[0:00:00]

[redacted]

Interviewer: Yeah, that’s fine, okay, just so that I know what we’re working with. Good. So we’ll have an informal chat just you and me and then if you need any breaks throughout please let me know, we can stop at any time, okay?

So my first question is… just for you to set a bit into the context of how did you become involved with Hungindon’s Disease, you were telling me earlier that your husband is affected.

Respondent: Yes, yes, my husband was diagnosed in [2015-2020], and we had no idea it was in the family at all so it was a complete shock and that’s really the first I ever really knew about Huntington’s, I didn’t really know what it was or anything so it was… I think the learning process of discovering what it meant and what the implications were was quite difficult.

And it was a huge shock to my husband too, obviously he… and of course we have a grown up daughter, he has children, he has grandchildren so, you know, the implications were just horrendous to begin with. How much information do you want me to give you?

Interviewer: Yeah, so when he was diagnosed what prompted the diagnosis, what was happening?

Respondent: Well, he’d noticed… he thought he had ADHD, he realised he couldn’t concentrate, he was still working at that time. I should say he’s [10-15] years older than me, so he’s nearly [75-80], and at the time he was still working. We both work from home and he began to realise that he couldn’t concentrate very well anymore, he was finding it difficult to concentrate or focus and I was noticing that his motor movements were becoming much less fine, he became quite clumsy and so we went along to the doctor and he said he thought it might be ADHD and the GP-

Interviewer: The GP?

Respondent: The GP, yes, and the GP said, “Well, let’s send you to a neurologist first,” and we had the most awful experience at the neurologist. He was dreadful, absolutely dreadful, awful bedside manner, he was accusatory almost, was rude, quite… rude, abrupt and he talked to me as if my husband didn’t exist, you know, “Does he take sugar?” type thing, it was awful.

And then he said, “You better go and have a blood… a genetic test, go down the corridor please and have it.” Yes.

Interviewer: No-

Respondent: We weren’t given the option of-

Interviewer: And this was in [2015-2020]?

Respondent: Yeah. We weren’t given the option of having genetic counselling, we had no idea what the implications were of this, so we toddled off down the corridor to have this test, so when the results came back [Name 2] had to go on his own because I was dealing with my father who was dying at the time, I was helping my mother look after him blah, blah, blah and that was awful.

And apparently the neurologist said to him, “Where’s your wife? How did you come? You’re not supposed to drive, you didn’t drive did you?” this sort of thing, it was appalling. I have to say we actually complained and they just rejected the complaint, I don’t know if I worded it badly or what but they-

[0:04:21]

Interviewer: And this was in [Location 1 this neurologist?

Respondent: Yeah. Do you want details or shall I keep it anonymous?

Interviewer: Oh, no, you can give me details because it will be anonymised.

Respondent: Yes. Well, it was at [Name 3] Hospital, I forget what the name of the guy was now, it was a [foreign nationality] neurologist, there’s a lot of [foreign nationality] staff up that way, in [Location 2] but it really was incredibly upsetting.

Interviewer: So did you say your husband is named [Name 2], was that-?

Respondent: Yeah.

Interviewer: Yeah. So [Name 2] came to the appointment, of course he had no idea what he was in for, nothing had been explained. So did the neurologist give him the diagnosis or did he send him home?

Respondent: No, he gave him the diagnosis there.

Interviewer: He gave him the diagnosis by himself.

Respondent: [Name 2] phoned me afterwards but it was… it was such a horrible experience, the first appointment when I was there it was just I couldn’t believe how he was treating [Name 2] for one thing, as if he didn’t exist, just sort of dismissing it as if it was oh, nothing very much, you know? “Oh, you’ll have to tell your children,” as if there’s no emotional side involved or, you know, it was just very, very abrupt and almost bordering on rude because he told [Name 2] basically he couldn’t drive, he shouldn’t drive anymore, should surrender his license and he said, “Well, you can always try and get it back but you’ll fail,” that sort of approach, you know, “You won’t succeed,” and things like this and it was just ghastly.

Interviewer: Oh, I’m really sorry because that’s… I mean there is never a good way to receive bad news.

Respondent: No.

Interviewer: But this is making, you know, well, a bad scenario just so much worse with I mean what a terrible experience, I am so sorry. And then what was decided in terms- I mean I can see the approach was very much like, “That’s it, nothing you can do now, just sit and wait for it”. Was there any, like referrals done? I mean did [Name 2] need anything because it sounded like he was working still, was he still working when he was diagnosed?

Respondent: Yeah, he was still working as well.

Interviewer: Yeah, he was working.

