understand, so [name 7], was he a neurologist or was he your GP?

Respondent: GP.

Interviewer: Ah, he was your GP. And when he retired, he referred you to another doctor?

Respondent: No, I got fed up with it, with going, and whoever was the sort of temporary doctor would just freak out every time they looked at, like, they’d say, “If you’ve come in about Huntington’s, we’re not specialised in that.” I said, well, “Even if I had, like, an infection?” I said, “No, no, don’t worry about that.” But then as time went on, I sort of investigated one of the partners there, one of the senior members, this [name 15], and I spoke to him and I said, “Right, look, I want you.” I said, “I don’t want to be floating now, so from this point on in time…” I think this is probably, like, two years in time actually, sort of where we were floating, but you know, he went on holiday or so on and so forth, but then we eventually went into the clinic. So yes, we were floating from [name 7], over time, for quite a long time.

[00:46:29]

Interviewer: Yeah, if you only got this [name 15] about two years ago, yeah, I mean…and you’re saying that those interim, that interim period, you were not quite allocated to a specific GP, so it meant you were seeing different people?

Respondent: Yes.

Interviewer: And they didn’t know of Huntington’s?

Respondent: No.

Interviewer: Okay.

Respondent: When I go into the GP and they put my notes up on the screen, so it’s got a banner up there, you know saying I’ve got Huntington’s, so anybody can see, and everybody saw, and the nurses saw every time you’d phone in, “Oh, are you okay?” which I appreciate and that’s what they’ve got to do. But then you’re being risk managed for a while, especially with a new person who was just filling in at that point in time. But you know, thanks to the team, with [name 4] and everybody else saying, you know, “Don’t float, let’s try and get somebody specific as a GP,” thankfully, as a tick in the box, because you know, you will encounter lots of horror stories, and especially from my sister in law, you know, [name 3] as I say, which was a train of wrack and ruin al the way through. One of the care homes, before she went to [location 2], that was perfect, you know, [name 2] should have gone there probably five years prior to when he actually did, and he probably would have lived 12 years, 12/13 years. But [name 2] got abused in…he wasn’t looked after, I don’t mean abused as in… They closed the home down, it’s out here, I don’t know what it’s called, but I still remember [name 3], to this day, saying, “I’ve whisked him out, he’s not safe, I’m not happy,” and then with three or four days, I think, they had inspectors in and they closed the home down, and then [name 2] went to [location 2] and was looked after, I think it was six/seven years there. But he had a fall, you know, he had a head injury. I could play pool with him, I’d go and visit him on a Sunday, you know, I could still talk to him, you know, although it was repetitive, but he was well enough for me to, say, you know, sit down and talk to some degree, have game of pool to some degree, but he could pick a pool cue up. He fell down…they didn’t feed him properly, and you know, he didn’t recover from that unfortunately, so my sister in law, [name 3], will hopefully tell you all about that.

Interviewer: Yeah, I would be interested in speaking to her about that. It’s not the first time I’m hearing about this. Alright, [name 1], so you’re being managed by [name 15], and [name 4] had put that direction to the importance of finding a GP so that you wouldn’t be floating between doctors, which seems to have helped have some continuity with your care.

Respondent: In actual fact, what I can say, and this is fuel for your fire, the idiocy of the surgery, the [location 4] health centre, when [name 7] retired, the idiocy that I’ve had there was when I go in and I’m talking to somebody for a common cold or I need antibiotics, and then somebody’s in there just filling in because the doctors surgery isn’t manned and they’re under-resourced, and I’m sitting there looking at a new person and I’m thinking, “Don’t freak out, I haven’t come to see you about Huntington’s,” and they say, “I’ve seen your notes, are you okay, we’re not a specialist?” And I say, “I know that,” so then bit by bit, as I then had an appointment for, let’s say, other things, and I learnt in the surgery who one of the partners are, got on the phone and I said to one of the receptionists, because I was waiting for different appointments, not specifically… I think it was to do with my hernia. I’ve had my hernia done, and I think that was an introduction, I had a double hernia, and that was, like, sitting down with [name 15] and we chatted about that. I mean, he did the letter, and I said, “You see the Huntington’s, can’t you be my GP so I’m not floating?” And I think as time evolved and then we waited, and now he’s taken me on. But it did, you know, there was a lot of frustration there.

