[0:00:00]

[redacted]

Interviewer: Good, so, [name 1], I want to start by asking about your Huntington’s disease experience, so you were saying you’ve been diagnosed, is that right?

Respondent: Well, yes, back in… when I was a child I heard that there was Huntington’s in the family. True family myth, so when I trained, I went back and said, “Okay, this is going on,” and I was told it was separate, it was a separate father further back, so I was like, “Oh, right, okay. That doesn’t affect me then”. And then I had a great aunt who died at [90-95] and in the last few years of her life, she had a lot of large movements, so that was in [2015-2020] and my second cousin said, “You need to get checked for this if you want to”. So, then, of course, Covid kicked in and we moved house. We were in a caravan by then living because we’d moved from [location 1], and then we built our house and I was like, I can’t do anything about that until we’ve sorted out… we were living in a caravan, building a house, there was no headspace to do anything else. During that period of time I had what I now realise was big periods of Huntington’s dysregulation, that’s the word I use because I hate any other words that people use. And I knew that I would go and get tested because that’s the sort of person I am. So, relating to my mum, she was misdiagnosed with [type redacted] dementia, and there were several things when she was unwell that I thought, “Well, that’s a bit strange,” but it didn’t click. And then clearly she had Huntington’s, as did my gran, but their symptoms were minimal in terms of small movements with their hands and their feet occasionally. My great aunt lived to [90-95] and it was only then that she had very big movements. But my mum had periods of personality change, they said, due to [type redacted] dementia. Clearly, it wasn’t, it was due to the Huntington’s disease. So, when my cousin said, oh, this great aunt, I though, ah, you know what, I think this is in my side of the family. That myth is no longer viable. So, I then was having periods of extreme dysregulation to the point of my daughters saying to [name 2], because he said your mother’s going… “You should leave her if she’s like that”. I didn’t know about that at the time and because I then went ahead and I got tested in… it took a year because one of my daughters didn’t want me to get the answer right near Christmas, so it was in the [end of Winter months] that I got my results.

[redacted]

Interviewer: So, just over a year you’ve known.

Respondent: Yeah, just over a year ago, yes. Now, when I got the results, it was the biggest sense of relief on the one hand because I knew that some of the behaviours weren’t me, as in that’s not my personality, and some… but at the other time it was like the consequences of all this for the family, so it was like a mixed feeling. But prior to knowing, my behaviour, I hate that, prior to knowing, my ability to manage my emotions, I’ll add it in a better way, wasn’t there in the same way. I’d always been a bit sharp, but not like I am now when I get dysregulated. Luckily, [name 2] stuck by me and because quite quickly, having got tested and got the result, it obviously became clear that this was what was happening. It wasn’t me.

[0:05:37]

Interviewer: Yeah, it wasn’t your fault, yeah.

Respondent: No. We’d lived in a caravan for [1-3] years during the pandemic and we’d just built a house, so there was a lot going on, which we managed. But during those periods I had periods of dysregulation. And now, in hindsight, I can see that that’s what that was. I couldn’t manage my emotions. When I was not in those periods of dysregulation I could make coherent, sensible and well-informed choices about everything and I still am like that, but I do have periods of dysregulation. Now, so then we had the… I had been in contact because during this also, to give you some context, also during this time, when I left [location 1], I’d had abuse in my childhood and it was a grandfather. But at the time that my father died, clearly it was the Huntington’s, but I didn’t know that at the time, my ability to manage my emotions went bizarre. And also my brother, who I am now not in contact with, said various things which I am now putting out that way because that’s how I… I can’t manage him, he can have to manage himself and I’ve given him options and that’s… I’m coherent and logical about that. So, I sought help as soon as that occurred, I sought help in [location 1], I sought help in a group about abuse. I went back from [location 2], where we were living at the time, to it, so I was very proactive and always have been in my mental health. But of course, the Huntington’s was mixing in with it in that time as well and I didn’t…

Interviewer: But when you were in [location 1] and [location 2], [name 1], you didn’t know.

Respondent: No, no.

Interviewer: You weren’t diagnosed, right?

Respondent: No, no.

Interviewer: But you were already feeling, as you were saying, some fluctuations or…

Respondent: In hindsight, it was clearly I had got a lot of the dysregulation, clearly. And also the tiredness, because one of the reasons… I run a [redacted] business, and one of the reasons that I stopped because I got very tired, and for me, and looking back in hindsight, my mother used to get very tired. So, those were the symptoms that I said to [name 2], “Oh, we’ll keep going for another year with the business. We’ll keep going for another year with the business”. I never had a, you know, I’m going to retire here date, but after one year I said, “Do you know what? I’m really quite tired now and whilst I don’t want to give up, I need to give up because I can’t manage it”. And also I couldn’t manage the cognitive… I’d noticed that when I started early, I had [15-20] years at it, I could do the invoices really quickly, I did all the business, you know, I did the [audits], everything, I employed people so I had all that side of it. By the end, that was all-consuming because I did not have the mental capacity to process the stuff at speed.

Interviewer: And , [name 1], can I ask you about when you decided to test? How did you go about that? Which profession?

Respondent: I went to the GP. I went to the GP. She was called [name 3]. She has been exemplary. She has supported me, I’ve needed to go in there, I was changing meds because of all things that were going on at the same time as getting on the antidepressants. I was having hot flushes and all of that so I went onto a medication for that. I’m no longer on it now, but I was changing from various antidepressants. Now I’m on citalopram. She has been excellent. If I need an appointment, they get an appointment quickly. I can’t knock our surgery. It’s been excellent. And she’s also asked questions in terms of informing herself.