Respondent: Yes, we were working together. No, I mean and he wrote to the GP obviously but it really upset [Name 2] so much he wouldn’t let anybody, not even… least of all the children, they were the last people that should know and that in itself was hugely traumatic, and in fact he didn’t accept the diagnosis even after the genetic result came through, for months he said he wanted a second opinion.

He got a second opinion from a neurologist who didn’t even specialise in HD and I wasn’t there but he apparently just said that he couldn’t comment because he didn’t specialise in HD, I mean what’s the point of having a second opinion from somebody who doesn’t know this? That was one thing.

And then somehow [Name 2] got on to the books of he was referred to the [Name 4], I think he went somewhere else first but we’re with [Name 4] now and have been for a while, and he saw another consultant a professor somebody on his own, he wouldn’t let me go with him. He blamed me for a lot of it, he blamed me for dumping him in it because the original- sorry, this is all very mixed up.

[0:08:23]

Interviewer: No, no, no, it’s alright.

Respondent: The original neurologist when we were talking about the driving he said to me, “Are you happy with [Name 2]’s driving?” and I said, “Well, to be honest, no,” because it was a bit scary by that time and so [Name 2] for months he blamed me for him losing his license, and of course these are all things which happen with HD, the rationality goes out of the window and so he’s blaming me for lots of things, blaming me for the diagnosis, everything else so it was a really, really difficult time.

And because he wouldn’t let me go along to the appointments he didn’t trust me because he thinks I dumped him it all the time and I’m telling the medical profession all these lies about him, you know, that sort of thing.

Interviewer: Yeah, I see, so in terms of mental health there was… so basically was channelling his frustration, yeah, onto you which isn’t ideal because you were… so he didn’t want to tell the children so he was going to the appointments by himself if he was going.

Respondent: Yes, but then he completely rejected any medical help whatsoever, he refused everything basically to begin with and I think after the one check up after about a year, this was with the HD clinic, he did have the one with professor whoever it was, I can’t remember. He said, “Right, I’m not going back, I can deal with this myself,” and meanwhile things were just getting worse and worse and his temperament was doing the typical HD thing.

And I think partly because I didn’t understand the mental processes that people with HD go through and how difficult it is to react in a logical way, which obviously they can’t, I didn’t understand that so I was kind of almost stoking the flames by my not understanding the situation, and this went on and on and on and it just got worse and worse and worse.

Somehow eventually we persuaded him to be referred again to the clinic and start seeing somebody and we found the most amazing lady at [Name 4], absolutely lovely.

Interviewer: Who’s that?

Respondent: Her name was [Name 5] and she just saved our lives, honestly I’ve got so much to be grateful for [Name 5]. To cut a very long story short, you may come to some of this before but she changed the… she gave him extra medication and he’s settled down and he’s absolutely wonderful now and it’s just completely transformed our lives so that’s in a nutshell how it’s been.

Interviewer: Yeah, but that just comes to show the impact of good treatment, good care.

Respondent: Absolutely, absolutely. [Name 5]’s no longer there, we’re now seeing [Name 6] is it, [Name 6], anyway she’s also lovely so it’s also good.

Interviewer: Yeah, no, I know [Name 5] left last year or was it last year? Yeah.

[0:11:30]

Respondent: Yeah. I didn’t know she’d left actually, she didn’t tell us she was leaving but [Name 6]’s just like so… it’s fine.

Interviewer: Yeah. So your… I mean again as you’re saying, somehow you managed to get him back like convince him and, you know, get him back on the clinic. So what was your experience of what was the clinic, you know, when he would go to the appointments what did these look like?

Respondent: Well, when he went… obviously I don’t know when he went to begin with but eventually when I persuaded him that I could go with him I should go with him, we went to… we got a third opinion actually, a private third opinion, at a different private clinic, that was separate and he did actually allow me to go into that one but when we finally got… I say we, I always talk about we, when [Name 2] got referred back to [Name 4] and we started going there regularly to see [Name 5] it was with just [Name 5] in her little office and she was just so thorough and she spoke to [Name 2] in a really adult but friendly way.

So she treated him like an individual and not like a patient and she was really interested and she really won his trust and so he was happy to see her, it was lovely, yeah.

I mean and she was also aware that at the time I was having difficulties so she was able to talk to me and then she actually made regular appointments for me as well which was fantastic, really helped me.

Interviewer: Separately [Name 1]?

Respondent: Separately, which was great.

Interviewer: She would see you separately.

Respondent: Yeah, she saw me six monthly as well to see how I was doing which was… which just felt so amazing, you know, that they were caring for the carer as well as for the patient and that was just amazing. The clinics are very straightforward, we just go and see either [Name 5] or [Name 6], have a chat, find out what’s going on and because [Name 2] isn’t really deteriorating very fast at all, he has the lowest possible reading of… CAG reading.