[00:51:29]

Interviewer: It wasn’t smooth.

Respondent: No, it wasn’t, and I was lucky, because you know, as you can tell, I’m compos mentis, I can make my own argument, I can talk to somebody on the phone, I can talk technically and clearly, you know, so yeah…that was frustrating. But I was more than capable of doing that.

Interviewer: So when you do have an issue related to Huntington’s or potentially related to Huntington’s, who do you contact first, what’s your first line of reach?

Respondent: So currently, where we are, where we’re up to date with everything, so it’s a new journey for me. So with [name 14] coming and visiting and [name 13] obviously, them as the team, that’s new for me, and it came out of…and that’s current, so that came out of the discussion about food with [name 4]. So yeah, so if I go up there and they say to me, you know, I’ve got…when you sit down in the chair, I know what it is, cause I’ve tried to do it. When you sit still, it depends, if I’ve done exercise or I’ve come in the evening, I know there’s a twitch, but what I mean as a twitch, I’m pretty certain it’s not a Huntington’s twitch, to be honest with you, because I’ve actually sat downstairs and I’ve thought, “Well, hold on a second,” not that I’m imagining it, don’t get me wrong, I’ve thought to myself, “Let’s explore this to the nth degree.” We’ve done the food investigation, which, with the team, you know, we’ve looked at being underweight, because that’s important to look at, because I’m a medium t-shirt, I’m a [30-35], I’m a slim, you know, [30-35] waist, and I look at myself and I think, “Oh god,” I’m happy, you know, I’m happy in my body, I have no issue with that at all, and I’m active, you know, I do 40-50km with the dog in a week, we go out and about because I’m retired since we paid the mortgage. I actually think, my wife and I were talking about this this week actually, so there’s two things that have saved me – do you want me to say this?

Interviewer: Yeah, yeah.

Respondent: Yeah, so in actual fact, this is current. So everybody lies about how much they drink, right, but I haven’t got an addictive personality. So recently, where we’ve been looking at all the books, saying feeding the gut, you know, we’re looking at food, we’re really looking at that, so we’re looking at porridge meals and muesli, you know, I drink a lot of squash, I have drunk a lot of squash. Now, because of my high atonia and my swallowing thing, for a long period of time, so this is really important – I can’t and haven’t been able to have fizzy drinks, so I wouldn’t naturally go to the supermarket and buy coke. I have lemonade for a shandy, or something like that. I wouldn’t have, in the early days, lager, yeah, I don’t touch lager. I drink beer, I have beer, you know, if I go to the pub, I’ll have a pint. I know it’s fizzy, but it’s not coke, you know, coke is probably…. Orange juice is, like, you know, orange juice is the devil in disguise because of the sugar, and actually, you need proper orange, orange juice, not, you know, the manufactured… So I’m healthy enough, and we’re looking at what processed foods we’re eating. A while ago, when we had the family at home, a lot of our food was processed foods.

Interviewer: Yeah.

Respondent: And that was why, my son would say to me in the videos when we were out with family, “You’re a porky.” And he’d say, I’d say, “What do you mean?” and then he’d show me the video, I’m, like, [30-35] waist. So the wife and I have chatted, so this is current information, because…so I’m not a drinker, so I’m not addictive. If I have a drink, it’s a social drink, and this isn’t, you know, when you ask people, l they always duck the subject and always lie, but in actual fact, I’m not, I haven’t got an addictive personality. So if we’re out at Christmas time, I’ll have, like, three or four, I might have a bottle of wine, but what I do is, well, that’s an exception. We go to [city] celebrating when the kids were at university, you know, collectively, in the family, I haven’t looked for alcohol to cheer me up as a depressant and I haven’t got an addictive personality. So social drinking, two beers, like when Arsenal were on the other week, then that’s an exception for me. But I knew I was having food as well, you know, I’m not siting there, getting soaking. Thankfully, for me, and we were looking at this, because there was another programme on the telly that’s all about food, and we’ve been looking at those. So I haven’t drunk excessively for a long period of time, two – I haven’t had fizzy drinks, like coke, because I haven’t done because of my [redacted] hernia.

[00:57:24]

Interviewer: Your hernia, yeah.