Interviewer: Yeah, so that’s what I was going to ask. So, for me it’s great that you’re saying that [name 3], the GP is great. So, she’s shown interest about learning more about Huntington’s, or did she already know about Huntington’s?

[0:10:28]

Respondent: No, no, she said she didn’t and [name 4], because I also have been in contact with [name 4] for the HDA before I got my diagnosis because I knew I’d need t support my family during this as well as myself, so I sought help via them and [name 4] sent information to her. So, it’s sort of like joined up in that way. So, the HDA supported by sending information to her.

Interviewer: That’s great, yeah. So, when you went to the appointment did you feel that [name 3] had gone through the information?

Respondent: As a GP, she said she doesn’t have time to read it deeply but she had scanned it and read it.

Interviewer: Yeah, she had an idea.

Respondent: Yeah, I did feel, and every time we go, she gives us a half-an-hour appointment.

Interviewer: She gives you a… okay. Which I imagine is half the time almost that she gives to other clients.

Respondent: She gives people, yeah, 15, it’s usually 15 minutes, yeah.

Interviewer: That’s great.

Respondent: So, yes, it’s very good.

Interviewer: And do you always see her when you go to your surgery?

Respondent: I try to. I try to. I’m not going now very often, but that’s fine. And they do tend to put me with her if they can. Usually, it’s not urgent so therefore I can wait.

Interviewer: Okay, so you prefer to wait.

Respondent: But if not, I have seen one other on another appointment when I needed to urgently, I’ve seen another lady and she was fine as well.

Interviewer: Yeah. So, is it because you feel they listen?

Respondent: Yeah, yeah.

Interviewer: They properly listen and they sort of like take a step back to learn from you.

Respondent: Yes. I always go in with a form, well, not a form, I always go in with my notes because [name 2] helps me do that, so I leave them a copy and they put that on the notes, and I have a copy that I can run through so it helps me cognitively be able to do that. And she says, “I’m going to scan this and put this on your notes. Is that okay?” and I say yes every time. So, it means that it’s also on my notes for others to see and, you know, it’s helpful for her to scan back through then.

Interviewer: And what notes are there. Is that like you saying what is it that you want to discuss or is that past appointments you’ve been to?

Respondent: Yes, yeah, about what I want to discuss at this appointment, yeah, or any results or sort of things like that. So, my GP has been very supportive.

Interviewer: Well, it also sounds that you’re making their lives easier.

Respondent: Yes.

[0:13:04]

Interviewer: Which very rightly so, because again, GPs maybe not know of Huntington’s disease, so you’re helping. You’re working as a team, as a team.

Respondent: Yeah, yeah, yes, and that works well.

Interviewer: Excellent. So, your GP, when you wanted to, well, maybe to check if you could be tested, you went to your GP.

Respondent: Yeah, and she referred me straight away. She listened to me. She explained the process. She said that the form is… “I’m very sorry,” she said, “But it’s the form that they do for cancer as well,” so there isn’t a specific form for other genetic testing, but that was fine, but that was an interesting point, you know. So, I filled that in and she was fine. I went and had my counselling with Charlene. She was very good. She was very supportive. I needed an appointment afterwards because I needed to talk things through with regarding informing the rest of the family, as in my brother and that side of the family, so she was very helpful with that. So, the service I got there was exemplary as well.

Interviewer: Where was this, this genetic counselling?

Respondent: It came via the [location 3], so she’s based in [location 3].

Interviewer: Okay.

Respondent: But she saw me in [location 4] and [location 5], and once in [location 3]. So, you get seen three times, so I got saw twice and my end result she told me in [location 4].

Interviewer: Okay, okay. Why the different locations? Is that because you were moving?

Respondent: The [location 5] one was where we started. The [location 4], I don’t know why that was over there. There was one in [location 3] because she said you can have a neurologist check you at the same time, as in a… so I said, “Yeah, yeah, fine”.

Interviewer: Okay, so you saw a neurologist as well.

Respondent: Yes, just checking. But I can’t remember who that was. It wasn’t [name 5], but I can’t remember. But you see, my symptoms are… and that’s… and also [name 6], I’ve seen [name 6] twice. She’s been very helpful. I don’t need to see her any more at the moment, and when I do I can contact her. The things I speak [name 4] about, she pops in occasionally to see us. In terms of me, there’s lots of carers’ meetings, but there are no meetings for people who have Huntington’s in terms of via the system. HDA, they don’t currently have them, although I’m getting support and I’ll explain that later, with HDA some of the things I’ve been doing, but before, because I’d already been getting support for the previous abuse, when I moved up here I went to the Yellow Door, I self-referred to the Yellow Door, which is a support in person in [location 3]. So, during the time of having the Huntington’s counselling, I was also going self-referred to them and getting support and working through issues there. I also, because [name 3] said these are the people that, you know, you can go to, so thanks to her, I also went to [location 6], which I did what’s called the decider course. That has been helpful in managing my emotions. I did and I took managing emotions course. Now, these were things that she had referred me to, not HDA and not [city name]. So, I was…

Interviewer: This was [name 3], [name 3] suggesting these.

Respondent: Yeah, and I was doing all of those and managing my emotions, apart from when I had periods of dysregulation, I was managing all of those emotions and managing to process stuff, and I’m out the other side with Yellow Door. You know, very quickly, I had about nine months there and I was fine. And I left it, I could have left a couple of months earlier but it worked better that way. So, during that time I have been very proactive in managing my emotions and seeking support for it.