Interviewer: Hmmhmm, yeah, you said he’s [75-80] now and he’s-

Respondent: He’s aged [75-80] and his reading’s [CAG redacted] so really they’ve all said, you know, he’s probably just going to deteriorate a bit and he’ll probably die of natural causes when it comes rather than of the ravages of Huntingdon’s so that was quite reassuring, incredibly reassuring for both of us, yeah, but it was just like a little discussion in the clinic really.

Interviewer: Yeah, with the neurologist as well or would it be mainly with the nurse, specialist nurse?

Respondent: Yes, with [Name 5], we saw [Name 5] several times, and seen [Name 6]. He has had one video appointment with the neuropsychologist or psychiatrist, I forget which it was there, again it was just very brief video appointment just talked through a few things, there wasn’t very much to say.

Came to the conclusion that [Name 2] is perfectly capable, he has capacity, yeah, there wasn’t very much of an outcome of that. He’s also been referred to an OT a couple of times. I find it a little bit confusing as to how to get hold of them, it’s probably because I forget who I’m supposed to be calling because there’s the… well, when we were in [Location 1] there was the [Location 2] community team and then there was the specialist OT physio things. There was a neurophysio as well that [Name 2] saw, so we did get referred to them, it was just a little bit-

Interviewer: Through the clinic?

[0:15:35]

Respondent: Through the clinic.

Interviewer: Through the clinic.

Respondent: It was a bit unclear as to what they would be able to achieve, they just… a lovely girl came along, neurophysio, came along and gave him some exercises but the thing with HD, which I found quite odd was that, you know, if they don’t want to do them they won’t do them, it’s just impossible so the exercises have been useless really because he’s not motivated to do them.

Interviewer: He’s not engaged to do them.

Respondent: Yeah, he’s not engaged, so I would have preferred… I mean I don’t know if there is such a thing, I would have preferred for her to, say, come down to the clinic or come down to my surgery, whatever, once a week or whenever it is and we can do them together, you know, would have-

Interviewer: Okay, so you think with [Name 2] it would have worked-

Respondent: …with actual assistance he might have done that.

Interviewer: Yeah, okay, so you think he needed a bit more like structure and like actual one to one support to get the exercises done…

Respondent: Yeah.

Interviewer: …because just be himself he wouldn’t…

Respondent: He’s not doing them-

Interviewer: Yeah, he wouldn’t do them, yeah.

Respondent: I mean with HD I can tell him… I can give instructions, make suggestions, if he’s not interested he will completely ignore me, you know, “Put this jumper on,” completely ignore me so… you can’t persuade someone with HD to do these things if they’re not interested.

Interviewer: So what happened with the neurophysiotherapy? So did he then like stop going or…?

Respondent: Well, she came three or four times, we were trying to encourage [Name 2] to go for walks. His mobility that’s the thing that’s suffered most is his mobility, he has now got a walker which helps actually, does help. He started off doing an exercise… we managed to do it a few times the one easy exercise and I could see that it was helping a little bit just standing up and sitting down holding on, you know, just sort of that standing up sitting down.

Interviewer: Yeah, yeah, yeah, that’s one of the things they like to do in the clinic to see if you can do it, right.

Respondent: Yes, well, it’s good for anyone sort of getting on a bit really that one, me too, if I remember I try and do them as well but it just it’s impossible to build a routine with [Name 2] and I know that they do say that people with HD like a routine but his routine that he likes is not having a routine.

Interviewer: Yeah, yeah, no, I was wondering the same, usually they like structure do they to know what to expect next.

Respondent: Yeah, so-

Interviewer: Well, you know, again each person is a person, you know, they’re individuals with their own characteristics so for [Name 2] it works best to be surprised and go with the flow I guess.

[0:18:43]

Respondent: Yes, just what he feels like doing and, yeah, so…

Interviewer: Okay, [Name 1] so I’m quite impressed that, you know, after such a terrible experience, you know, with getting the diagnosis from the not so empathetic neurologist he was able to trust, you know, you were able to trust again into the clinical team-

Respondent: Well, I think it was more he was really forced into it because he began to get almost… he began to get quite violent in his mod swings and there came a point where I had to leave the house because he tried to pull me out of bed and throw me out the house in the middle of the night, it was getting that bad. And I left for a few days and actually that’s when everything blew up and my family, the children, discovered because the girls, who are all in their… they’re all adults, I mean his daughters are now in their [45-55s]…

Interviewer: Oh yeah, yes, of course.

Respondent: …yeah, they didn’t know about it so they went round and I was out, I was staying with my mum at the time, and they confronted him saying, “What’s going on?” and he blurted it out, his daughter was there, she drove home had an accident on the way home, it was just… oh, it was just awful.