Respondent: So I’ve been drinking squash, I drink squash all the time. I know that’s good for the brain, you know, I knew that from the beginning, when they were trying to do studies and you know, you’re sitting at home and you’ve got to replenish. And also, I’m not getting the Chinese, if you like, or getting that, I’m having a jacket potato, I’m being very careful. So I think that those have been major contributing factors to why I’m physically sitting here at [60-65] and I’m healthy, for me.

Interviewer: I mean, I always say to people, you know, what’s good for your brain will help with your journey through Huntington’s, isn’t it? If you can treat your brain the best way so you’re exercising, you’re eating healthy, you’re drinking things that are good for you, so it can only do you good.

Respondent: And you see, the thing is with you today, when you asked me about the beginning, and how devastating that was, obviously I’d look at the periscope that way, and feel that it was going under at 20 years old. But obviously, sitting there at 61, with what I’ve said to you now, and obviously when you look at, you know, when you think about a very recent period in time, and thankfully, with [name 4] help, I made a decision, there was some things that I needed to talk about with my wife, and basically I was really, really unhappy. So because she purported…so when my daughter and wife, so they don’t live at home now, so it was a year and a half ago, but when my daughter came back from [location 5], she took on a therapist, and basically she blamed me for a lot of her failed relationships. Now, my wife supports my daughter a lot, and my son, who is married, he wasn’t living at home, was very concerned about that period of time. Now, that was my worst mental period of time ever. So I was really surprised that I didn’t have any more adverse reaction to that, especially from the mental stress side of it. So sitting at home here, where I am, that was a year and a half ago. Right, I said to my daughter, because my wife alluded that early signs of Huntington’s was, like, anger and reacting and running out of patience, I’ve gone through all this with [name 4]. She has been my main support, talking to her, I send her an email, “How are you doing?” you know, I say, “Yeah, I need to talk, need to talk,” and talking about these in-depth…

My wife’s alcohol problem, they’re saying my wife dumping, you know, all her issues. All the family are gobsmacked. Some of the cousins that I’ve gone out, I’ve come down with – this is related – I sent them the letter and one of my cousins who I’m really close to cried in front of me in the pub. He’s never cried. He said, “How can that be you?” But what I had to work through at that point in time with everything, and manage the family, was – and my son said to me, “Dad, [name 5] having the therapist at home is going to destroy the family, and if we don’t get her out sooner rather than later…” So after about eight months, you know, that was intense pressure. So I agreed to do, like, some anger management therapy. We did it through Mind, because it was just cheap and easy, and I did two or three, and I was happy to do it, to be honest. And I had to say to my daughter, for the sake of our family, “I’m prepared to do it, you know, to heal the bridges.” So I mean, I’m still with Mind, I mean, they haven’t helped me for Huntington’s, they don’t know about Huntington’s, but [name 4], in her entirety, has helped me with e4verything, you know, not just, as I say, from the Huntington’s point of view, but even advising us of how to tell [name 6]. We knew I had Huntington’s, so the genetic clinic said, when he was going through the genetic counselling that they wouldn’t tell him his test result until I tod him. They wanted it to be current.

So of course, because we kept it a secret, you know, we hadn’t actually officially said that I’d had the gene for a long period of time. My wife, again, ducking everything under the carpet. But that was a very difficult time, you know, it was horrible, a lot of conflicts, a lot of horribleness in the house. Now, I’m very thankful that next week we’re all going on a family holiday, which includes the daughter, my son and his wife, and my wife as well. So we’ve obviously moved forward with a lot of those issues and talked about them, and what I’ve had to do is prove that my behaviour isn’t Huntington’s-related. Now, I’ve had menopause challenges with the wife, my wife is a very, very intelligent person, very, very intelligent person, right, very capable, intelligent person. And you know, I’ll say to her about her drinking problem, and that was causing me…it was one of the issues a little while ago. And she’s open about her drinking. So she drinks, I mean, she has a glass when she gets in, if we’re doing a meal, if I’m at home, I’ll cook a meal. But she was very, very subversive in her drinking, and I chatted to everybody, and you know, I react in a way to something, it might not be that specific thing I’m reacting to, and then my wife convinces the family that we need a Huntington’s meeting, and she says, “No, I’m getting angry.” So initially, at that point in time, I would react, because of other things that were going on, and issues that I was trying to contain at that point in time.