[0:18:06]

Interviewer: Did you meet any other people with Huntington’s in this?

Respondent: I went to an AGM and I did meet one person then, but it hasn’t worked out that we’ve been able to meet people because various things have been happening in life. So, [name 2] has been going to a, what’s the word I’m looking for, a carers’ support group in [location 7], and at Christmas we went over there because they had a Christmas thing for everybody and I met two other people there, well, more than that, but I talked to two other people with Huntington’s. Oh my goodness, that was amazing because I knew and I kept saying I really need to talk to other people because emotionally I’m working this through, but in terms of the connection of being able to say something to somebody and they fully understand it is so different to being able to articulate it to somebody else because if you say to somebody, “Oh, you know, people look at you when you jerk,” because sometimes I do and I wear a bracelet that says Huntington’s on it, people look and then they see that and they go, “Oh”. They don’t know what it is, they don’t read it, but, you know, it’s something. I’ve seen people look across a room. But when you say something like that to somebody else, they just think, oh, you know, why would they understand exactly how that feels? But when you speak to somebody else who has Huntington’s, they’re sort of like, “Oh, yes,” and it’s sort of like you’re able to really… they have their own experience, of course they do, but it’s a common understanding of where you are. So, when they had the Christmas do, I then said to [name 2], I’m going to ask those two people if they want to meet up when you have your carers meeting over there. So, we have met up once and we are going to meet up again. They have their carers’ meeting there and we meet in a café, it was amazing, you know. We laughed, we joked. We laughed and joked about the illness. Now, you need to be able to do that because you have to keep batting it away, you have to be able to joke about it to see the lighter side of it to enable yourself to cope with it on a day-to-day basis. It felt very much a caring thing like that. So, I think that is an area that there needs to be more support.

Interviewer: So, the Huntington’s Disease Association doesn’t have the…

Respondent: Currently, they don’t currently, they don’t have a group for… I know [name 4] is working on it, currently they don’t have that. And apparently in [location 3] they used to, but since Covid it hasn’t come back into place and they are hoping to start again, because I’m a bit of a pushy person. (laughs) I ask questions.

Interviewer: Well, you’re an advocate. You’re advocating for you and for your family.

Respondent: That’s the word, yeah, advocating for myself. So, in terms of that, it’s… I’m able to do that at the moment and I can see the people that I did get to together with and we are going to get together again, but I had Covid this time now so when they had the meeting, and [name 2] couldn’t go either, so that was fine. And we will meet up, and I’ve also met up separately with one of the people and their partners, so we met up. It’s sort of like early friendship, if you see what I mean. So, that’s positive. But I can also see that one of the things that I know is that lack of initiative, when I’m very tired, I do lack that initiative and I can see that in others, and so they’re slightly further on than me, I believe. And when I said I’d like to arrange the meeting, they said, “Ooh, yes, can you organise that?” and I said yes and I did and it was fine, but one of the, yeah, that’s an area that I feel really needs support for…

Interviewer: Sort of like so that things still happen if people can’t… don’t have the strength to, yeah, organise it themselves.

Respondent: The mental capacity, yeah, so something will happen.

Interviewer: That it still happens, there’s already…

Respondent: Yeah, it should be within the system.

[0:22:57]

Interviewer: Yeah, absolutely. Yeah.

Respondent: Also, in terms of all this going on, and my consultant didn’t know the things that were going on, I went to see [name 5] and I’ve got to… I’ve been putting it off, I have to write to him as an advocate of my disease because I had a letter back from him, from the appointment that I went to, now I try to go to every new appointment with a new professional with a positive attitude. Now, sometimes that’s difficult because you’ve already had previous incidents, but I went thinking, “Oh, you know, he’s really good. I’ve heard a lot of positive things,” and I know you work with him but I think it’s important to get it out there…

Interviewer: You can be absolutely honest.

Respondent: Yeah. And I will send you a copy of the letter that I got. I came away from the first appointment, he got me to walk on a line, he got me to test my balance, he got me to do all sorts of different things. Now, for the last [5-10] years we’ve been doing Pilates, body balance and all of those sorts of things. When I moved here, I started Nordic walking to increase my fitness, so I’ve… my balance isn’t an issue for me. It is when I’m tired, but it isn’t generally. It’s the dysregulation that is. And when I came away from the meeting, my first consultant appointment, I was like, “Mmm, don’t feel very comfortable about this at all”. Now, sleep on it, [name 1], because it might be you. So, I slept on it. Well, I didn’t sleep well that night because I was awake, thinking. And then I came to [name 2] in the morning and I said, “[name 2], how did you find that appointment yesterday?” And I didn’t say it in a negative way, I just said, “Oh, [name 2], how did you find the appointment yesterday?” And he said, “Well,” he said, “I don’t think he quite gets it. I don’t think he understands,” and so that reassured me that it wasn’t me having a negative response. I didn’t feel comfortable and left it like that. I felt even more uncomfortable when I received a letter saying that I was an overwhelmed woman because all that time and I continue to seek support and continue to do research and continue to advocate for myself, he has no idea of what was going on in my life and I was not overwhelmed, I’m not overwhelmed by the disease. Yes, I have moments when I slip and I cry. They used to be 20 minutes at a time, they’re now 5 or even a couple of minutes just to emotionally allow emotional release. But I’m not overwhelmed. All the time previous, we were building a house, we were living in a caravan, I am not overwhelmed. And I feel really… I’m going to write to him because I think it’s important that this disease hits way before, way, way before the movement disorder for some people, for a large amount of people, I would say. We’ve been on to… because we’ve got two daughters, we’ve attended the HDA about talking to adult children about it, and on there there were people who had divorced their partners and were on their… and they’d divorced their partners because of the change in their personality. Now, luckily, [name 2] didn’t do that, but this was all happening in hindsight. Now, Huntington’s disease, the chorea is, for me, minimal, and it appeared to be minimal for my mum, but the actual changes, emotional dysregulation is fast. And yes, some people do get this, but for me, yes, I have days when I’m like this, but not until the end of the day the actual implications of this disease early on are far greater and are overlooked, I feel. So, I don’t think there’s enough for…

Interviewer: I guess what the professional sees is just the tip of the iceberg of what goes on, yeah.