And so, yeah, he ranted and raved for a few days but eventually his two daughters went round, talked to him and said, “You’ve got to see a doctor, you’ve got to,” because he wouldn’t even see the GP and so he agreed. I’d phoned the clinic in the meantime, told them what was going on and they said, right, [Name 5] said she would phone through some medication, she knew exactly what he needed, a strong antidepressant, Mirtazapine. She prescribed that, the doctor sent the prescription straight through to the pharmacy and we got that and it transformed our lives, just that one little tablet it just settled him, it was fantastic.

And then once he was settled we were able to say, “Right, it would be a good idea to go and see [Name 5], she’s really nice,” etc., etc. and that’s when he agreed.

Interviewer: Yeah, you sort of had to dig him out of the hole first, he was in too deep and then you were able to move forward.

Respondent: Yeah, that’s why I said (inaudible 0:21:19).

Interviewer: Yeah, yeah.

Respondent: (Inaudible 0:21:22).

Interviewer: And to see you on your own as well which is something, you know, I’m really pleased we’re talking because that’s not something I’ve heard, you know, at all before.

Respondent: Really?

Interviewer: And I’ve done a few interviews already.

Respondent: Yeah.

Interviewer: So it’s something people ask, you know, it’s something that people need. As you’re saying, you know, you got HD dropped on your lap coming out of nowhere, no real explanation of what to expect while your husband of course was already like showing symptoms so you need your time as well, you need your care so I’m so pleased that she was offering you that and that for me it’s outstanding, you know, I’ve known her-

Respondent: Fantastic, the space, that was fantastic, yes.

[0:22:15]

Interviewer: She would see at the hospital?

Respondent: Yeah, she did, yes, in the-

Interviewer: Yeah, the clinic, yeah, okay. You didn’t get offered like home… there was like no home visits?

Respondent: Not from the clinic, no.

Interviewer: Not from the clinic, yeah, okay.

Respondent: We didn’t need them to be honest, it was fine going in. If we’d said they might well have arranged it, I don’t know, we didn’t need it but I think the help that I got was so vital because she took the time to explain what’s happening in the mind of somebody with HD and how long they take to respond to things, these sorts of things and how you have to give them time to process information. It was all this which made me realise that I had no idea about any of this and so I was able to help [Name 2] by understanding this situation so we instantly got on much better because of that and these rows and these horrible, horrible rows where I… I was on a rollercoaster, I didn’t know where I’d be in two weeks’ time, you know, that sort of thing. Will I be in the house? Will he throw me out? Should I move out? All that, which is so normal I know from the HDA forum I know that that’s so normal for HDA carers and partners.

And because she took the time to explain these things to me it just transformed everything and I suddenly got this understanding of how an HD person’s mind works as much as it’s possible to get from-

Interviewer: Yeah, well, but I guess you were a bit like why is he being like that to me, you know, without… you know, you thought he was being like nasty on purpose or while basically-

Respondent: Well, yeah, I mean I’d read up on it, I knew these mood swings happen but I couldn’t work out what it was that was triggering him and I was thinking what am I doing? Am I doing something? And in fact, yes, I was not giving him the time and space he needed to absorb the information that I was trying to give him and so once I realised that and I stepped back and I didn’t overload him with information.

Because somebody with HD will shout “F Off, I want a divorce,” what that means is you’re not giving me enough time to process what you’re saying to me, that’s all it means, you know?

Interviewer: Yeah, yeah.

Respondent: And it was that realisation.

Interviewer: Yeah, it’s so important, yeah.

Respondent: So, yeah, it was great to have that opportunity.

Interviewer: Are you still having these one to ones with [Name 6]-?

Respondent: I had a quick catch up by phone and I said, Look, you know, you can discharge me now because I don’t need this,” but she said any time I can just email and if I have any problems just email and they’ll answer, which is great. So I really feel that they have our backs and we have a really good direct line to them, which is fantastic, we didn’t have that before, before we met [Name 5].

Interviewer: Hmmhmm. I mean they don’t do weekends or like it’s like office hours, right?

Respondent: Yeah, yeah, yeah, of course, yes.

[0:25:31]

Interviewer: And is that okay or, like, if something happens-

Respondent: It’s fine, I mean once before [Name 2] had this new medication, the Mirtazapine, I was in a terrible state and I didn’t know who to turn to, I couldn’t phone the GP. I did try phoning the mental health crisis line but they didn’t have any idea about HD at all so it was a complete waste of time but now, now that things are much more settled, I don’t feel… I can’t see myself needing urgent support at the weekend anyway so it’ll be fine.