[01:04:57]

Interviewer: So it sounds like, again, [name 4] has been absolutely key to help you manage all these family crises as well, and actually, it sounds like you’ve succeeded despite being so hard, and a lengthy struggle as well, but it sounds like, you know, the fact that you’re all going on holidays together, it sounds like you’ve got some peace, at least for the moment. Yeah, not everything can be blamed on Huntington’s, that’s for sure.

Respondent: No, no, so I mean, we had…and this is why we’re in place with a lot of the paperwork, because some of the action plans from the first Huntington’s meetings would say, like, “Get the doctor, get this power of attorney sorted out, get the wills done,” and the wife and I sorted that out, you know, we went down to [location 7] and then once we had, let’s say, the second Huntington’s family meeting, it was more about my relationship with the daughter, but she really didn’t want to talk about that at that point in time, because she was still living at home. She doesn’t live at home anymore, she moved out, which is good, and it’s the best thing for all of us.

Interviewer: Who was guiding you through, you know, these life decisions of power of attorney and doing your will and…who was guiding you through this, if anyone?

Respondent: Somy family are quite bright, so it was my daughter, [name 5], my sister in law, [name 16], [name 6] wife, they got married, you know, they’ve known them for quite a long time. So it was my wife, my daughter and then [name 6] and [name 16]. And then also, from the Huntington’s, on the monthly Zoom call, they looked at doing power of attorney for different people, and I think it was the family meeting I went along to at [location 8], a year before, was it, oh, it was last year, where actually we got chatting about different things, and about doing the paperwork. So my family said to us at the end of that, and collectively, I looked at some of the paperwork, we looked at doing it only, but then we actually… And then also I did it from a Huntington’s point of view, about the swallowing and, you know, I said, “Look,” to the wife, you know, “[Name 2] couldn’t eat, he lost a lot of weight, he was in the bed, you know, it got past…and they were sort of, like, drip feeding him.” So I said, you know, recently, because the wife had ducked that as a physical issue, and writing it, to say, you know, “I’m saying to you, I don’t want to get as poorly as [name 2] has, and you’ve seen him.” My wife wouldn’t go and see him, so I put that into the power of attorney, I put that in Huntington’s specific, [name 4] helped us with that, and the wife did it, and we did it together collectively.

Interviewer: Okay, thank you. So what do you think, I mean, this is your experience of course, but you’ve known of other families, is there anything you think that needs to be improved for Huntington’s Disease care in your county? What do you think, is there anything that needs to be improved?

Respondent: Well, when I go to the socials, as in, like, you know, the bowling, there’s 20-30 people there at various different ages, and they’re elderly, you know, 80-85, and those people who’ve got the journey through the family Huntington’s, so I’m, like, the secretary of the society. So when I come along, you know, and I’m saying to them, “They’ve had that journey that you really need to capitalise on.” Because you know, when I sit there, they’re almost so worn out and you hear the same things from them about, you know, trying to pull everybody together, trying to do the political side of it, and just one side of the nursing, you know, fighting against the other. I think with the society, with the Huntington’s charity now as it is, the awareness there in that team with all of the people that go to the socials, it’s just contributed to more awareness. My sister in law, definitely, obviously because of my brother in law, [name 4] can’t tell you others, but as I say, there was 22-30 people sitting there at the bowling do round the corner. So they’ve either, you know, had somebody pass away close. There’s one lady who’s had two members, her husband and son, so she’s unfortunately gone through that experience as well. And obviously when she turns up, you know, she’s sort of turning up to be supportive, but she’s already had that nightmare, because everybody is very upset about the treatment…everybody seems to support my sister in law with, you know, nightmare stories, which is exactly why you’ve decided to take this on for your thesis, no doubt.