Respondent: Yes, yes. And I think that the personality changes occur and, you know, they can be ascribed to other things, and they were for me. So, one of the things he said, you need to go and see if you need to have… if this is hormonal. No. It isn’t, it’s very different. It’s very different. And so it’s not hormonal. You need to go and see a psychiatrist to speak about it, well, I happily went ahead and did those things, but they didn’t want to see me. So, in terms of they reviewed my case and I didn’t need to be seen by them, I’m now being seen by a lady from [location 6] and that’s working for me. That’s all I need at the moment because actually I’m not emotionally… I get Huntington’s emotionally dysregulated, but I’m a highly reflective individual and can reflect on things within me, within my family. I try and put in support for them, but when I’m in that period of dysregulation, I can’t do anything. So, it’s that period of dysregulation can initially, when I was not up to my medicine, it could last for 24, 48 hours. Now, [name 2] is better at managing it, I’m better at managing it. Some of the things that I have done, the [location 6] things, the talks, the research I’ve done and spoken to people, those sorts of things have been helpful and they’re not connected to the Huntington’s disease, but they have been very helpful to me. [Location 6], like I say, Decider and what’s the other one? I wrote them all down here, managing emotions. I saw [name 7]. She’s doing research. Have you…?

[0:30:24]

Interviewer: Yeah, yeah. No, I’m…

Respondent: Yeah, yeah, you know [name 7] probably.

Interviewer: Yeah, I know her.

Respondent: So, we took part in that and that was very helpful. Also, [name 8], she was talking about… I can send you links, if you like, she was talking, asking what people use, the terms people used for your Huntington’s behavioural issues, agitation, all sorts of things that professionals use, and I said, hmmm, I really dislike that because in terms of the… I can be agitated because my husband can be a pain in the neck, I can be agitated because my daughters can be awkward. That is totally different. It is not agitation. I don’t have behavioural issues, not on a general basis, I don’t. No, we all have issues, but they’re not… the Huntington’s dysregulation, when [name 8] said about what you want to describe it, I said, “I’d like to describe it for everybody else and I’ll continue using that, Huntington’s dysregulation,” because this is something… not agitation, it’s not behavioural issues, it’s not something that… it’s not an issue, it’s an illness. And so that’s the term I use now and that term helps [name 2] understand it as well. It helps [name 2] understand that I’m not annoyed with him, I’m in a dysregulated state, and we use that term together. And no, life isn’t perfect, but it’s a lot better now because of our ability to talk about… my ability really to talk about these sorts of things and manage them for other people as well as myself. So, I’m also taking part in… Huntington’s Disease Association have got ACT for Huntington-positive people, acceptance and commitment therapy and I’m on that at the moment. We’ve done three weeks of that, so, again, that’s connecting with people who are positive, gene-positive, and they are people all over the country, so that’s been positive as well because, even though it’s over Zoom, you’ll hear…

Interviewer: Yes, is it online? I was going to ask you.

Respondent: Yeah, yeah. You’re hearing and speaking to people who are exactly, you know, different places in their lives but have a…

Interviewer: Yeah, that common understanding, yeah. And I wanted to, before we move on, I wanted to ask a bit more about your experience with the neurologist. So, you went to that first appointment where you felt uncomfortable. The letter didn’t leave you feeling any brighter about it.

Respondent: No.

Interviewer: Have you been since?

Respondent: No, I haven’t. I will be because that’s one of the things I’m talking about with the [location 6] person. I do one thing at a time rather than two, and I said to her that I will be writing, but I have to be in the frame of mind where I can put it in a coherent, advocatey way rather than a don’t you talk to me like this sort of thing.

Interviewer: Yeah, you want to put it in a constructive…

Respondent: I want to put it in a constructive way, yes. But if I hadn’t got that drive, I’d have come away from that thinking, “Well, that was a waste of time and what does he know?” and I’d be less inclined to go along. So, I’ve always been proactive, and my mum, as I say, was in the care home, I saw things there that… she was well-treated, it was a good care home, there’s no doubt about that, it was fine, but people within a care home are managed in a particular way, aren’t they? And because I had the [redacted] background, I said to my dad, because he was still alive at the time and he set a lot of carers’ things up for [location 1] and because that’s what he thought she had, dementia, carers’ cafes and all sorts of things like that, I said to him that in terms of our growth at an early stage with the children that I’m working with, adults are losing their skills and they’re disabled rather than enabled. And once they get into the care home, they are totally, unless it is of an exemplary level, they are not enabled to be proactive within those care homes. Now, I also know there are some situations in my life that… in the morning in find it harder to get up, I could stay in bed all day. But that’s a lack of initiative. Now, once I get out of bed to go to the toilet, I don’t want to stay in bed all day. So, the dis-incentivisation to do things is part of my lack of wanting, it’s not that I… and I’m still able to say, “But that’s not you [name 1]. That’s not you, [name1]. That’s not what you were like. Get up. We’d be up at 6.00 in the morning”. Kids were active. That wasn’t me. I was a get-up-and-go sort of person, so this is a real change in me.