Interviewer: That’s excellent, it means that, well, there aren’t these crises happening because, you know, [Name 2] and you are being dealt with properly throughout instead of waiting for something to happen and then react.

Respondent: Yeah.

Interviewer: It’s really good.

Respondent: And we’re not having those crises anymore which is just-

Interviewer: Yeah, yeah, yeah, because he’s, well, he’s with a good treatment.

Respondent: Yes, he’s on the right medication.

Interviewer: Yeah. [Name 1] can I ask you just to go a bit back when you were saying you had you’re not sure if it was like a neuropsychologist or neuropsychiatrist video appointment, I’m curious about how did that go, like the video appointment in terms of could [Name 2] communicate well and use the system or…?

Respondent: Well, I have to be there for these things for him, with him, and I checked, you know, with [Name 2] and with the psychiatrist I said, “Are you okay with me being there?” because [Name 2] doesn’t hear very well, we haven’t got hearing aids organised yet and he can’t manage the technology on his own so I am his hands in that regard and his ears so I was sort of the go between if you like.

Interviewer: Yeah, yeah. So how did you feel about having the appointment online? Is that something that you were used to doing with other professionals or…?

Respondent: Oh yeah, I mean, well, obviously in COVID I spent half my life online anyway and [Name 2] doesn’t mind either. He’s happy not to have to go in frankly so he was much happier. I think if he’d been made to go in he probably would have refused so I think that was quite useful to have it online.

Interviewer: When you say it was a short appointment so to go to the hospital just for a few… 15 minute appointment.

Respondent: Yeah, yeah. I mean I’m sure that psychiatrists can gain more from a face to face appointment obviously but he seemed satisfied with the outcome. I can’t even remember what we were talking about or what [Name 2] was… what he was asking him, I forget really but it was all very… it was actually not as in depth as I thought it would be but perhaps that’s just the nature of this sort of thing that you can’t really go too much in depth with somebody with HD because it’s a different level of communication perhaps, I’m not sure.

Interviewer: It depends on what the aim of the appointment was, what were they trying to… what was the objective I guess.

Respondent: I don’t really know actually, I can’t remember.

Interviewer: I guess that’s where the lack of clarity comes from.

[0:28:51]

Respondent: Yeah, yeah.

Interviewer: And perhaps the professional also wasn’t sure.

Respondent: Yes, yes.

Interviewer: Sometimes it happens that we’re not quite… yeah, someone has booked an appointment and-

Respondent: Yes, well, I think [Name 5] did book it because at the time I think it was when… before [Name 2] had gone on to this medication and he was still quite erratic and making, you know, strange decisions towards me and being quite hostile towards me so I think she wanted him to check whether he actually he wanted him to be checked over to make sure he was still had capacity this sort of thing because clearly there’s nothing that can be done if a person has capacity, there’s no decisions that can be taken outside of that if they still have capacity, they have to be involved but, yeah, that was before [Name 2] settled down, yeah.

Interviewer: Okay, alright. And you’ve mentioned the HDA forum that you see, you know, now like with the conversations that some of these behaviours normal.

Respondent: Hmmhmm.

Interviewer: So is that some support that you often look for with the charity or not really?

Respondent: I did a lot, I found a lot of support from it when [Name 2] was still in his phase of mood swings before he came onto the new medication, I used it to rant a lot and lots of people would say, “Oh yes, exactly the same,” and other people were describing and I would say, “Oh, that’s exactly my situation,” so there was a lot of that on the forum.

Since [Name 2] has settled down to be honest I’ve not been on it because I don’t really like forums myself, I’m not a social media type or forum discussion type person, it was really useful during a very difficult phase I must say.

Interviewer: Yeah. Did you ever contact your, like, local adviser or was it (inaudible 0:30:59)?

Respondent: To begin with I did… I think we were looking or I was looking more for emotional support and it’s not what she could give, she’s more she had the sort of the practical side of it and would have known the contacts and that sort of thing but it wasn’t the kind of support I was after at the time so…

And she did arrange… actually she arranged a coffee morning for a couple of other ladies who had HD husbands and we got together once or twice but that was it, it didn’t take off really, a shame in a way.

Interviewer: Are you close to any other like peers, any other people in your situation that as you were saying that you would meet up for a coffee or…?

Respondent: No… er, well, I mean we’ve moved out of the area now but I did meet up with one of the ladies subsequently but it didn’t happen regularly, it was just a one off and now I haven’t even thought about that because in a way now I don’t feel that I need sort of special support anymore because life is going along very nicely-

Interviewer: Yeah, which is, you know, I’m pleased your living with, you know, as any chronic condition, you know, living with a disease, yeah.

Respondent: Yeah.