[01:11:10]

Interviewer: Okay, so what is it that people, like, in their social way of…

Respondent: Everything, calamitous lack of support, you know, my sister in law with [name 2], my brother, is par for the course. Every single stage, you know, the idiocy and the frustration, all the way through, you know, especially going to the bad care home. I’ve forgotten what it was called. You know, we know how much money they were getting, it’s, like, it doesn’t pass the… And they gave [name 2] a step, I walked in and I thought…and they were, like, “It’s okay, you didn’t have to support him.” And I went into his room and he had a step where the bed was, and it was, like, I thought, “Surely this is a glaringly obvious thing that needs to be changed straight away?” They didn’t feed him the right food, he was constipated. [Name 2] was quite a healthy person, because he had asthma, he always kept himself, as he did karate and canoeing, and funnily enough, they’d tell hm off for going to the fridge and every time I’d turn up, he’d say to me he wouldn’t like this condensed milk, or this…it’s…not orange juice, it was fruit juice, it was like one of those old tins of fruit juice that was really horrible, but it was…it kind of had, like, cherries in it, and pineapple in it. So because [name 2] was constipated because they were feeding him the wrong things, he knew to drink this, so every time he’d go and get some freedom, he’d go to the fridge. He couldn’t communicate at that point in time, and I’d say, “Well, what was it?” an then he fell down, he, you know, he was poorly with his stomach, and then things just started getting worse.

Interviewer: Yeah, okay.

Respondent: But my sister in law categorically, you know, she’s the first person that I’m going to get you in contact with because you need…

Interviewer: Yeah, I would appreciate that, yeah, but you know, I’ll leave it with her if she wants to be in touch.

Respondent: She is on a crusade, she’d love to be able to talk to you and give you all the information.

Interviewer: Oh, thank you. So [name 1], what do you think is the most important thing about your care right now?

Respondent: I think we’re there. So you know, we’re up to date, so you know, I’ve got [name 15] after two years, you know, I’ve said to him, “No, no, I want you there every time.” So if I need to use it going forward, w4’ve cut through all the red tape, you know, my wife can phone, we’ve got the team, we’ve got [name 14] coming from [name 16], so we’re having… so pre-symptomatic, let’s say, I’m healthy and pre-symptomatic, I’ve done everything I can to look after myself. We’re taking guidance from the charity, with the Zoom calls, on how to do the wills and the power of attorneys, and then the family have turned round and said, you know, “Please get that going,” you know, let’s say that took a year and a half. So we’re very lucky, you know, even, as I’ve said to you, the problems I’ve had in the family, I have actually still got a family, and they’re there to support. You know, when I see some of the people that are sitting at home by themselves, you know, that must be one of the most soul destroying things to be able to do that, especially when you’ve got Huntington’s as well.

Interviewer: So do you think, I mean, listening to you, it sounds like you’re obviously, that these family conflicts were really affecting your quality of life? So the fact that you’ve managed to navigate through, I mean, clearly with a lot of [name 4] support, gives you some peace of mind?

Respondent: Yeah, I mean, if you turn, say, even the two year time period, and the daughter sitting in the bedroom all the time, which is where she was, she’d have the door shut, you know, we’d have… Everybody gets hungry, but… For the wife and I to have a conversation recently, say, within the last couple of weeks, and actually, with the information that I’ve said to yourself about why I think I’m fit and healthy, is that we’re out and about, and we were counting our blessings, that we are where we are, especially for myself and my health point of view. And we just opened it up and I said, “Well, surely it’s because I’m not a drinker, I’ve been drinking and also aware of the food that I’ve been eating as well.” Because on the telly, these seem to be two contributing factors of why people, you know, were poorly, not obviously from a Huntington’s point of view, some people. And I just said, “Well, I think that’s what saved me,” because we were saying, you know, with the stress that I’ve had, from a life point of view, with all the things that families have, all families have it at some point in time, everybody has redundancy. You know, I told my place of work about it, they very strategically at that point in time took a year, and then they made me redundant. They were very strategic…Yeah, and so they took a year to get rid of me, because it was very manual systems at that point in time, it was very early computer systems, you know, 33 years, so it was, like, then the building industry took a crash and then they racked it up. I knew what they were doing, you know, I had two very close friends there that I’m still in contact with, and from the material side, because I looked after all the purchasing and contracts side. And they said to me, “Well, you know, this guy there was taking this bit, this bit and this bit,” so for me, doing it as a one man memory machine, this is a long time ago, in my 20s, I don’t mean, you know, in my 20s and my 30s. Then once I told them about Huntington’s, within year, they’d officially made me redundant.

[01:18:28]

Interviewer: Oh, I’m so sorry, [name 1].

Respondent: Yeah, I was useless though, you know, I couldn’t function, it took me five years. The bereavement cycle is five years, but yeah…

Interviewer: Okay, I’m sorry, [name 1]. It’s hard.