[0:36:35]

And in terms of cooking, my processing isn’t there in the evening. I’m too tired. Now, some of that is quite good because actually, do you know what, I can’t be bothered to cook, I’ve done it for years and actually it’s nice that somebody else does it. That’s nice. But when I want to, I would say to [name 2]., “Shall we sort something out today?” and it will be a slow cook or something like that, and prep it in the morning together so that we can still have that time doing stuff. Now, but a lot of people wouldn’t… not a lot of people… [name 2] isn’t always able sometimes to let go of the fact that he needs to care for me. There’s a fine line between care and dis-enablement. [redacted family details]

Respondent: Yes, but it’s a very prepared environment, so it’s not a managed environment in the sense that the children are managed to do things, or they certainly weren’t in my setting, but they were given opportunities and things were enabled. I mean we had [less than 2 years] children, even, you know, children who would sit in their high chairs still and just have a mirror with a flannel. You know, they didn’t finish cleaning, well, cleaning is not the word. They didn’t finish wiping the food off their mouth, but they were enabled to do it even as a very small child. And we, in our society, disenable people in the latter stages of life. And so it was interesting to partake in that as well, which is also when I… sorry, go on. You need to ask some questions.

Interviewer: Yeah, it’s alright. So, I was going to ask about… I mean you’re clearly very proactive and resourceful. You put energy into being like that, which I can appreciate it. What I’m thinking is how do you see your peers, like your friends that you’ve met, you did say they look like they’re a bit further down the line.

Respondent: Further on, yes. But I think to enable people to be able to do those things, those things need to be there. If it’s not there, I don’t think that… I’m lucky I’m able to draw on my previous experience to see how it would benefit because where I am at the moment. I think that it would be really beneficial for people to have those things made available for them in an environment that is inclusive but proactive in providing them. So, I don’t think generally, in fact I know because of other people, not with Huntington’s in my family, but other people who are friends and things like that, lots of people aren’t proactive. Lots of people stick their head in the sand. Lots of people don’t make decisions. Now, as soon as I had my diagnosis, I went back to [name 3] and I said, after a period of time, I said, “Okay, please put in place my DNR”. And she didn’t question me. She said, “You know what that… you’re okay with that? That’s the purple form,” dah, dah. She didn’t question. I said, “Yeah, absolutely fine. You know, I know what I’m doing and I want it in place, please”. Now, I spoke to another friend who also trained as a nurse and she was a nurse until very, very recently. Now, one of them said, “Fantastic, that’s what I’d do”. One of them said, “What, even if you had a heart attack now, you wouldn’t want to be resuscitated. But you’ve got a lifetime to live yet,” and I said, “I’d rather go now like this than end up how I may well end up, so yes, actually, I do want that DNR in place”. Talking to friends, not the GP, but talking to friends. So, I think that I’ve made that choice, but that comes from my experiences in life and if you haven’t had those experiences, you aren’t going to know that that is available there. I’ve made my advanced decisions. We had LPAs in place. The LPAs were because of my dad and he said, “You really need to get these sorted out”. So, in terms of all those sorts of things, all of these need to be available for people, but they’re not. Everybody’s afraid to talk about these things.

[0:42:39]

Interviewer: And what you’re saying is that if you don’t ask, you’re also not told until…

Respondent: No.

Interviewer: Probably too late.

Respondent: Yes. And that’s one of the things. I watched an interesting thing on Huntington’s in Holland, and there was a lady there and they showed two examples of a different process of people’s journeys, a small part, obviously, but one of them was talking about end of life and one of them… and she hadn’t reached that yet but she knew what she wanted, and it was Dignitas. And the other one was a younger guy and the care he wanted was to die in the supportive Huntington’s disease residency that was provided. Now, that’s wonderful because it’s open conversation, and that’s what it needs to be, I think, open conversation, and it needs to be early because people need to be able to process these things. And because of my experience, I have made those decisions. So, I’ve talked about it with my family. It’s not easy, but, you know, [name 2]…

Interviewer: So, [name 1], do you have any idea about, you know, because my project is specifically looking at improving joined-up care…

Respondent: Yeah, so if you…

Interviewer: Have you…

Respondent: Go on.

Interviewer: No, I was going to ask how do you see different teams and professionals working together?

Respondent: It doesn’t look like they do. It needs… it doesn’t feel like they are. Now, I know that HDA and [name 6], they work closely. But there is no… and again I’ve looked it up, there is a pathway, isn’t there, in the process of trying to work out a pathway for Huntington’s. It doesn’t feel like it’s fully joined up to me because if I had… I found out about the [location 6] and stuff because my GP recommended it. Now, those sorts of things could be beneficial to other people as well, they really could be. Now, that should be… there should be a, what’s the word I’m looking for? There should be… oh, that’s the wrong word. There should be something that you can dip in and out of, either be it online or whatever, where you can actually see what you might be able to access, where perhaps [name 6], if it was ideal, it would all be there, laid out, and you could say, “Actually, I could benefit from this now so I’ll go and do that Decider course”. Or [name 6] might say, “Ooh, this is available. This course has been…” and it’s… it needs to be that people can plug in and pull out as they need, but in a way that actually is visible because it… I feel very isolated, even though I’ve done a lot of different things, it can be a very isolating disease.