[0:32:22]

Interviewer: Okay, okay. [Name 1], what happens with this…? I mean you’ve moved in the beginning of April, how has this affected in any way [Name 2]’s care?

Respondent: Well, we’re just waiting now to be enrolled in the local surgery and then we’ll have to go along and introduce ourselves, and obviously on the paperwork for the surgery we filled in [Name 2]’s condition and everything and so it will just be good to understand what local services there are and how to contact them.

[Name 6] at the clinic has actually or is writing to the GP practice here to provide the details of contacts that she thinks would be good for [Name 2] and sort of to provide an outline of [Name 2]’s condition and that letter will probably arrive before we’re even enrolled at the rate it’s going.

I’ll get in touch the [geographical location] Carers, [name redacted] Carers was very helpful actually on helping me with various things like applying for… [Location 2]’s where we used to live, so I was a member of the [name redacted] Carers Association and they were very helpful with filling out forms for attendance allowance and applying for a disabled badge, that sort of thing, they were really helpful.

Interviewer: So, that’s… yeah, the place where I used to live had this like community group and they would be able to give like practical support.

Respondent: Yeah, yeah.

Interviewer: Oh that’s great.

Respondent: Carers committee or group, whatever it was called and there seems to be one in every area there’s a group for carers, I think it’s probably set up by the council, I know there’s one for [geographical location] Carers as well so I’ll be joining that.

Interviewer: Is that for transitioning to the mirror organisations-

Respondent: Yeah.

Interviewer: Yeah, there’s the same thing where you are now.

Respondent: Yeah.

Interviewer: And for the specialist clinic it will keep at [Name 4]?

Respondent: Yes, they’ll keep us on, we’ll just pop up there or we’ll use video, telephone, whatever, go up there if necessary, yes. Before we looked at moving down here I did check with them because I really wanted us to stay with them.

Interviewer: Okay.

Respondent: And they said it’s no problem, yeah.

Interviewer: Good, alright. So it looks like, I mean now it’s going really well.

Respondent: Well it is, you know, I look back and think about those… it must have been about fi- well, [2015-2020], yeah, [3-5] years or so where it was awful, getting worse and worse and all of a sudden things have been fantastic since [Name 2] got the new meds and it’s just been really manageable and like you said, it’s just like having any other sort of chronic condition or sort of age related disabilities and that sort of thing.

Interviewer: Hmmhmm, I’m really pleased, yeah, a positive report for once.

[0:35:48]

Respondent: Yeah, it is and sometimes I forget, you know, that there is this hanging over the daughters because none of them wanted to get tested, have wanted to, one already has children herself who are now in their teens and that was difficult for them all obviously and still is, and they’ve found ways of kind of coping and putting it aside. Our own daughter has therapy sessions once every two weeks where that’s what she deals with and the rest of the time she’s able to put it aside, that’s what she does.

One of the others is constantly worrying about every twitch and every movement, it’s really… it’s awful, and I can’t put myself in their shoes because I don’t have this, you know, I know I’m not getting it and-

Interviewer: Were you able to understand where did it come from? I mean I know like you had no idea it was running in the family but now sort of like looking back is there any-?

Respondent: Yes, we’ve got an idea and his father, we think it came from his father’s side of the family. His grandfather, his paternal grandfather, died [redacted] in his 50s, his own father actually died of [type redacted] cancer but when I look at his behaviour towards his wife, [Name 2]’s mum, I can see a lot of similarities in the mood swings, he had dreadful mood swings. He didn’t necessarily have the chorea that I noticed but I think that’s where it came down, it certainly wasn’t his mother’s side of the family because they all lived until over 90, one was over 100 so, yeah. And his-

Interviewer: Does [Name 2] have chorea?

Respondent: Pardon?

Interviewer: Does [Name 2] have chorea?

Respondent: Yeah, he does, he moves about quite a lot, yes, and it was the twitchy fingers and twitchiness that I first noticed actually some years before he got diagnosed so it’s been a very, very gradual thing like that, very long term. I mean I think I first noticed it it would have been a good… where are we now, 2024, 20 years ago easily.

Interviewer: Yeah, yeah. You said he has the lowest CAG repeats then for…

Respondent: Yeah.

Interviewer: …I mean still, yeah, ill but…

Respondent: Still positive but…

Interviewer: Yeah, still positive but on the lowest side.

Respondent: Yes.

Interviewer: Okay. And I mean his children and the children you have in common they’re all adults as you said, none of them are tested, that’s right, yeah? That’s what you said.

Respondent: Yeah.

Interviewer: Okay, alright, I mean it’s a very personal, yeah, choice, I’m sure you’ve-

Respondent: Yeah, yeah.