Respondent: It was a long time ago, as I say, at [60-65] , we’re sort of looking forward, we’ve got the green light, you know, sort of feel very positive about things.

Interviewer: Yeah, I mean, you know, you definitely…they say what doesn’t kill you makes you stronger, and you definitely sound strong.

Respondent: Yeah.

Interviewer: Okay, so thinking of your experience, the rest of your family’s experience and these socials and the bowling, if I ask you to picture…so if I tell you, “My care is excellent,” how do you picture this looking?

Respondent: “My care is excellent”?

Interviewer: Yeah. What makes care excellent, you know, if you think about what you have accessed now, is this an excellent level of care? Is this what you want from your care, or is there anything missing?

Respondent: Well, we don’t know, do we? So you know, let’s say when I’m 70, I’m in [location 2], you know, so the only way…I said about being PEG fed, and I said about doing an assessment of, you know, where I think I might be from a Huntington’s point of view, possibly, then that was the first time we’d sort of really sat down and said, you know, “We don’t want to get there, do we?” with the wife, and she wrote down my words to say, no, she will make a decision about my health prior to this point in time. Now, obviously I think a lot of the other people you’ll talk to will be, you know, there’s….are having a Huntington’s experience already, now, a lot of the people, there was a new guy at the bowling do, bless him, and I, you know, and his son and his wife were there, and the fear on the son’s face, you know, there was empathy for his dad, but also fear for himself. And I suddenly thought…and then I went over and I started chatting to the son, we were chatting about football, and the guy…I can’t remember his name now, but you know, he was pre-symptomatic, or you know, started. And you know, it was sort of just…he was a little bit mobile, if you like, and had a bit of twitching. And the gentleman that I did…myself and the gentleman, I think from the [location 8] branch, so the three of us crossed the [redacted run]line together, so it was my sister in law, [name 3] and myself, and this other gentleman. Now, he was poorly, he is poorly, and wobbly, but I didn’t like to say, I didn’t like to ask him. So when we were walking, so we walked around, again, I said to my sister in law, “I’m not going to ask him, obviously he’s got Huntington’s, I’m not going to turn round…” Everybody knew who we were because we were [name 3] family, if you like, knew who I was, because she’d spoken to everybody. But I met a lot of new people that were pre-symptomatic, if you like, and already under care. So I think this gentleman was from the [location 8] branch, so he was still able to walk a bit, but he found it difficult going uphill.

[01:22:53]

Interviewer: Okay, so I’m going to just go back to my questions, to ask if where are you now, like, with your ducks in a row, it sounds like you have aligned, your decisions are made, you have your GP, you have a specialist nurse, you have [name 14], you have [name 4]. Is this what good care looks like or is there anything missing?

Respondent: I can’t quantify it because I’m still at the starting line.

Interviewer: No, of course, at this stage that you’re at, is this what you need at the moment? You have all the care, all the support you need?

Respondent: No, I understand, yeah, so where we currently are with waiting for the…it will be a cursory, I think it will just be, and then we’ll be going along to [name 14] maybe three times, you know, when [name 16], we just…That’s jut a safety-wise, if you like, because it’s practical to do that, you know, it makes sense, common sense to get this far and not say, “Let’s not,” if that is offered to me. I haven’t been there, you know, that’s new to me, so…

Interviewer: The clinic?

Respondent: Yes, with [name 14], it’s the first time I’ve done, and it’s the first visit I’ve had from [name 16]. So yeah, so that’s why it’s new, new for me at this point. So with the food, as we’ve been talking about, and my weight, my waist, I’m [30-35] and a medium t-shirt, so when I was chatting to [name 4], we were saying about being concerned about food, but my explanation about my journey with food in its entirety is important, because I think there were two contributing factors as to why I am actually healthy, very healthy from a Huntington’s point of view, it’s got more to do with it than just being physically active.

Interviewer: Yeah.

Respondent: Yeah, I’m not an alcoholic, you know, and…yeah.

Interviewer: Yeah, you mentioned your, yeah, you’re being very careful with your food choice and you’re not drinking. Okay, [name 1], so you’ve said earlier that you’re [60-65], that’s right?

Respondent: That’s right, yeah.

[redacted]

[End of Transcript]