[0:46:39]

Interviewer: So, what you’re saying is that it would almost be like a Huntington’s pipeline, you’re in the pipeline at some stage and you want to know which resources are available.

Respondent: Yeah.

Interviewer: So, depending on whatever is it that you need, but it’s almost like in that pipeline if there could be some triage questions, sort of like, “What help are you looking for? What is it that you need?” and then it would indicate the resource you could access to.

Respondent: Yes, yes, yes.

Interviewer: And like who can help you get that, for example.

Respondent: Yes, but also prompts for people, i.e. early on in the diagnosis I was lucky, I’m not a long way along, but things that need to be prompted, i.e., you know, what sort of thing are you looking for your end-of-care life? What is your… you know, what is your… don’t avoid those questions. What is your preference? How do you want your end-of-life care? What do you want. Now, they’re uncomfortable questions to ask, but I have put a DNR in place, I have advanced decision, I don’t want a PEG. I am advocating for and I’m open to people about it because I think it’s important. I know that they cause issues, but I want… I’m part of Dignity in Dying because I’m still able to do that. And I have joined Dignitas because I don’t want to be in a position where I have no choices. Now, when I did that, I had such a weight lifted off my shoulder. It was almost like I may never use it, I may never use it. I might have a heart attack before I get there. But in terms of discussing it with my husband, discussing it with a friend, when I joined that, it was almost like that weight’s gone. I can enjoy life. I get on and enjoy life. I really love life. We’ve been on a cruise recently. I’ve got my mobility scooter. The positivity of life when those decisions have been made have changed me in the sense that I don’t need to worry about that any more. I may even get there, but in terms of it’s not like that, life now is (overspeaking).

Interviewer: Yeah, it’s not hovering over you.

Respondent: No, I look outside and I think… so it’s not hovering over me. So, the openness in society isn’t there, I think. I think people need, yes, what help you need, but also gentle prompts within that pipeline of, you know, “Have you thought about this?” And [name 4] does do that. They say, “Oh, have you got LBA and things,” [name 4] and [name 6], but there’s not an openness, I think, that perhaps there is in other societies. It’s very medicalised over here. It’s not holistic. That’s what I feel. It may be different in other areas, I don’t know, so this is just my experience, and I’m aware it may well be very different in other areas. It feels very medicalised, not a socially based model of care in the sense that… yeah, it just doesn’t… and as I say I’m very early on so I can only say from my position how it is.

Interviewer: Do you think because… I was thinking if because of the experience you had with your mother, if it made you more, you know, be concerned with the end stage and be prepared for the end stage?

Respondent: No, she had a good death in the sense that she didn’t have large movements. She spent the last [2-4] years though of her life in a care home. She had a spell before she went there that I wouldn’t want to repeat. She had… but then she didn’t know at that stage that she had Huntington’s, so the management and care would have been different then. She had periods of dysregulation where she was in an assessment unit and they didn’t know what to do with her and they spoke to a hospice and said, “Look, we’ve got this lady who is exhibiting these symptoms,” and what the hospice came back and said was, “Try and sedate her to rest her brain for a period of time”. Now, they did that, pulled her out, and she was just enough… pulled her out enough to eat and have stuff, she had a drip up and things, but she was still eating. And then she came out of that, I can’t remember how long it was that they did that, but she came out of that and she was different. We all thought, “Oh my goodness, she’s going to have to go into a care home. How is this going to happen? She will really kick off,” because six months previously when she’d had to go into the assessment centre, it had been highly traumatic for everybody. And we turned up there one day and she said, “Oh, [name 1],” she said, “I’ve been speaking to the nurses,” and I said, “Oh, that’s good”. She said, “They’ve found me a new flat”. And I’m saying, “A flat, mum, that’s fantastic”. She said, “Oh, yes, they’ve got me a new flat that I’m going to move into”. And I’m like, “Oh my God, this is amazing”. Obviously, they way they put it to her was very good and then she moved there and by the time she died, she was on no medications. They’d managed to take her off medications in the time that she was there, the [2-4] years, and she ended up on no medication at the end. So, they’d managed to… it was a good care home in the sense that they’d managed to manage her very well. So, her death was actually good. It was the period beforehand that wasn’t.

[0:53:50]

Interviewer: But she was never diagnosed, right, [name 1]?

Respondent: No, no.

Interviewer: I mean not with Huntington’s, I mean she was supposed to have [redacted] dementia, yeah.

Respondent: Yeah, and also, but the funny thing was she never swore when I was a child. She did swear a lot with Huntington’s. Now, I tend to do that more. I’ve got less inhibitions. In terms of she had not got what I would call the general dementia symptoms in terms of her memory and of course now it just clicks straight into place. She’d say, “Oh, [name 1], lovely to see you,” and I’m thinking, “Oh, we’re very lucky that she’s able to remember who we are”.

Interviewer: So, [name 1], earlier you were talking about the pipeline or some pathway, some map and with prompts along it so that people think about it and make decisions in advance. So, if these things were in place, what difference would you think it would make to people?