Interviewer: And as you said, we can’t put ourselves in their shoes because-

Respondent: No, and I can’t imagine what I would do, I just can’t imagine, yeah.

[0:39:06]

Interviewer: Okay, [Name 1] as I was saying, you know, you’ve gone through… I mean I don’t want to… what’s the expression like shorten the brie- no, so you had a really hard period, it’s not like it was nice sailing throughout, it was hard during a period of time. It sounds like [Name 5] was pivotal in, you know, getting [Name 2] into the right treatment, managing his moods and with that it started to improve, you also mentioned that you know who to go to when there’s something that needs discussing or fixing and even with this transition to your new home you know who is looking after like the Huntingdon’s Disease part so…

I mean you don’t seem very fussed about the GP hasn’t been sort of like sorted yet because either way you wouldn’t go to the GP for the Huntingdon’s matters.

Respondent: Yeah.

Interviewer: I mean of course people are allowed to have more than just Huntingdon’s, I mean [Name 2] may have other conditions but it sounds like you know who to count on, you know, like at the moment.

Respondent: [Nods head].

Interviewer: Is there anything now that would make a difference for you or [Name 2] in terms of improving care or what’s the most important aspect at the moment?

Respondent: It’s difficult to say really, I went through a phase where I thought he might need some assistance with swallowing but that seems to have sorted itself out, he’s not choking really, he seems fine with swallowing. His speech is quite slurred but again I don’t know if it’s bad enough to warrant speech therapy or, you know, if… and it might also be partly due to the fact that his hearing’s not great and, you know, if you’re not hearing properly then you tend to speak too quietly or too indistinctly because it echoes round your head inside but his speech is a little bit slurred and sometimes people find it difficult to understand what he’s saying but it’s not deteriorating madly.

And to be honest, we don’t come together with many people very often, he doesn’t have any friends really or any activities that he does and now that we’ve moved we’ve got to sort of start all over again anyway with all that so it’s not an issue at this point.

And also because I’m there I can usually interpret what he says.

Interviewer: Yeah, yeah. Have the friends gone out with HD coming in?

Respondent: Well, the thing is [Name 2] has never been a madly sociable person. He’s from [Location 3], he came across, we got married in [Location 3], I’m English but I went out there and he’s been living in this country since [the 80’] and he’s never really made any friends here because he’s not a gregarious type so it’s not like we had a group of friends who suddenly all disappeared when he got ill or anything. His friends are dotted all over the world from when he was in [Location 4] and he contacts them still on Facebook and that’s how he likes it.

Interviewer: Yeah, yeah, okay, okay, so it’s not like there’s been this massive shift.

Respondent: No, no, there hasn’t been any of that.

Interviewer: Yeah.

Respondent: And my friends have been, yeah, very sympathetic I mean again my friends are also dotted all around all over, but I think people are a bit unsure, when you tell them people don’t really know anything about it because it’s so rare that people may have heard of it, like I had vaguely heard of it but didn’t really know what it was about and, yeah, I’m just trying to think when we went through the difficult patch people did say to me, look, do come and stay if you want to, to me, you know, so they were quite supportive at that time.

[0:43:45]

Interviewer: Hmmhmm.

Respondent: Yeah, we haven’t had any issues otherwise, negative issues in terms of friendships, no.

Interviewer: And in terms of the speech and language therapy it’s a bit like that you’re unsure if you’re in need of help or not.

Respondent: Yeah, I mean the way I see it is if it’s really impacting on his quality of life then we’ll do something about but it’s not so.. and also he’s got enough to deal with at this point so we leave these things until we really think it’s essential to do.

We did need the neurophysio to get him a walker and a very good guy came, it happened very quickly in [Location 2], it was great, got him a walker, it was fantastic so I know that when they’re there, well, at least I did in [Location 2], that they were there promptly, they were very good, we didn’t have to wait for ages and I-

Interviewer: (Overspeaking) or- sorry.

Respondent: Pardon?

Interviewer: Sorry.

Respondent: Pardon?

Interviewer: Your community group then they helped you apply for like the Zimmer frame or…?

Respondent: The walker, it’s a walker, no, no, I just suggested to [Name 6]. Oh, no, I did have a contact detail from the previous one and I contacted her directly, the previous physio, it was a different one that he saw this time, and she said, “Oh, I’m not dealing with that anymore, contact x, y, z,” so I did and he came round and we got the walker within a few days, it was amazing.

Interviewer: But did you have like to pay for it or was it…

Respondent: No.

Interviewer: …provided?

Respondent: Yeah, provided, NHS, it was great.

Interviewer: Okay, that’s good.

Respondent: Very impressive.

Interviewer: Okay. Nearly done. So you’ve mentioned you sort of take the decision based on is this important for [Name 2]’s quality of life?

Respondent: Yeah.

Interviewer: I’m trying to understand how to picture… the people picture like excellence, you know, how do they measure success? See if I wanted to-

Respondent: As a service user you mean?

[0:46:08]

Interviewer: Yeah, what success looks like or what good looks like? You’ve mentioned a couple of things, like, you know, the single point of contact, knowing who to go to.

Respondent: Yeah.

Interviewer: And you’ve mentioned [Name 2]’s quality of life, is there anything that comes to your mind, you know, that you would say this is how I would picture, like excellence, measure excellence?

Respondent: Yeah, I think earlier on when I was reading up about all sorts of different things about Huntingdon’s and read in America that they have multidisciplinary teams looking after you and I thought, do we have that? Is that happening here? Because it did seem a bit disjointed between our GP who clearly didn’t know very much about it and there didn’t seem to be any communication at the time between… very much between her and.. or whichever one we happened to get to see, which is another issue of course and the clinic but that has become much better.

Now I realise that because we have a good relationship with the clinic the multidisciplinary team is there when we need it and we can then mention to [Name 6] now or she will assess something, “I think you might benefit from x, y, z,” and then it will be arranged through her, so it is there in the background, it’s just that we don’t have a sort of piece of paper saying ‘Here is your team and this is what it consists of.’

And in a way I think that might be quite useful to at the start of the care have a plan and say these are the sorts of people who are available if you need them, like a speech and language therapist or an OT or the neurophysio.

These things came about almost not by accident but sort of they just happened every now and again we heard that there was such a thing whereas we didn’t have, and it would have been very helpful to have at the beginning, this is what the care roughly looks like and these are the sorts of people that you might be able to contact if you need them, not even with contact details just these are the sorts of people that we bring in to care for HD patients, and that gives-

Interviewer: Like a road map.

Respondent: Yeah, yeah, and that gives me as a carer then a kind of a framework within which to work so that I know what there is if we need it, that was the only thing that’s missing I think.

Interviewer: As you’re saying it’s sort of like it’s there but you have to think about it like to be able to…

Respondent: Yeah.

Interviewer: …almost like do it yourself to be able to clarify it in your head and actually a lot of these things you didn’t know about them until you needed them and someone said, “Oh, you might need,” instead of actually saying, “Oh, you know what [Name 2]’s speech is getting a bit worse, maybe now it’s the time to contact a speech and language therapy,” and something can be arranged or… sort of like having more control over what the next steps are, yeah, I can see that being helpful.

Respondent: It’s not even control over steps, it’s just being informed as to what there is if you need it and a sort of just a vague outline of the people that might be involved in his care because obviously for HD there will be certain people involved in general like these therapists that we’ve just mentioned.

Because I did feel at first that we were very much on our own. I think it may have been something to do with the fact that [Name 2] was not keen to involve the medical profession at all, that was probably what it was, but I felt that it wasn’t until we got to meet [Name 5] and that it all began to fall into place and I began to feel that things were there if we needed them so it’s just like a sort of an information framework if you like to know that these are the people that if you need them you can call on or the services and this is where you go for that etc. because it was a bit disjointed and a bit sort of haphazard to begin with but other than that can’t complain.

[0:50:36]

Interviewer: Well, you can because again it was not always so clear.

Respondent: Well, no, I mean now, now.

Interviewer: As it is now, yeah, yeah.

Respondent: As we did earlier, so that awful guy. [Name 7], yes, I’ve just remembered his name [Name 7].

Interviewer: Oh, the neurologist?

Respondent: Yes, which you’ll have to anonymise though.

Interviewer: No, no, oh yeah, that’s fine, yeah, don’t worry but, yeah, okay. Good. I like that idea of having a road map, I think it would be…

Respondent: Hmmhmm, I think it would be very helpful, you know, for the people… for the carers, it’s just useful to have that information, there might even be something on the HDA website or something, I don’t-

Interviewer: Well, what I find when there are documents available of these sorts they are very long and actually there’s multiple documents and I see people losing… of course no-one has the time, the patience or the energy to go through all of them and to have something like more accessible, yeah, even more like visual to give people some aid.

Respondent: Yeah.

Interviewer: Okay. [Name 1], I’m just going to do a couple of boring questions to you just that I have to ask everyone, so how old are you?

[redacted]

Interviewer: Okay. Is there anything you’d like to add to our chat today? Anything we may have missed or something you thought, oh I thought she was going to ask me about whatever and she didn’t?

Respondent: No, I don’t think so, I mean I can happily rabbit on for hours, it’s just nice to have the opportunity to talk about these things.

[redacted]

[0:53:07]

[End of Transcript]