Respondent: I think it would make a lot of difference in terms of [name 7] and talking to her helped both of us, and in fact my daughter talked to her as well. So, it was… she came into our house and what she offered, she was doing it obviously for research, but it felt very therapeutic. And [name 8] was asking questions about how does it make you feel and what do people ascribe it to. So, following diagnosis, you almost need indicators for people to say, “You could go here and explore this. You could go here and explore that. You could go here and explore that. You could go here and explore that. You’ve moved along a bit, why don’t you try this?” or, you know, you feel like you’re back there again, “What about this?” Like the ACT that I’m doing now, it was through the [location 6] person, she said, “Oh, well we’ve got… there is some therapy, ACT,” and I said, “Well, actually, I’ve seen that on the Huntington’s Disease website,” I said, “But that’s for carers”. I thought I’m going to message them and say, “Hmm, I want to take part, please, as gene-positive”. And actually they’d already had one cohort through of gene-positive. So, there needs to be, and I’m in the right place to have that now, so that would have been a really good pointer. But I found that out myself from speaking to… so the local person. So, there needs to be, and nobody goes along the pathway, do they, in order, but there needs to be prompts along the way as you’re going along to… and there will be a point where my Huntington’s dysregulation, I’m sure, will kick back in again more, hopefully because I managed it, there may be more things that I’ll be able to have. But I’ve encouraged my husband to get support. Now, that is really important. So, I had to push him to get support, you know. “You need to get support for yourself.” “Oh, well I don’t want that.” So, again, it needs to be a prompt on the pathway, you know. Yes, there is the carers’ group, but at a deeper level there needs to be more therapeutic psychological support for carers as in allowing them to talk about things.

Interviewer: So, who do you think, we’re talking about these prompts, someone sort of like guiding you through the options and putting options forward, who will do this, do you think?

[0:58:19]

Respondent: I think everybody. I think that it’s important that it’s seen as a joined-up service so if it’s something that [name 6] offers or she can guide people to, then she’s able to do that. If it’s something that the HDA do, like the ACT, I think that that… I think that everybody should have a wide idea of what goes on but not have… and be able to say, “Oh, well that’s the one, [name 4] needs to talk to you about that one,” or, “[name 6] needs to talk to you about that one,” but I think it needs to be a… everybody has a broad understanding but within their area they have an in-depth understanding. Then you would feel like you’re listened to. That’s the most important thing, that you feel like you’re listened to. And [name 4], I do feel listened to and [name 6] I feel listened to. I didn’t feel listened to by the consultant, but that may have been a bad day for him. But it needs to feel more joined-up.

Interviewer: I think my question was as you’re saying you’re very proactive, but not everyone that you’ve met that has…

Respondent: No, no.

Interviewer: I mean rarely probably anyone is as proactive as you are, so what I’m thinking is the people that aren’t advocating for themselves because of different reasons, who should be checking on them and making sure they are on that pipeline? Who takes the responsibility I guess my question?

Respondent: Who takes the responsibility? In an ideal world, it would be everybody, wouldn’t it? In an ideal world it would be… where we are in our society, it’s very medicalised. So, it would have to come from the medical profession probably because… but then [name 4] is very proactive. [name 4] is very good, but you have to… and people do seek out [name 4] and the HDA, so it could be the HDA and it could be the professionals. It would depend where you came into the pipework, wouldn’t it? But if you were a person that came in and you were a long way down and you were, you know, very large movements and the dysregulation was high and then it would need to be at diagnosis, so therefore the medical profession because the medical profession points, you get that diagnosis. You’re given that diagnosis. It needs to go like that, right, you’ve got the diagnosis, here we are. This is and we are, this is what we do and here it is. If you’re earlier on and I hope that earlier on it would be picked up, because there are some studies of trying… I can’t remember now, there are some studies that are trying to get it picked up earlier, as in earlier symptoms. if you’re picked up at that point earlier, you’re more able… you would be more able to talk about your needs. And again, depending on your background as well, so it would need to be less medical at that point, medical for the meds but not for the psychological support. It could be more of a local support because I’d got the [location 6] support and that was very helpful, the decider and various things, and they’d also had another person with Huntington’s. So, other than that, I don’t know, but they’d also had another person with Huntington’s. So, people are accessing some of those things already, but it should be, “Right, here you are, this would be a really good course for you to go on. Perhaps both of you should go on it”. [name 2] suffers from anxiety about this and I said to [location 6], “I’m okay about it. I haven’t got high anxiety levels, but I think my husband has”. And she said, “We’ll get him in and we’ll say both of you are going to do the course. Do you think that’s a good idea?” and I said, “Perfect”. So, I did it, and she knew I didn’t need it, but I did it and he did it. And so it needs to be a more social model earlier and a more medical model at the time of diagnosis and then not so, but if you’re further along, then it needs to be a lot more… I can speak for those people who are further along because I’m not there yet.

Interviewer: You’re not there yet. Yeah. Have you ever needed social workers to be involved, [name 1], in any of your care?

Respondent: No, no, not yet, not yet, no. I’m very lucky, we have got a… we built a bungalow that has level access. It has walk-in showers because we didn’t want baths because we saw our parents didn’t use their baths for 20 years. We’ve got a very accessible home by luck.

Interviewer: Well, not by luck. You thought it through, you prepared.

Respondent: But in terms of… yeah, so… sorry, I’ve talked a lot, haven’t I?

[1:05:13]

Interviewer: No, that’s alright. We’re nearly done. I have one last question and I’ll do the boring questions that I need to do. I want to ask… yeah?

Respondent: Another thing that I wrote down is that when I went to the GP, I said, and it’s a subtle things, I went up to the GP, they’ve been really good. Went to the dentist and I said, “Ooh, I don’t know if you know, I’m…” they did know I’ve got Huntington’s because I told them, and I went and I said, “Right, I have a DNR in place now. Could you put that on your notes, please?” and they were like, “Well, we haven’t got (inaudible 1:05:52) put on our notes”. And I was thinking, “Why not? Why not?” So, anyway, that was interesting. And also, again, the dentist was very good because she asked me questions and she said… so this is joined-up care, an example of it. She said, “Do you mind if I ask you a question?” So, I said, “No, okay, go ahead. Ask whatever you like”. So, I had longer appointments and she asked all sorts of questions. She said, “So, what does your Huntington’s dysregulation look like?” and I explained. “What does it affect you cognitively?” dah, day. And various questions, and she said, “Thank you,” she said, “Because what we want to be able to provide is care that if we ring you, if the receptionist rings you,” she says,” and you’re in a period of dysregulation, we don’t want the receptionist to think, oh, she’s an awkward person. We need the information on your file to say, you know, if you get that response, try calling her another day. It’s not the person”. So, that was very joined-up care.

Interviewer: I love that.

Respondent: Yeah. So, that is, you know, an open, joined-up way of…

Interviewer: Yeah, that’s person-centred.

Respondent: Yeah, it’s person-centred care, yeah.

Interviewer: Love it. Was this dentist in [location 3]?

Respondent: No, this was the dentist here in [location 9]. And it goes up steps, and she said, “As soon as you’re not able to come up the stairs, you’re to say,” you know. But she didn’t say, “Oh, well we’ll see you next time downstairs”. As soon as you’re not able, so again, I clocked that and I though that’s very thoughtful.

Interviewer: Yeah, love it. Alright, so I’m going to ask you if you would picture, if you would imagine your care looking excellent, you know, my care is excellent, how does that look like?

Respondent: I can’t fault the care I had at the beginning. The care with regarding consultant care, that needs to change. So, feeling… really feeling heard at that point in time, being able to go into and out of information that is supportive, “Have a look at this video,” or, “Why don’t you talk about this?” or people flagging up to others decisions to be made, “You really need to talk about your end-of-life care now. It may seem a bit odd whilst you’re like you are now, but what would you like?” And that, we should be asking everybody that, I shouldn’t just be… I was very lucky. [name 2]’s mother trained as a nurse and she had in place the care she wanted at the end. She had [cancer redacted] and she came in and she did all the care she needed and then one day she turned around and she said, “I don’t want any more of the treatments”. She’d lived ten years rather than the couple of years that she’d been told. She went into [location 10] and she passed away there. She didn’t even want her blood pressure taken at the end, it was all clearly in place. Her advanced decision was there. Now, that made it really easy for [name 2] and us as a family. It made it really easy for the doctors in there and also they said, “Oh, shall we give her some Fortisip?” and [name 2] said, “No, because remember she doesn’t want life-sustaining stuff. If she wants chocolate, fine. If she wants an ice cream, fine, but not Fortisip”. They were like, “Oh, yes, of course. That’s absolutely fine”. So, it needs to be a… perfect care would be having all those things in place so the pressure is taken off not just the individual but the family because with Huntington’s, I have to be a role model for my children because they may well have this. So, to enable the next generation to feel comfortable that they’re getting positive care is important as well so you’re not just dealing with me because… and my journey, it’s the whole family as well, so it needs to be… so perfect care would include talking about those things even if it makes people feel uncomfortable. It should be the norm, so it should change, in the future it would change from being, well, the odd person that sorts this out to, ooh, these are the things that we need to talk about, these are the things we need to sort out.

[1:11:20]

Interviewer: And as you’re saying, it’s a disease that may continue, may well continue, so it’s important that family’s cared for and involved in the decisions as well.

Respondent: Yes, and that’s why I, you know, I am aware that I may have passed it on to my daughters and my granddaughters, and that’s the hardest feeling. That is harder to me than the actual dealing with the disease myself. So, in terms of… so I feel it’s really important for me to role model that.

Interviewer: Well, I don’t think they could have a better example than you.

Respondent: Well, that’s not… yeah, but what I mean is society needs to provide a bigger joined-up care. I mean I listened to [name 7] talk and she said it’s very much society-based in [third world country] where she goes over, it’s very different care over there. There’s not the money in the same way. Yeah, so it needs to be…

Interviewer: Yeah, but I think what [name 7] sees and what you were saying earlier that ideally it would be everyone. When I asked who takes responsibility…

Respondent: Yes.

Interviewer: You were saying it should be everyone because what you’re saying is that we should have a more compassionate community…

Respondent: Yeah, yes.

Interviewer: So that we do look after each other instead of just worrying with our own bellybuttons. Yeah.

Respondent: Yeah. And also I have told people here because there is… I started a nitter-natter group here because I thought, well, even if I’m in a bad state, people can come into my home. So, now we’ve got [25-30] members, it’s mad. And so they… and I actually told them about it and I’m open about it, one, to educate people because I think we really need to educate people, but also there have been occasions when I’ve had to say… I was due to go and play skittles and I was not as well regulated that night. I wasn’t regulated at all and I went to bed early and I messaged and I said, “Look, I’m really sorry. I’m not able to come tonight. I’m in a period of dysregulation,” and they said, “Thanks for letting us know, [name 1].” And then the next day I had support from them saying, “How are you today, [name 1]?” So, you need to be open with people and vulnerable with people to enable other people to support you. You need to be vulnerable. So, I tell people about it. I wear this so people can ask. When I need it, I’ll put on my lanyard. I’ve got the lanyard that says about it. So, yeah, we need a more holistic society. Sorry.

Interviewer: No, no, thank you. I agree with you. Okay, [name 1], onto the boring questions that I need to ask everyone. How old are you?

[redacted]

[End of Transcript]